

ACCC's Prostate Education Project Final Report

According to the American Cancer Society, in 2013, there were an estimated 238,590 new cases of prostate cancer, and an estimated 29,720 deaths from the disease.

In 2010 ACCC launched its “Prostate Cancer Programs: Developing Tools and Measuring Effectiveness” education project with a goal of providing cancer programs with data and tools to help improve care and patient satisfaction for those with advanced or metastatic prostate cancer. Phase one components included an initial (2010) survey of ACCC members to better understand how cancer programs measure effectiveness of prostate-specific cancer services, and assess the use of patient education and decision-making tools for patients with metastatic or advanced prostate cancer. The survey found that few practical tools exist to measure effectiveness of the prostate-specific cancer service line. The survey also found variability in the patient education and decision-making tools that cancer programs use with patients who have advanced prostate disease.

Phase Two

In early 2011, ten community cancer programs were chosen to participate in the

second phase of this education project, in which ACCC worked to identify both clinical and non-clinical criteria for measuring outcomes that indicate success in treating patients with metastatic or advanced prostate cancer (see box on page 47). These programs completed a questionnaire and participated in follow-up interviews either by phone or email to assess:

- Core services
- Referral sources
- Assessment tools
- Patient and family education
- Use of decision aids
- Use of patient navigators
- Outcomes data collection
- Use of clinical guidelines
- Community outreach
- Patient engagement
- Treatment
- Coordination of care among specialties (i.e., medical oncologist, primary care physician, radiation oncologist, urologist).

For this latest phase, the project's expert Advisory Committee considered a range of outcome measures and agreed to incorporate the following measures into a descriptive study:

- Duration of survival
- Time from diagnosis to androgen deprivation treatment (ADT)
- Time from ADT to chemotherapy
- Time to first medical oncologist visit
- Percent advancing to chemotherapy
- Use of patient navigation services and/or financial counseling for advanced patients

- Cumulative exposure to ADT (in months)
- Cumulative exposure to ADT conditional on receiving chemotherapy
- Referral to and/or use of palliative care, social services, oncology rehabilitation, nutrition counseling, and support groups.

Two selection criteria were used to identify patients eligible for this education project. Selection Criteria 1 (SC1): Biochemically Recurrent Prostate Cancer—those patients who have a rising PSA after local treatment, with or without evidence that the disease has spread to bone or other organs. Selection Criteria 2 (SC2): Metastatic Prostate Cancer—those patients who are diagnosed with metastatic disease at the onset.

Once outcome measures and selection criteria were identified, a data collection protocol, a data dictionary, and a data capture template were created and shared with the project's Advisory Committee and participating sites.

Collection of Outcomes Data

Nine cancer programs submitted outcomes data from their cancer registries for their patients with metastatic or advanced prostate cancer. Data were captured for the entire 2011 calendar year.

Participating cancer programs were asked to use a “toolkit” that included the EPIC-16 CP tool and some additional supplemental educational materials with their advanced prostate cancer patients. (For more on the toolkit, see box on page 47.) Use of the EPIC-16 CP was required, while use of the other materials was suggested. Participating



cancer programs were invited to join in a training webinar to review the EPIC-16 CP, as well as the other materials in the toolkit. Over several months, challenges and successes were gathered through conference calls, email communications, and finally an online survey. Eight of the nine original participating sites took the toolkit evaluation survey; six sites completed the assessment in its entirety. The 27-item survey assessed:

- Use of tools
- Ease of use
- Usefulness in facilitating treatment decision making
- Appropriateness for the population
- Deficiencies or gaps in tools and challenges in their use
- Suggestions or opportunities for adaptation
- Impact on care delivery and referrals to support services.

The project results were described in a final report released to ACCC members in December 2012 (www.accc-cancer.org/prostateinfo).

Initial Findings on Use of EPIC-16 CP

Through ACCC's education program, participating cancer programs implemented the EPIC-16 CP with their advanced prostate cancer patients. Some participating sites also implemented EPIC-16 CP with early-stage disease patients. While urologists most often used the tool, other healthcare professionals involved in care of patients with advanced prostate cancer also successfully

implemented the tool. Users overwhelmingly found the EPIC-16 CP to be practical, efficient, and easy to implement in clinical practice with little to no adaptation. The tool provided useful information about prostate cancer patients' quality of life that could be evaluated and meaningfully contribute to treatment decision making for this population. Key findings from the 2012 report include:

- Across the sites the EPIC-16 CP was most often used by urologists (83.3 percent) followed by patient navigators (66.7 percent) and nurses (50 percent).
- 67 percent of the participating sites implemented the EPIC-16 CP at advanced prostate cancer diagnosis; others did so at early stage as well.
- At half the sites a healthcare practitioner administered the EPIC-16 CP, and at half the sites the patient self-administered. All were scored by a healthcare practitioner.
- At two sites patient self-administered tools were returned by postal mail and electronically. Both were then scored by a healthcare professional.
- Most sites found the tool useful in facilitating treatment decision making.

Although challenges with the EPIC-16 CP were few, they included patient discomfort with the questions, a need to explain the questions to patients, and difficulty sharing results across providers.

Some sites indicated that ACCC's educational project in general and the patient decision-making tools heightened awareness of, and referral to, support services. In general, this finding was not

attributed to use of the EPIC-16 CP alone. Sites indicated that it was too early to assess the impact on care delivery and referrals, but that they believed use of the tools facilitated patient flow through services. Sites reported that they now had an increased awareness of the tools available and when these tools can be used.

Follow-Up Data Collection

In 2013, five of the cancer programs that participated in the 2012 study continued data collection. These centers were:

1. Augusta Health Cancer Center, Fishersville, Va.
2. Bozeman Deaconess Cancer Center, Bozeman, Mont.
3. Middlesex Hospital Cancer Center, Middletown, Conn.
4. Palo Alto Medical Foundation, Palo Alto, Calif.
5. Southside Regional Medical Center Cancer Center, Petersburg, Va.

The 2013 study included fewer patient records—90 as compared to 175 patient records in the 2012 study. Highlights from the continued data collection include:

Referrals into the program. Both studies show similar results. Urologists were the principal source of referrals for individuals meeting SC1 and SC2, although primary care physicians also referred.

Referrals to palliative care. In the 2013 study the majority of cancer programs referred patients to palliative care, a change from the earlier study in which most programs did not refer to palliative care.

In a follow-up interview, Palo Alto



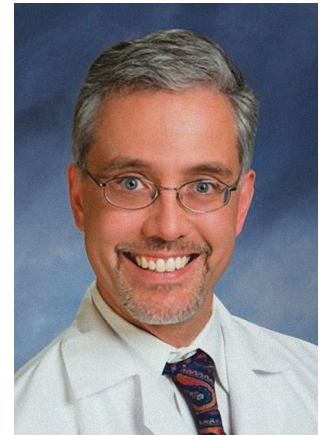
Dorothy Carvalho, RN, OCN



Frank delaRama, RN, MSN, AOCNS



Moritz Hansen, MD



Edward Myer, MD

Medical Foundation (PAMF) noted that in the past year their program added outpatient palliative care services. “We now offer palliative care, along with oncology nutrition and oncology social work services,” said prostate cancer patient navigator Frank delaRama, RN, MSN, AOCNS. “These services are now ‘headquartered’ in medical oncology. So when we assess these patients with advanced prostate disease, we have more resources for them, including survivorship and caregiver workshops.” The palliative care team consists of a physician champion medical director, a nurse practitioner, an RN, and social work and administrative support. Previously, other PAMF staff coordinated hospice and pain management services, but now with dedicated palliative care services, “It’s another specialty and support available for patients and their families,” he said.

Maine Medical Center, a participant in the original data collection, noted in a 2013 follow-up interview that at their program how palliative care services are offered to patients depends on who is seeing the patient. Many of the advanced prostate cancer patients are seen by the medical oncology group that offers palliative care services. How these services are provided also depends on what the program is palliating. So, for example, if the patient is receiving palliative care for bone metastases,

he is sent to radiation oncology for palliative care. If the pain is related to general musculoskeletal pain, the patient would be seen in the Maine Medical Center Pain Clinic. At this program, palliative care services are available throughout inpatient and outpatient services.

Referrals to other supportive care services. The 2013 data reflect low numbers of referrals to social services, oncology rehabilitation, nutrition counseling, and support groups, consistent with the data from the early study. These data may reflect inadequate processes for tracking the use of these services. There were no consistent assessment procedures across the cancer programs.

In follow-up interviews, participating sites were asked whether use of the EPIC-16 CP tool resulted in increased identification of supportive care needs among the population of patients with advanced or metastatic prostate cancer.

Maine Medical Center, which continues to use the EPIC-16 CP tool with all prostate patients, responded with a “qualified yes.” “The EPIC-16 tool includes questions related to issues of hot flashes, depression, and lack of energy,” said Moritz Hansen, MD. “We certainly see that and review that with all patients with advanced disease. It can certainly help us determine if it’s a small

problem or a big problem for these patients.”

At Middlesex Hospital implementation of the EPIC-16 CP tool did not lead to development of new support services, but did have some impact on the format for support groups with more outside speakers invited to present. In addition, participation in the data collection process and use of the EPIC-16 CP tool with patients helped Middlesex Hospital highlight how it could better use some of the support services available through the program, according to nurse navigator Dorothy Carvalho, RN, OCN. For example, as a result of use of the EPIC-16 CP tool, more patients are being referred to the prostate support group and to the recently established pelvic floor rehabilitation program.

Use of patient navigation services. A greater percentage of patients used patient navigation services in the 2013 study than in the earlier study.

Impact on Care Coordination across Specialties

In follow-up interviews, participating sites were asked if use of the EPIC-16 CP tool had affected care coordination across different specialties involved in the care of prostate cancer patients including medical oncology, radiation oncology, and urology.

“I think any time you have a tool that requires multiple specialists to get together to agree on its use in a like manner it improves assessment of patient needs and the ability to communicate different domains to other providers in the system. I think use of the EPIC-16 [CP] has improved communication [among providers and with patients],” said Dr. Hansen, Maine Medical Center. “I think use of the EPIC-16 clearly improved communication about care, and it ultimately improves care to be able to identify these various domains. If you look at the very end of EPIC-16, there is a whole section on vitality and hormonal symptoms. [These data] were not being routinely collected before. We were mainly interested in urinary and sexual functioning, but this form [EPIC-16 CP] is more inclusive. It’s straight forward. It’s easy to fill out and collects data in a standardized way,” he said.

At Middlesex Hospital, all patients with prostate cancer—not just those with

advanced disease—are given the EPIC-16 CP. Use of the tool has helped “open the door to a conversation” between the physician and patient regarding erectile dysfunction, noted Edward Myer, MD. Previously these data were not consistently collected and addressed. Use of the EPIC-16 CP has helped this cancer program “appreciate the problem in a much more quantitative fashion and address the problem better,” he said.

Participation in the ACCC project has also affected how Middlesex Hospital is collecting data. “Prior to the EPIC-16 CP score we really hadn’t been collecting this type of data. We weren’t really measuring erectile dysfunction in any way except in terms of broad subjective picture that the patient was giving us. This allows us to measure the data and record this data in a more quantitative way and it gives us something reproducible that we can compare visit to visit,” said Dr. Myer. The program has also

Programs Participating in Initial Data Collection

1. Augusta Health Cancer Center, Fishersville, Va.
2. Bozeman Deaconess Cancer Center, Bozeman, Mont.
3. Florida Hospital Cancer Institute, Orlando, Fla.
4. Ironwood Cancer and Research Centers, Mesa, Ariz.
5. Maine Medical Center Cancer Institute, Scarborough, Maine
6. Middlesex Hospital Cancer Center, Middletown, Conn.
7. Palo Alto Medical Foundation, Palo Alto, Calif.
8. Saint Joseph’s Hospital of Atlanta, Atlanta, Ga.
9. Southside Regional Medical Center Cancer Center, Petersburg, Va.
10. West Georgia Health, Enoch Callaway Cancer Clinic, LaGrange, Ga.

Prostate Cancer Toolkit

The participating sites used this toolkit to help prostate cancer patients participate in decision-making about healthcare options. It included the following resources:

- The EPIC-16 CP Tool
- Us TOO! Advanced Prostate Cancer Resource Kit

Educational materials and resources

- Ottawa Personal Decision Guide
- Ottawa Family Decision Guide Sample
- Ottawa Family Decision Guide
- Ottawa Decision Support Framework
- Ottawa Decision Support Tutorial

The screenshot shows the ACCC website interface. At the top, the ACCC logo features a '40 YEARS STRONG' anniversary. The main header reads 'Association of Community Cancer Centers' with the tagline 'The leading education and advocacy organization for the cancer team'. A navigation bar includes links for 'HOME', 'ABOUT ACCC', 'MEMBERSHIP', 'MEETINGS', 'PROVIDER RESOURCES', 'POLICY & ADVOCACY', 'PUBLICATIONS', 'CAREER CENTER', and 'MEDIAROOM'. Below the navigation, a search bar is present. The main content area is titled 'PROSTATE CANCER Resources & Tools for the Multidisciplinary Team' and includes a 'Projects Overview' section. A sidebar on the right offers a 'Search Prostate Cancer' function and lists resources such as 'Prostate Cancer Projects', 'Prostate Cancer Outcomes', 'Prostate Cancer Best Practices', and 'Other ACCC Resources'. At the bottom right, a 'SANOFI' logo is displayed with a note: 'This project was made possible through an educational grant from Sanofi U.S.'.

Physician Survey of Impact of Payer Policies on Medically Appropriate Off-Label Use

A report from the the Association of Community Cancer Centers (ACCC), the Biotechnology Industry Organization (BIO), Boston Healthcare Associates, Inc., and Pharmaceutical Research and Manufacturers of America (PhRMA)


In 2013 Boston Healthcare Associates conducted a Web survey among ACCC members from office- and hospital-based oncology practices to assess developments in the use of off-label anticancer therapies. Among survey respondents, off-label use is at least somewhat important to 64 percent; it is extremely important to 27 percent. Off-label use for the treatment of specific types of cancer with no or few on-label treatment options is the primary reason respondents consider off-label use important. About 41% of respondents report that their frequency of off-label use of anticancer therapies has decreased over the past five years; they attribute the change primarily to coverage and reimbursement challenges. In brief, here are the other survey findings.

- For 83% of respondents, peer-reviewed medical literature is somewhat important or extremely important in their use of off-label anticancer therapies.
- 63% consider drug compendia at least somewhat important.
- About 70% report that payers restrict off-label use of anticancer drugs. Notably, the use of post payment audits to restrict off-label use has increased over the last five years.
- 84% report that payers deny coverage for off-label uses supported by peer-reviewed medical literature; 80% report coverage denials for uses supported by compendia.
- 95% report that coverage and reimbursement policies concerning off-label uses of anticancer drugs cause providers to alter their clinical decision making.
- Medicare contractors primarily use claims denials to restrict off-label coverage and reimbursement; private payers most

commonly use prior authorization requirements to restrict off-label coverage and reimbursement.

- Compendia publications are the primary means Medicare uses to support off-label coverage and reimbursement; private payers use clinical guidelines as the primary source of information to support off-label coverage and reimbursement.
- For 50% of respondents, off-label coverage and reimbursement policies result in up to five treatment delays per month. Respondents say their primary response to restrictive off-label payer coverage

policies is to alter drug regimens.

- 27% have partnerships with payers to follow clinical care pathways for cancer treatment; these respondents see coverage denials of off-label use of an anticancer drug not included in clinical care pathways about four times per month.
- 21% have risk-based contracts with health plans, resulting in standardization of the use of protocols, regimens, and supplies; 88% of these respondents predict that their participation in risk-based contracts will increase over the next three years. 

Survey Conclusions

- Off-label use of anticancer therapies is a common practice among oncologists.
- Providers consider compendia and peer-reviewed literature to be important sources of information to guide decision making around off-label therapy use.
- Off-label therapy use requires strong clinical evidence to support coverage and reimbursement.
- The changing payment landscape is impacting clinical decision making as providers move towards increased assumption of risk and more defined care pathways.
- Increasingly restrictive requirements for coverage of off-label therapy may result in patient access issues.

Survey Recommendations

- Providers should continue to highlight the clinical importance of off-label therapy throughout a patient's course of treatment.
- In response to increased physician risk and payer scrutiny of off-label use, drug manufacturers should bolster the development of clinical evidence to support decision making around off-label use.
- Payers should have transparent standards for off-label therapies and ensure emerging policies allow for timely access to medically accepted, off-label use.
- As healthcare reform and related policy changes continue to be implemented, stakeholders should actively monitor the impact of these changes on oncology practices and patient access and care.