

Treating Small-Population Cancers in the Community Setting

{ Findings from ACCC's CML Educational Project }

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Many community-based cancer care providers see a large number of patients with breast, lung, colon, or prostate cancers. Practice patterns are relatively well-established for these cancers, and resources are available for both providers and patients. Many other cancers, however, are seen less often in the community setting. These low-incidence or small-population cancers present different challenges for community-based cancer care providers because:

- Patients usually come from underserved or elderly populations and do not have the resources or desire to be treated at large academic institutions
- Physicians treating small-population cancers have limited time and resources to incorporate emerging clinical data into practice
- Other healthcare professionals, including nurses, social workers, and pharmacists, see these cancers less frequently and need information to better support their physicians and patients.

In 2010 the Association of Community Cancer Centers (ACCC) launched a ground-breaking educational program to provide the community-based cancer care team members the resources they need to improve the quality of care for patients with small-population cancers. This educational project, entitled “Treating Small-Population Cancers in the Community Setting,” was initiated with a focus on chronic myeloid leukemia (CML). The project has three main goals:

1. Improving the quality of care for patients with small-population cancers
2. Raising awareness among the public and healthcare providers about challenges presented by CML
3. Assessing barriers to treatment and effective practices within the community setting for patients with small-population cancers.

To identify those cancer centers with more effective practices, ACCC developed three surveys to address the adequacy and effectiveness of: 1) overall resources and

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Florida Hospital Waterman Cancer Institute, Tavares, Fla., one of the Community Resource Centers in ACCC's CML educational project.



processes, 2) specific clinical processes, and 3) support services used in care of patients with CML and other small-population cancers. These surveys were developed by an advisory panel of oncologists, nurses, and social workers, along with Health2 Resources, a healthcare consulting company.

While more than 100 organizations started at least one of the three surveys and 61 completed at least one of the three surveys, only 27 organizations completed all three surveys. These 27 cancer programs are likely representative of programs with a stronger than average focus on managing care for CML patients. They are, however, not taken to be representative of all cancer programs.

ACCC members can view complete study results online at: <http://www.accc-cancer.org/education/education-CML-landing.asp>.

Findings at a Glance

For most cancer programs, the experience with CML is limited and will likely remain so. More than 60 percent of the 27 responding programs report fewer than 10 new CML patients annually and even those small numbers are divided among several oncologists within the program. Even in programs with a high volume of CML cases (case load above 25), CML represents only a small share of the cancers seen (less than 5 percent of the total).

What Are Small-Population Cancers?

- No single, widely accepted definition (less than 20,000 cases/annually)
- Sometimes referred to as low-incidence cancers or forgotten cancers
- Small-population cancers are those less frequently occurring cancers in which the incidence rates are not as high as other cancers: CML = 1-2 cases per 100,000 people annually (NCI SEER, 2009)

What Matters Most in CML Care?

- ✓ Team-based Approach
- ✓ Managing Drug Therapies
- ✓ Clinical Guidelines
- ✓ Patient Monitoring
- ✓ Patient Education
- ✓ Annual Training for Staff
- ✓ Effective Use of Health Information Technology

More than two-thirds of the 27 responding cancer programs evidence at least a minimum critical mass of clinicians, including at least five board-certified medical oncologists, at least two hematologists, and a number of oncology-certified RNs.

Almost all the cancer programs surveyed have access to and use national guidelines, such as those from the National Comprehensive Cancer Network (NCCN), for treatment of CML and other small-population cancers, and almost half of those have also adapted those guidelines to some extent to fit their particular situations. A few programs with access to national guidelines have developed their own guidelines.

Many successful cancer programs take a team-based approach, deploying case managers or navigators to coordinate care, which may include home and family assessment, nutrition and pharmacist consults, and easy access to the physicians, social worker, nurses, and dietitian.

Most responding cancer programs offer tyrosine kinase inhibitor (TKI) therapies, and thus are offering the most advanced therapies. Many of the cancer programs surveyed have services in place to help uninsured or underinsured patients access these therapies, which are costly.

A key element in effective treatment is ensuring that the patient acquires the drugs and continues to take the drugs. A large majority of cancer programs (81 percent) schedule regular visits to check compliance with drug regimens and also check for drug side effects. However, less than half of the programs follow up between visits to check whether drug prescriptions have been filled (41 percent), and only one program was identified as having specific policies or guidelines concerning actions to ensure drug regimen compliance.

The more effective programs assess drug side effects during visits and make sure patients purchase their drugs and use them appropriately between visits. However, electronic health record (EHR) support for CML treatments (EHR with flags, or integrated with CPOE systems) remains limited to less than half of respondents.

Effective management of patients with CML includes long-term care monitoring for support service needs since *continued on page 24*

Effective Approaches to Managing CML

A component of ACCC's "Treating Small-Population Cancers in the Community Setting" educational project is the development of Community Resource Centers (CRCs) where providers may contact peers who have indicated an interest in small-population cancers and have demonstrated significant progress in implementing effective practices related to CML. Identified through the survey process and in-depth follow-up interviews, ACCC's advisory panel determined four cancer programs to have exemplary programs for managing and treating CML patients:

- Florida Hospital Waterman Cancer Institute, Tavares, Fla.
- Harbin Clinic, Rome, Ga.
- Sierra Nevada Memorial Hospital, Comprehensive Community Cancer Center, Grass Valley, Calif.
- The Nebraska Medical Center, Omaha, Nebr.

These four CRCs will act as mentors and facilitators to assist ACCC-member programs by providing timely information, advice, and responses to questions about care for patients with CML. Staff from these four programs will monitor a new online destination called "ASK" (Answers, Solutions, and Knowledge) on CML within ACCC's MyNetwork community (<http://mynetwork.accc-cancer.org/ACCCANCER/ACCCANCER/Home/>) that features blogs, a resource library of articles, and useful tools. ACCC members gain insight from the experts on the "ASK" community on MyNetwork. These CRCs will provide a useful advance toward more effective management of CML and other small-population cancers throughout the country.

Also identified by the survey and through follow-up telephone interviews with respondents were a number of effective practices in managing CML. We review these below.

Team-based, Coordinated Care

Many successful cancer programs take a team-based approach, deploying case managers and navigators to coordinate care. At The Nebraska Medical Center, each physician is paired with an RN case manager who coordinates the patient's care. Generally, the team focuses on a particular type of cancer. Sutter Cancer Center in Sacramento, Calif., has a separate hematology and pathology tumor board that includes physicians, a pathologist, pharmacists, and nurses, as well as support staff, the social worker, nutritionist, care coordinator, and financial coordinator. These staff members work together to formulate a best-practice treatment plan.

Sutter Cancer Center and The Nebraska Medical Center have a weekly steering committee meeting to discuss patients, regardless of disease, who are getting ready for transplant.

At Florida Hospital Waterman, clinical and non-clinical staff sit in on the cancer conference, which sometimes includes physicians from other practices. The specialists coordinate closely with the primary care physicians (although they do not generally attend the cancer conference). Informal meetings on patient care keep the entire team apprised. The center has low staff turnover—none in the last two years—so patients and staff bond. Familiarity with patients helps ensure continuity of care.

Monitoring Processes and Outcomes

Systematic monitoring of patient outcomes and patient satisfaction provides a gauge of how well a program and its clinical staff are doing. An effective program will systematically monitor performance to target improvements. Sierra Nevada uses a cancer registry to monitor patient outcomes; it has followed each of its cancer patients since 1995. In addition, the weekly tumor board is routinely attended by 50 healthcare professionals (25 physicians, 25 allied health professionals), including the non-oncology physician.

At The Nebraska Medical Center, the tumor board (or "bone marrow conference") is a multidisciplinary conference that includes not only medical staff but also the nurse case manager, the social worker, and other non-physician team members. Many successful cancer programs also assess patient experience, using the feedback to drive quality improvement.

The Nebraska Medical Center, among others, uses Press Ganey to send surveys to oncology patients. The responses can be broken down by diagnoses so each provider team can review its results. Certain metrics can be targeted for improvement. One recent target: management of and education about side effects of medications. The Nebraska Medical Center began updating its printed information, determining the best time to provide such information, and coordinating with the case manager. The cancer center provides updated, written information for patients to review at their leisure, and the provider team offers ongoing reinforcement. As a result, patient satisfaction scores have improved.

Sutter Cancer Center and Florida Hospital Waterman Cancer Institute also share Press Ganey results with the entire team. At Sutter Cancer Center, all managers and directors review the scores during a weekly meeting; results are published in a weekly internal newsletter. On the inpatient side, each floor posts its results.

Managing Drug Therapies

Tyrosine kinase inhibitor therapies, or TKIs, have transformed the treatment of CML. Effective use of these therapies includes not only clinical diligence in assessing drug side effects and monitoring the progress of the disease, but also managing the financial issues

facing the patient, since these drugs are costly. The more effective programs assess drug side effects of their patients with CML during visits and make sure patients purchase their drugs and use them appropriately between visits.

Florida Hospital Waterman Cancer Institute prescribes drugs one month at a time to monitor compliance. Nurses discuss medication and side effects, provide extensive in-person patient education via handouts about the therapy and side effects, and monitor lab work. If necessary, someone from Florida Hospital Waterman Cancer Institute will check on the home situation to identify challenges to adherence.

At Sutter Cancer Center and at Sierra Nevada's Comprehensive Community Cancer Center, patients bring in their medications, and a nurse counts the pills. Lexington Medical Center, Cancer Program, in West Columbia, S.C., also uses the pill-counting approach, and some of the specialty pharmacies it works with offer assistance in monitoring patient compliance.

Nutrition consults, timely lab tests, and easy access to the physician and social worker are three effective ways that Sierra Nevada Memorial Hospital, Comprehensive Community Cancer Center, helps address side effects; Sutter Cancer Center cites education, care coordination, dietitians, and pharmacy support.

Support Services

Most cancer programs provide access to a broad array of support services, including financial support, emotional or mental health support, and patient education. A key to effective provision of support services is a staff professional (RN, social worker) to help the patient or family navigate among the needed clinical and support services, some of which may be provided by external organizations.

Immediately upon diagnosis, Sutter Cancer Center conducts a psychosocial assessment and identifies any needs, including financial, caregiver, and transportation concerns. (The social worker meets with each patient in person.) It offers music, art, pet, dance, and massage therapies. These therapists must be certified in their fields and trained by Sutter Cancer Center. It also offers a variety of onsite support groups, including one for children of cancer patients.

The Nebraska Medical Center offers many support groups and provides many support services on site while working closely with the Leukemia & Lymphoma Society for others. Patients are assessed using a distress scale and referred to a social worker if the score is above the determined threshold.

At Sierra Nevada Memorial Hospital, Comprehensive Community Cancer Center, the social worker and nutritionist are both on site and in the same building, so patients can receive the support services they need right away. The center uses a distress scale (modified from one provided by the American Cancer Society) to assess a patient's support needs. Volunteers are trained to monitor for signs of depression or distress and report them to the staff. A range of support services are pro-

vided, including patient navigation, collaboration with major medical centers, and free psychological and nutritional support. The cancer center also offers 19 support groups. Some of these are disease focused, but others, such as those devoted to writing and art, are not.

Florida Hospital Waterman Cancer Institute also uses the ACS distress scale. The social worker's office is in the waiting area, and patients are welcome to call or drop in. A monthly Leukemia & Lymphoma Society meeting (run by a nurse) is conducted onsite.

Florida Hospital Waterman Cancer Institute offers a general cancer support group, as well as one for lymphoma and leukemia. Other support services include pet therapy ("puppy day"), twice-weekly high teas in the waiting area (which creates bonding and socialization), and pastoral care.

Financial Guidance and Assistance

Most cancer centers provide in-house financial support services. Sutter Cancer Center, for example, helps patients complete paperwork for disability. It connects patients with programs, such as those through pharmaceutical companies, transportation options through the American Cancer Society, and assistance through the Leukemia & Lymphoma Society.

At Florida Hospital Waterman Cancer Institute, the social worker and financial counselor have a robust—and ever-growing—list of resources for patients who need assistance. They can be referred to the appropriate community agencies and/or to the Leukemia & Lymphoma Society. The team actively gathers information on assistance resources from national meetings, networking, pharmaceutical reps, and professional organizations, such as the Lake County Oncology Nursing Society.

Use of Health IT

From integrating guidelines into the EHR to the use of registries, many successful programs use health information technology to improve processes and procedures. At Sierra Nevada Memorial Hospital, Comprehensive Community Cancer Center, the entire provider team, including support staff, can access the hospital medical record system. Clinicians enter notes, as do the nutritionist and the social worker. All lab and radiology reports and ER visits are available. The cancer center increased the number of patients who visited with the nutritionist by flagging the records for the receptionist, who would in turn remind the patients. Nutrition consults increased 15 percent (the target) almost immediately.

Outreach and Early Intervention

Sutter Cancer Center prides itself on early intervention. It actively markets to area hospital emergency departments and lets them know that it has an acute leukemia program. Sutter Cancer Center is a transplant center, and it promotes its program actively in the community. As a result, it is able to achieve earlier diagnosis and treatment. 📞

How Much Do You Know About CML?

- CML is a likely example of small-population cancer because it best represents the challenges faced with all small-population cancers. These include (select all that apply):
 - It is seen mainly in rural communities.
 - Patient prognosis has not substantially improved with the advent of tyrosine kinase inhibitors (TKIs).
 - It falls outside the category of more prevalent cancers, such as lung, breast, or prostate cancers, but is still seen with moderate frequency by cancer care providers.
 - Current quality of CML patient care depends on the number of oncologists in a practice.
- Small-population cancers present different challenges for community-based cancer care providers for several reasons. These challenges include (select all that apply):
 - Limited physician and cancer care team knowledge of emerging clinical data.
 - Difficulties in incorporating new clinical information into practice.
 - Complex managerial and administrative processes.
 - Administrative costs and personnel involved in keeping track of oral drug adherence.
 - Drug reimbursement issues.
- Landmark discoveries over the years that have impacted the treatment of CML include (select all that apply):
 - Discovery of the Philadelphia (PH) chromosome.
 - Characterization of the breakpoint cluster region on chromosome 22.
 - Demonstration of the BCR-ABL fusion gene.
 - Discovering the direct pathophysiology of the tyrosine kinase ABL-driving signaling pathways to cause the disease.
- Chronic myeloid leukemia (select all that apply):
 - Accounts for about 15 percent of adult leukemias in the United States.
 - Annual incidence is estimated to be about 5,000 new cases.
 - Is growing in prevalence due to improved survival.
 - Accounts for almost 50 percent of adult leukemias in the United States.
- Treatment for patients with CML has changed dramatically because (select all that apply):
 - Stem cell transplant survival has increased and has been shown to be the only curative treatment.
 - Molecular diagnosis now easily confirms the diagnosis of CML, although it is not helpful in managing the disease.
 - Advances in intravenous cytotoxic chemotherapy have improved survival.
 - New drugs have been developed that target the molecular changes in CML.
- BCR-ABL tyrosine kinase inhibitors, such as imatinib, are the mainstay of treatment of CML. When should imatinib not be prescribed for a CML patient? (Select all that apply):
 - If a bone marrow/stem cell transplant is being considered.
 - If the CML cells are negative for BCR-ABL.
 - If there is an allergy or intolerance to the medication.
 - If standard chemotherapy or interferon has not yet been tried.
- One of the challenges in treating CML is that patients sometimes need alternative therapeutic options to imatinib because of drug resistance or intolerance. What are the signs that a patient is not responding to BCR-ABL tyrosine kinase therapy (imatinib)? (Select all that apply):
 - The CBC normalizes, but the molecular tests for BCR-ABL are still elevated.
 - There is a fever and an increase in the white blood count.
 - The molecular tests for BCR-ABL (FISH or PCR) showed initial decline but are now increasing.
 - There is increasing spleen size or peripheral blasts.
- What are the treatment options for a CML patient whose disease has progressed on imatinib? (Select all that apply):
 - Increase the dose of imatinib.
 - Switch to an alternative tyrosine kinase inhibitor (dasatinib, nilotinib).
 - Switch to erlotinib.
- Untreated, CML usually progresses through three phases within 3 to 5 years. What is true about the final phase, blast crisis? (Select all that apply):
 - Tyrosine kinase inhibitors can delay the onset of blast crisis, in some patients indefinitely.
 - Tyrosine kinase inhibitors cannot be used to treat CML in blast transformation.
 - Any CML patient with a fever should be considered to have blast transformation.

Answers on page 24.



On The Web

HIGHLIGHTS AND FULL REPORT

are available to ACCC members online at: <http://www.accc-cancer.org/education/education-CML-landing.asp>.

PODCASTS about CML and the issues related to drug resistance in patients taking TKIs are also available on the same web page.

BLOG with us at: <http://acccbuzz.wordpress.com>. Check out CML blogs from May 25 and May 21 and send us your comments.



Learn More

Visit the “Treating Small-Population Cancers” section on ACCC’s website at: <http://www.accc-cancer.org/education/education-CML-landing.asp> for a full project overview and a wealth of resources. Explore patient and healthcare provider educational resources on CML. Listen to podcasts on CML topics. View the archived “Effective Practices for CML” webinar. Access the CML “ASK” community on ACCC’s MyNetwork.

the patient is not cured by the therapies, but instead is stabilized with an ongoing need for monitoring drug therapies. Support services within the most

effective programs are comprehensive and include a broad array of in-house support services. These support services, however, are unlikely to be tailored to CML, and many programs report that their support service professionals have little training or experience with CML.

For most cancer programs, opportunities for communication seem to rest mostly on informal conversations. Fewer than half of respondents automatically notify support staff if an appointment is missed, and the support team meets after the initial patient visit in less than 25 percent of the centers. Although EHRs are becoming fairly common in oncology programs, the EHR is not yet in widespread use for CML support services.

Finally, effective cancer programs provide systematic patient education about CML and how to effectively manage both the condition and one’s life, given the illness. Patient education can take many forms, including brochures, group or individual educational sessions, mentoring relationships, and support groups.

Next Steps

A high percentage of survey respondents indicated that they would like to see ACCC develop resources that target CML and other small-population cancers. In particular, respondents indicated that they would like to see patient education resources, educational programs for professionals, and model policies and checklists. Most cancer programs will need continuing external support to help their clinicians remain current and to help their support services to be well targeted.

Clinical guidelines for treatment of CML and other cancers are generally available to clinicians and support staff at cancer programs, but those guidelines are not yet universally incorporated into protocols. Survey results revealed that only about half of respondents have incorporated clinical guidelines into protocols, and only 15 percent have guidelines incorporated into their EHR. For support staff, about two-thirds have access to guidelines, and about half of the cancer programs have incorporated guidelines into the support staff’s daily round by having policies, or by having forms or checklists to help implement the policies.

Raising awareness around the need for targeted clinical and support approaches will be an important method of encouraging more cancer programs to adapt their protocols and EHR software to include clinical guidelines. Since guidelines can help make up for the lack of experience in

management of CML, the issue is particularly important for small-population cancers.

ACCC can support the introduction of protocols, and EHR-based protocols in particular, by highlighting those cancer programs with effective protocols and EHR applications, and reporting how processes and outcomes have been positively affected at those programs.

For staff not directly tied in to clinical care, education about the special needs of patients with CML or other small-population cancers may be the more important effectiveness factor. Support staff can play a significant role in helping patients understand and cope with high treatment costs, drug side effects, drug compliance, and long-term survival. Each of these areas should be part of the support staff’s annual training.

Because direct patient experience is more limited for small-population cancers, keeping current about new treatments is particularly important. Annual CML training for clinical and support professionals keeps them up to date on new therapies and processes and up to speed on existing ones. Given that the financial implications of CML drug costs can be unique and somewhat daunting, the whole team, including financial counselors, would benefit from training about the needs of patients with CML. 📄

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Answers

- | | |
|--------|------------|
| 1. c | 5. d |
| 2. a-e | 6. b and c |
| 3. a-d | 7. a,c,d |
| 4. a-c | 8. a,b |
| | 9. a |

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