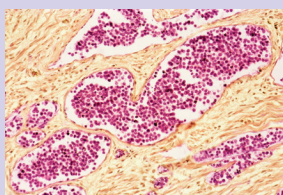


■ Online Exclusive Article

Treating Chronic Myeloid Leukemia: Improving Management Through Understanding of the Patient Experience

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The tremendous progress made in chronic myeloid leukemia (CML) treatment affords patients more options than ever. Five currently available BCR-ABL inhibitors form the mainstay of CML treatment, including first-generation imatinib and more potent second-generation BCR-ABL inhibitors dasatinib and nilotinib, with bosutinib and ponatinib having been recently approved for market inclusion. Studies show that dasatinib and nilotinib exhibit greater efficacy than imatinib in first-line chronic-phase CML (CML-CP), allowing more patients to achieve deeper, more rapid responses associated with improved outcomes. With alternatives to imatinib for first-line CML-CP and the wealth of information (and misinformation) on the Internet, a tremendous need exists for clear, accurate facts to assist patients in making treatment decisions. Patients appreciate the guidance of their oncology nurse in providing disease, treatment, and monitoring information tailored to meet their needs. Oncology nurses who are able to clearly explain emerging data, including the meaning and significance of faster, deeper responses, will be a valuable resource to their patients.

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Chronic myeloid leukemia (CML) is characterized by excess proliferation of hematopoietic stem cells triggered by a constitutively active tyrosine kinase encoded by the BCR-ABL oncogene on the Philadelphia chromosome, an abnormal chromosome created by reciprocal translocation of the *ABL* gene from chromosome 9 onto the *BCR* gene on chromosome 22 (Goldman, 2007). The BCR-ABL protein inhibits cell apoptosis and DNA repair, leading to genomic instability and further genetic abnormalities. Most patients (60%) are diagnosed in the initial chronic phase (CP) of the disease, in which patients experience night sweats, general malaise, diminished appetite (caused by a swollen spleen), fatigue, and breathlessness. The remaining 40% of patients are asymptomatic and identified by a routine blood test. If left untreated, CML-CP progresses to the accelerated phase (AP) and then to the fatal blast phase (BP) in three to five years (Sawyers, 1999; Vardiman, 2009).

The CML treatment landscape has evolved tremendously when imatinib was approved for market inclusion in 2001, leading to additional development of BCR-ABL tyrosine kinase inhibitors, both for newly diagnosed patients (first-line treatment) and for those switching treatment because of side effects or lack of response (second- or third-line treatment) (Ariad Pharmaceuticals Inc., 2012; Bristol-Myers Squibb, 2011; Novartis Pharmaceuticals, 2012a, 2012b; Pfizer Inc., 2012). As more effective treatment options arise, patients are keen to receive the best therapy. Information on the Internet enables patients to be proactive in their treatment, even referring themselves to clinical trials using www.clinicaltrials.gov or online resources provided by national cancer support organizations (e.g., www.trialcheck.org). Although the Internet provides a plethora of resources, misinformation makes the need for clear patient information about current CML treatments greater than ever.

Oncology nurses who understand the patient experience and educational needs are the key to proper information transfer and customized delivery of the highest-quality care. This article provides a summary of efficacy and safety data on BCR-ABL inhibitors necessary for evaluating treatment options, as well as insight into patients' perspectives on CML treatment and issues arising in the day-to-day management of their disease.

Therapy History

Imatinib

The introduction of imatinib, approved by the U.S. Food and Drug Administration (FDA) in 2001, changed the lives of patients diagnosed with CML. Within a few years, average life expectancy for patients with newly diagnosed CML-CP went from nine years for those treated with first-line interferon-alpha to nearly 20 years for patients treated with first-line imatinib (Reed, Anstrom, Li, & Schulman, 2008). The International Randomized Study of Interferon and STI571 (imatinib) (IRIS) in patients (N = 1,106) with newly diagnosed CML-CP (O'Brien et al., 2003) led to the FDA approval of imatinib for treatment of CML. After a median follow-up of 19 months, complete cytogenetic responses (CCyRs), defined as reduction of Philadelphia chromosome numbers to levels undetectable by fluorescent in situ hybridization (FISH), were achieved in about five times as many patients on imatinib compared with interferon-alpha plus low-dose cytarabine (76% versus 15%, $p < 0.001$) (O'Brien et al., 2003). Side effects generally were mild to moderate in severity (grade 1 or 2). The most frequent side effects were low blood counts, all-grade anemia (occurring in

45% of patients), neutropenia (61%), thrombocytopenia (57%), superficial edema (56%), nausea (44%), muscle cramps (38%), and rash (34%) (O'Brien et al., 2003). After eight years' minimum follow-up, 92% of patients still followed had not progressed from CML-CP to more advanced disease (CML-AP or CML-BP), and 85% of patients were still alive (Deininger et al., 2009). Although only hematopoietic cell transplantation offers the potential for a cure, small studies in Europe are investigating whether long-term use of BCR-ABL inhibitors can induce a deep level of remission sustainable after withdrawing treatment (Mahon et al., 2009, 2010; Redaelli et al., 2004; Robin et al., 2005).

Although many patients benefit from years of imatinib treatment, some develop intolerance or resistance; in the IRIS trial, 24% of patients had not achieved a CCyR after 18 months of treatment (O'Brien et al., 2003). In many cases, resistance is caused by mutation of BCR-ABL that diminishes imatinib binding, although other mechanisms have been identified (Kantarjian, Talpaz, Giles, O'Brien, & Cortes, 2006).

BCR-ABL Inhibitors

Dasatinib: Preliminary phase I data first presented in 2004 showed that dasatinib may have efficacy against imatinib-resistant mutations (Sawyers et al., 2004; Talpaz et al., 2006). Consequently, the SRC/ABL Tyrosine Kinase Inhibition Activity Research Trials (START) program (phase II) was initiated. After two years' minimum follow-up in the START-C trial, dasatinib induced CCyR and major molecular response (MMR; a reduction of BCR-ABL mRNA transcript levels by three log values from baseline) in 53% and 47% of patients with CML-CP, respectively, with 94% overall survival (Mauro et al., 2008). After two years' minimum follow-up in the START-R trial, dasatinib showed higher rates of CCyR and MMR versus imatinib (CCyR: 44% versus 18%, $p = 0.003$; MMR: 29% versus 12%, $p = 0.028$) (Kantarjian, Pasquini, et al., 2009). In June 2006, dasatinib 70 mg twice daily was approved for the treatment of adults with CML resistant or intolerant to prior therapy, including imatinib. The currently recommended 100 mg once-daily dasatinib dose for patients with CML-CP was established through a large phase III trial that compared the efficacy and safety of different dosing schedules (Shah et al., 2010). After two years' minimum follow-up, all schedules studied had similar effectiveness, but the 100 mg once-daily schedule was associated with fewer side effects (grade 3 or higher thrombocytopenia [$p = 0.003$], all-grade neutropenia [$p = 0.03$], all-grade leukocytopenia [$p = 0.017$], and all-grade pleural effusion [$p = 0.05$]) (Shah et al., 2010). The recommended dasatinib dosage for patients with CML-AP or CML-BP is 140 mg once daily (Kantarjian, Cortes, et al., 2009; Saglio, Hochhaus, et al., 2010). In October 2010, dasatinib was approved by the FDA for the treatment of newly diagnosed adult patients with CML-CP. That followed results from the phase III Dasatinib Versus Imatinib Study in Treatment-Naive CML Patients (DASISION), in which the 12-month rates of confirmed CCyR (assessed on two consecutive occasions 28 days or more apart) and MMR were significantly higher in patients receiving dasatinib versus imatinib (confirmed CCyR: 77% versus 66%, $p = 0.007$; MMR: 46% versus 28%, $p < 0.0001$) (Kantarjian et al., 2010). In addition, those responses were achieved significantly ($p < 0.0001$) faster with dasatinib versus imatinib (Kantarjian et

TABLE 1. Recommended Dosages for Oral BCR-ABL Inhibitors for Chronic Myeloid Leukemia (CML)

Drug	Dosage
Bosutinib	500 mg orally once daily with food for chronic phase CML, with resistance or intolerance to prior therapy Consider dose escalation to 600 mg daily with food for patients who do not achieve complete hematologic response by eight weeks or complete cytogenetic responses by 12 weeks
Dasatinib	100 mg once daily for chronic phase CML 140 mg once daily for accelerated or blast phase CML
Imatinib	400 mg once daily for chronic phase CML 600 mg once daily for accelerated or blast phase CML 340 mg/m ² per day for pediatric chronic phase CML
Nilotinib	300 mg BID for newly diagnosed chronic phase CML 400 mg BID for resistant or intolerant chronic and accelerated phase CML
Ponatinib	45 mg once daily with or without food, for the treatment of adult patients with chronic phase, accelerated phase, or blast phase CML that is resistant or intolerant to prior tyrosine kinase inhibitor therapy

Note. Based on information from Ariad Pharmaceuticals Inc., 2012; Bristol-Myers Squibb, 2011; Novartis Pharmaceuticals, 2012a, 2012b; Pfizer Inc., 2012.

al., 2010). Data suggest that the achievement of faster molecular responses (i.e., lower BCR-ABL transcript levels) correlates with better long-term outcomes (Marin et al., 2012). For patients receiving dasatinib, the most common side effects were hematologic: 21%, 19%, and 10% of patients experienced grade 3 or 4

neutropenia, thrombocytopenia, or anemia, respectively. Other grade 3 or 4 side effects occurred in 1% or fewer of patients. The most common nonhematologic side effects (any grade) were diarrhea (17%) and fluid retention (19%), including pleural effusion (10%; grade 1 or 2) (Kantarjian et al., 2010).

TABLE 2. Side Effects of BCR-ABL Inhibitors

Category	Imatinib	Dasatinib	Nilotinib	Bosutinib	Ponatinib
Most common side effects	Myelosuppression (low blood counts), edema, nausea, vomiting, muscle cramps, musculoskeletal pain, diarrhea, rash, fatigue, and abdominal pain	Myelosuppression (low blood counts), fluid retention, diarrhea, headache, dyspnea (shortness of breath), musculoskeletal pain, rash, fatigue, nausea, and hemorrhage (bleeding)	Myelosuppression (low blood counts), rash, pruritus (itching), headache, nausea, fatigue, myalgia (muscle pain), nasopharyngitis or upper respiratory tract infection (sore throat, sneezing, runny nose, cough), constipation, diarrhea, abdominal pain, vomiting, arthralgia (joint pain), pyrexia (fever), back pain, asthenia (weakness), hair loss, and muscle spasms	Diarrhea, nausea, thrombocytopenia, vomiting, abdominal pain, rash, anemia, pyrexia, and fatigue	Hypertension, rash, abdominal pain, fatigue, headache, dry skin, constipation, arthralgia, nausea, pyrexia, thrombocytopenia, anemia, neutropenia, lymphopenia, and leukopenia
Serious side effects or warnings or precautions	Myelosuppression (low blood counts); edema and severe fluid retention; severe congestive heart failure and left ventricular dysfunction; severe hepatotoxicity (liver damage); hemorrhage (bleeding); gastrointestinal perforations; cardiogenic shock or left ventricular dysfunction; bullous dermatologic reactions (rash); hypothyroidism; liver, kidney, and cardiac toxicity; immunosuppression; fetal harm; growth retardation occurring in children and pre-adolescents; tumor lysis syndrome; and impaired ability to operate motor vehicles	Myelosuppression (low blood counts); bleeding-related events (mostly associated with severe thrombocytopenia); fluid retention, including ascites, edema, and pleural and pericardial effusions; QT prolongation; congestive heart failure, left ventricular dysfunction, and myocardial infarction (heart attack); pulmonary arterial hypertension; and fetal harm	Myelosuppression (low blood counts), QT prolongation, sudden death, elevated serum lipase, liver function abnormality, electrolyte abnormalities (blood salt imbalances), tumor lysis syndrome, and fetal harm	Gastrointestinal toxicity, myelosuppression, hepatic toxicity, fluid retention, and embryofetal toxicity	Thrombosis and thromboembolism, hepatotoxicity, congestive heart failure, hypertension, pancreatitis, hemorrhage, fluid retention, cardiac arrhythmias, myelosuppression, tumor lysis syndrome, compromised wound healing and gastrointestinal perforation, and embryofetal toxicity
Specific symptoms that should be reported to a physician	Fever, shortness of breath, blood in stool, jaundice (yellow skin and eyes), sudden weight gain, and symptoms of heart failure	Fever or any signs of an infection; unusual bleeding or bruising of the skin; bright red or dark tar-like stool; a decrease in level of consciousness, headache, or change in speech; swelling all over the body; weight gain; shortness of breath; cough; and fatigue	Unexplained bleeding or bruising, blood in urine or stool, unexplained weakness, jaundice, sudden stomach area pain with nausea and vomiting, sudden headache, changes in eyesight, and lack of awareness of surroundings (confusion)	Diarrhea, nausea, vomiting, abdominal pain, bloody stools, fever, any suggestion of infection, signs or symptoms suggestive of bleeding or easy bruising, jaundice, swelling, weight gain, shortness of breath, respiratory tract infections, rash, fatigue, loss of appetite, headache, dizziness, back pain, arthralgia, or pruritus	Chest pain, shortness of breath, weakness on one side of the body, speech problems, leg pain, leg swelling, yellowing of the eyes or skin, tea-colored urine, drowsiness, palpitations, dizziness, fainting, headache, nausea, vomiting, abdominal pain, abdominal discomfort, unusual bleeding, easy bruising, abdominal swelling, weight gain, or fever, particularly in association with any suggestion of infection

Note. Based on information from Ariad Pharmaceuticals, Inc., 2012; Bristol-Myers Squibb, 2011; Novartis Pharmaceuticals, 2012a, 2012b; Pfizer Inc., 2012.

Nilotinib: In 2004, clinical trials began for nilotinib, an imatinib derivative now approved by the FDA for treatment of adults newly diagnosed with CML-CP (300 mg twice daily) and adults with CML-CP or CML-AP intolerant or resistant to previous treatment, including imatinib (Novartis Pharmaceuticals, 2012b). In June 2010, nilotinib was approved by the FDA for first-line therapy in CML-CP following results from the phase III Evaluating Nilotinib Efficacy and Safety in Clinical Trials—Newly Diagnosed Patients (ENESTnd) study, which compared nilotinib with imatinib (Saglio, Kim, et al., 2010). Twelve-month response rates were higher for patients on either dose of nilotinib (300 or 400 mg twice daily) compared with imatinib (CCyR: 80%, 78% versus 65%; MMR: 44%, 43% versus 22%; $p < 0.001$) (Saglio, Kim, et al., 2010), as were three-, six-, and nine-month MMR rates (Saglio, Kim, et al., 2010). Consistent with the finding that faster decreases in BCR-ABL transcript levels correlate with better long-term outcomes (Marin et al., 2012), time to progression to CML-AP or CML-BP was significantly longer for patients receiving nilotinib versus imatinib in ENESTnd (Saglio, Kim, et al., 2010). As for imatinib and dasatinib, low blood counts were the most frequent side effects in patients taking nilotinib; for the 300 mg twice-daily dose, rates of grade 3 or 4 neutropenia, thrombocytopenia, and anemia were 12%, 10%, and 3%, respectively. Other common side effects (any grade) were rash (31%), itching (15%), and headache (14%) (Saglio, Kim, et al., 2010).

Recently Approved Oral BCR-ABL Inhibitors

Bosutinib, an oral BCR-ABL inhibitor (Remsing Rix et al., 2009), and ponatinib, a new oral multikinase inhibitor that can inhibit the T315I BCR-ABL mutant insensitive to all clinically available BCR-ABL inhibitors (Kantarjian et al., 2006), received FDA approval for market inclusion in September 2012 and December 2012, respectively, and are important additions to the armamentarium to manage and extend the lives of patients with CML (see Table 1).

Patient Issues

Side-Effect Management

BCR-ABL inhibitor side effects can be debilitating for some patients. Even low-grade side effects take their toll during an extended period of time. Long-term management of side effects and maintenance of quality of life is important. Table 2 summarizes BCR-ABL inhibitor side effects: the most common, the most serious, and those that should be reported to the physician. Table 3 shows side-effect management strategies. For all BCR-ABL inhibitors, the most common side effects are low blood counts; the risk of other side effects differs from drug to drug. Oncology nurses can help patients understand the vital importance of reporting

side effects early so that they can be managed before becoming serious, allowing treatment to continue unimpeded.

Side effects usually are managed by dose reductions or treatment interruptions, but occasionally treatment discontinuation is required (Bristol-Myers Squibb, 2011; Novartis Pharmaceuticals, 2012a, 2012b). Oncology nurses can provide guidance to manage side effects associated with additional medications and must reassure patients regarding the effects of these medications on BCR-ABL inhibitor efficacy. The DASISION study showed that 12-month CCyR and MMR rates were unaffected by the number of co-medications (Guilhot et al., 2010); however, some patients experience gastric reflux with BCR-ABL inhibitor treatment and are prescribed proton pump inhibitors that may interfere with BCR-ABL inhibitor efficacy (Bristol-Myers Squibb, 2011; Novartis Pharmaceuticals, 2012b).

Drug Access

In addition to side-effect management, another important patient issue is access to medications. Because of their specificity, BCR-ABL inhibitors are more costly than therapies targeted to larger patient populations. Equitable access remains a problem for many patients regardless of country of residence because of cost and reimbursement issues, including high copays, loss of private insurance coverage, and lack of government reimbursement for certain newer therapies. Patients may spend an exorbitant amount of time trying to access CML drugs, and clinicians often spend valuable clinic and office time working on drug access for their patients. This issue is critical and requires continued attention.

Treatment Adherence

Because CML is a disease that, in the initial stages, may manifest few symptoms (Sawyers, 1999), patients may have difficulty staying motivated to continue treatment, particularly if they experience unpleasant treatment-related side effects. As with any disease, the possibility of lifelong reliance on therapy is disheartening. Patients routinely skip a dose (unintentionally or intentionally) or take a “drug holiday” for a variety of personal reasons. Therefore, patient adherence to their prescribed CML treatment regimen can be low and decrease over time (Gater et al., 2012). When choosing among BCR-ABL inhibitors, differences in treatment-related factors such as dosing regimen, side effects, evidence and immediacy of benefit, cost of treatment, and complexity of treatment regimen should be considered (Boonen et al., 2008; Darkow et al., 2007; Osterberg & Blaschke, 2005; Partridge, Avorn, Wang, & Winer, 2002; Ruddy, Mayer, & Partridge, 2009; St. Charles et al., 2009; Tsang, Rudychev, & Pescatore, 2006; Yood et al., 2012).

Treatment adherence often is measured using prescription refill history to calculate the medication possession ratio (MPR)—the total days’ supply dispensed divided by the total days during observation time (Darkow et al., 2007; Gater et al., 2012). MPR is less than 100% for patients who occasionally skip doses and for those with treatment interruption (drug holiday) (Darkow et al., 2007). Two retrospective surveys of U.S. healthcare claims data showed that average MPRs for patients taking imatinib were 78%–79%; patients were not taking imatinib 21%–22% of the days during the periods studied (Darkow et al., 2007; Wu et al., 2010).

Exploration on the Go

The Oncology Nursing Society offers additional clinical resources information about chronic myelogenous leukemia. To access, open a barcode scanner on your smartphone, take a photo of the code and your phone will link automatically.



Or, visit www.ons.org/ClinicalResources/CML.

Adherence to CML treatment is vital for the success of therapy. In one study, researchers found that patients with suboptimal responses to imatinib had a higher degree of nonadherence than those achieving optimal responses (23% versus 7%, $p = 0.005$) (Noens et al., 2009). In another study, in patients who achieved a CCyR, adherence over three months was the only independent factor tested to effectively predict failure to achieve complete

molecular response (CMR; the absence of detectable BCR-ABL mRNA transcripts) (Marin et al., 2010). Adherence cannot solely be the burden of patients. Oncology nurses, with the rest of the multidisciplinary healthcare team, can help patients find ways to remain adherent. Factors shown to influence adherence among patients with CML include physician experience; length of initial and follow-up visits; physician awareness of nonadherence; and

TABLE 3. Management of Selected Side Effects for BCR-ABL Inhibitors

Symptom	Management
Bone pain	Bone pain may be severe when patients first start therapy because of cells being killed in marrow. However, it usually resolves within days to weeks, but may persist. Nonsteroidal anti-inflammatory drugs may be used and, rarely, short-term opioids are needed.
Constipation	An increase of fruits and vegetables in diet is recommended, as are plenty of fluids because dehydration worsens constipation. Other commonly used items include stool softeners, psyllium seed (Metamucil®) or other fiber, and a mild laxative.
Diarrhea	Avoid sorbitol, mannitol, and maltitol (common ingredients in "sugar-free" foods). Antidiarrheal medication such as loperamide (Imodium AC®) may be helpful to take half or one tablet daily to prevent diarrhea. Other treatments include psyllium seed (Metamucil®) and lactase enzyme supplements (Lactaid®) with milk products, if sensitive. Lactose intolerance may occur temporarily after gastrointestinal illness; acidophilus can restore normal gut bacteria, particularly after antibiotics.
Dry skin, pruritus (itching)	Apply moisturizing lotion after bathing.
Fatigue	Correct anemia, if possible. Moderate regular exercise, starting very gradually, often is helpful. In addition, rest before exhaustion; otherwise, recovery time is increased. A daily nap may be needed. Set priorities and ask for help when needed. Treat depression and anxiety, which can also cause fatigue (this often is overlooked). Check thyroid function. Fatigue often improves as marrow recovers, but it may persist. In some cases, no cause can really be identified. Fatigue leads to lifestyle modification for some people, although many continue full-time work or other activities.
Heartburn or dyspepsia	More common in patients with a history of dyspepsia or gastroesophageal reflux; avoid overeating, avoid spicy foods, and decrease caffeine and alcohol. In addition, patients can try elevating the head of their bed six inches using blocks under the bed (not pillows). Antacids should be given two hours before or two hours after tyrosine kinase inhibitors. Concurrent use of H ₂ blockers such as famotidine or proton pump inhibitors such as omeprazole with dasatinib are not recommended; use antacids instead. In addition, avoid proton pump inhibitors with nilotinib; if using an H ₂ blocker or antacids, separate doses by several hours.
Low platelet count or thrombocytopenia	May require dose interruption, reduction, or platelet transfusions. Take precautions to prevent bleeding.
Low red blood cell count or anemia	May require dose interruption, reduction, or red blood cell transfusions.
Low white blood cell count or neutropenia	Managed with dose interruptions, and possibly dose reduction, as determined by healthcare provider. If the absolute neutrophil count is less than 1,000, precautions should be taken to prevent infections. Granulocyte–colony-stimulating factor (filgrastim) or pegfilgrastim may be indicated to stimulate white cell production.
Muscle and joint pain	Muscle and joint pain can be difficult to treat when persistent. Nonsteroidal anti-inflammatory drugs are helpful but have cardiac and kidney risks as well as possible stomach bleeding and upset side effects. Patients' vitamin D levels should be checked.
Muscle cramps	Muscle cramps may be helped by calcium, which may be taken in divided doses of 500 mg two to three times per day. Calcium citrate is more easily absorbed than calcium carbonate, but vitamin D is needed for absorption. Low potassium may contribute to cramps in people on diuretics Tonic water (quinine) is very effective for some patients (quinine pills are not recommended). Adequate hydration is very important in hot weather and with heavy exercising. Patients' potassium, phosphorus, and magnesium levels should be checked.
Skin problems or rash	Topical hydrocortisone cream (nonprescription) may be used. Other items include stronger steroid creams (e.g., triamcinolone) or antihistamines (diphenhydramine, loratadine); however, hold the drug and use oral prednisone for severe cases. Prednisone may be used to control a rash; the BCR-ABL inhibitor should then be restarted once the rash is under control. Rashes may come and go or be more constant.
Weight gain	Weight loss is common before a chronic myeloid leukemia diagnosis. Metabolic rate often drops following treatment. Patients can decrease calorie intake and increase exercise as well as decrease sodium intake to minimize fluid retention. Thyroid function should be monitored.

Note. Based on information from Liboon et al., 2012.

patient understanding of their disease, therapy, and consequences of nonadherence (Gater et al., 2012). The healthcare team should maintain continuous dialogue with patients to remind them of the detrimental effects of missing doses. Models for counseling and a coordinated team approach are detailed in current literature (Holloway et al., 2012; Moon et al., 2012). If patients understand both the short- and long-term goals of treatment—to reduce disease burden and achieve treatment milestones quickly—adherence may increase significantly.

Lifestyle Changes

Lifestyle modifications can help reduce side effects and provide life-affirming goals. Changes in routine may lead to greater adherence as new habits are formed. Simple steps such as putting medication near a toothbrush or on the night stand can be very effective. Patients experiencing fatigue may be encouraged to start an exercise program that balances appropriate levels of activity with rest (American Cancer Society, 2012), and eating smaller meals or avoiding alcohol may help patients cope with other side effects. Oncology nurses have numerous strategies that can be matched to the personality and needs of each patient.

Patient Education

Patients receive information about their disease in a variety of ways. Some are satisfied simply to learn what CML is and the basic hallmarks of the disease. Other patients want a more detailed understanding, perhaps even to the level of comprehending monitoring assays such as FISH and polymerase chain reaction. Because nurses play an important role in patient education, they can explore how much information is desired and help the patient access accurate and comprehensible information.

With ever-increasing frequency, patients obtain information from the Internet, including online chat groups and a variety of Web sites. The Web sites of the CML Society of Canada (www.cmlsociety.org) or the National CML Society in the United States (www.nationalcmlsociety.org) offer comprehensive, easy-to-understand information about CML and have been accredited by the American Society of Hematology as patient information and resource centers.

Patient Quality of Life

The CML Society of Canada is embarking on a Pan-Canadian Quantitative Quality of Life survey to determine the extent to which CML drugs affect patient quality of life. Although the initial population is too small to draw definitive conclusions (N = 18), results from a preliminary survey indicate that imatinib as monotherapy at 400 mg per day is the most common therapy, but optimal response remains elusive for some. Patients reported numerous side effects with treatment; most frequent (i.e., more than 50% of participants) were weight gain, rash, skin changes (including increased fragility reported by 100% of respondents), night sweats, weakness, peripheral edema, increased frequency of urination, insomnia, memory loss, heart palpitations, flushing, reduced visual acuity, periorbital swelling, increased photophobia, and joint pain. However, most participants reported confidence in their treatment and in the healthcare team with little effect on self-esteem. Some issues

Implications for Practice

- ▶ Five currently available BCR-ABL inhibitors form the mainstay of chronic myeloid leukemia treatment, and dasatinib and nilotinib exhibit greater efficacy than imatinib in first-line chronic-phase chronic myeloid leukemia.
- ▶ As patients seek out information about therapy options, oncology nurses can help them understand and interpret data about the efficacy of the different BCR-ABL inhibitors, help with side-effect management and access to treatment, and provide counseling to ensure quality of life during treatment.
- ▶ Understanding the patient experience and educational needs is the key to proper information transfer and customized delivery of the highest-quality care.

with personal and work relationships were reported and, perhaps most significantly, the majority of patients reported an impact on household income. Based on these findings, the survey has been refined and launched to a broader patient population. Preliminary results were presented at the European School of Hematology meeting in Baltimore, MD, in September 2012. More information is available at <http://cmlsociety.org/quality-of-life-survey-ii/>. The outcomes of this survey will hopefully help change access to drug therapy and amend the long-term management approach to patients with CML.

Conclusion

The outlook today for most patients is very hopeful. The “Holy Grail” of CML treatment is a cure—absence of disease and lack of recurrence. Researchers continue to explore whether BCR-ABL inhibitors can be discontinued in patients who demonstrate a long-term response (Mahon et al., 2009). In small initial studies, some patients who discontinued treatment relapsed and required treatment reinitiation (Branford et al., 2007; Rouselot et al., 2007). Oncology nurses can help patients understand and interpret trial results and should ensure that patients do not arbitrarily stop treatment while research continues in the controlled setting of official clinical trials.

Treatment of CML has changed significantly since the early 2000s—introduction of imatinib dramatically improved the life expectancy of patients with CML. Newer BCR-ABL inhibitors will likely further improve outcomes by offering alternative treatments for patients with CML intolerant or resistant to imatinib and by offering more patients the benefits of earlier, deeper responses predictive of improved long-term outcomes.

What patients need most from their oncology nurse is education about their disease, help understanding and interpreting information about the efficacy of the different BCR-ABL inhibitors, help with side-effect management, help accessing the right treatment, and counseling to ensure a high quality of life during chronic treatment. The healthcare team should provide strong support to patients who want to be self-advocates involved in the decision-making process for their treatment, including treatment selection. That fosters a collaborative partnership that will help many patients with CML manage their side effects, improve

their response to therapy, and make lifestyle changes that will improve overall health.

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