

Activities and Achievements, 1998-2005

The Prostate Cancer Action Committee (PCAC) was convened in 1998 to address the priority. The PCAC has undertaken several related projects to implement the initial MCC prostate cancer priority:

By 2006, prostate cancer patients will have their knowledge and understanding of prostate cancer, treatment options, side effects, and quality-of-life issues measured by patient surveys, with findings used to develop, disseminate, and evaluate new patient education materials.

Surveys conducted to evaluate the knowledge of patients newly diagnosed with prostate cancer in Michigan determined that many men lack knowledge of treatment alternatives (only 62% knew standard treatment options) and of side effects. White men reported higher rates of knowing their Prostate Specific Antigen (PSA) result, stage and grade (92%, 93% and 99% respectively) than African American men (69%, 88% and 85% respectively). Ninety-five percent of all men wished to participate in their treatment decisions.¹

A critical review of existing patient education materials (PEMs) available from major cancer education organizations was then performed. In this review, it was noted that most patient education materials did not describe all of the standard treatment options. The 42 PEMs that did describe alternatives were largely found to be accurate, but insufficient to support informed decision-making.²

These findings suggested the need for more effective PEMs. The PCAC developed new patient education materials in booklet, audiotape, and web versions, which include quantitative comparisons of side effects from treatment options, and are unique in addressing a broad audience, including low literacy men. Complex medical information has been “translated” for a low literacy audience. This PEM is titled *Making the Choice: Deciding What to Do About Early Stage Prostate Cancer*.

Focus groups were conducted with men newly diagnosed with prostate cancer to assure that the booklet was non-biased and was a low literacy tool with utility in this population. The evaluation found the materials to be clear and useful in reaching a treatment decision. Newly diagnosed patients reported more discussions with doctors about treatment options, and showed increases in knowledge of side effects of radiation therapy. The plain language materials presenting medical evidence in text and numerical formats appeared acceptable and useful in decision-making about localized prostate cancer treatment.³

¹ Wei, J.T., Dunn, R., Sanda, M., Hembroff, L., Taub, D., Demers, R., Tiwari, A. Survey of men newly diagnosed with localized prostate cancer: implications for patient education. *J Urol* 2003, 169: 14.

² Fagerlin, A., Rovner, D., Stableford, S., Jentoft, C., Wei, J.T., Holmes-Rovner, M. Patient education materials about the treatment of early-stage prostate cancer: a critical review. *Ann Intern Med* 2004, 140: 721-728.

³ Holmes-Rovner, M., Stableford, S., Fagerlin, A., Wei, J.T., Dunn, R.L., Ohene-Frempong, J., Kelly-Blake, K., Rovner, D.R. Evidence-based patient choice: a prostate cancer decision aid in plain language. *BMC Medical Informatics and Decision Making* 2005;5:16-27.

The website for the online format of the product was activated in August 2003. Distribution of the booklet and audio set began in November 2003. The materials have been well received as demonstrated by the orders for the booklet and audio set and the website statistics that include users from 46 states, Canada, Pakistan, Holland, the U.K., and Ghana in addition to Michigan individuals and organizations. To maintain its evidence-based status, the content of the text has been updated in December 2004 and in October 2005. A statewide dissemination plan is currently being developed.

In addition to implementing a MCC Initiative priority, these projects fostered an intensely collaborative effort among Michigan State University, the University of Michigan, Wayne State University, and the Henry Ford Hospital System. This collaboration is in itself a remarkable achievement, consistent with the mission of the MCC to be a “forum for collaboration to reduce the burden of cancer among the citizens of Michigan.”

In addition to the implementation of the prostate cancer priority, other prostate cancer activities have included the following:

1) The Cancer Burden in Michigan: Selected Statistics

The MPHI Cancer Epidemiology and Program Evaluation team develops this report in support of the MCCI on a regular basis, now yearly; the most recent edition is December 2005. The data from this report is the basis for much of the decision making on priorities for prostate cancer work. The most recent data on prostate cancer is summarized in the section “The Burden of Prostate Cancer in Michigan” and presented in detail in Appendices E and F and at www.michigancancer.org/Resources/SpecialMCCReports.cfm.

This report describes the cancer burden in Michigan in terms of morbidity and mortality, and the human and financial cost associated with five cancer sites: breast, cervical, colorectal, lung and prostate. Data are from the Michigan Resident Death Files and from the Michigan Resident Cancer Incidence File, which are provided by the MDCH, Division of Vital Records and Health Statistics. Michigan rates are compared with national mortality and incidence rates from the SEER Cancer Statistics Review. Also presented are data on the stage at diagnosis for cases reported in Michigan.

A summary of data on cancer-related behavioral risk factors were obtained from MDCH’s Behavioral Risk Factor Survey System (BRFSS), the Michigan State Board of Education’s Michigan Youth Risk Behavior Survey (YRBS), and the Special Cancer Behavioral Risk Factor Survey (SCBRFS) from MDCH and MPHI. In addition, analyses of years of life lost due to the selected cancers are presented as well as analyses of some of the financial costs of cancer.

2) The Prostate Health Awareness (PHA) Curriculum

This community presentation was developed by researchers at the Karmanos Cancer Institute (KCI) and Wayne State University. Because of the disparate burden of prostate cancer on African Americans, the main target audience of the initial program was the African American community of Detroit. The program has been presented to African American and other ethnic groups through the KCI Community Education Department. Over the past three years, the PHA Curriculum has been adapted to be culturally competent to the Hispanic community of Michigan

and then translated into Spanish with the addition of information on local community resources. Currently, focus group testing is being done on the Spanish version. In the next year, methodologies to make this resource available throughout Michigan will be developed and then implemented.

3) Basic Pathology Lexicon Project

In 2003, a committee was established to address the inconsistencies and variations in cancer pathology reporting practices throughout Michigan and to develop a standardized pathology Lexicon and reporting format to assist with treatment decisions and to provide health care policy makers and analysts with accurate data to determine the cost-effectiveness of various health care measures. This work was initially limited to prostate cancer and colorectal cancer; however, through information obtained in regional meetings and from the MCC Board, a decision was made to expand the pathology lexicons to include all common cancer sites. This expansion of scope was primarily based on the assertion that pathologists are more likely to adopt the lexicon for prostate cancer (and other specific cancers) if the lexicon for the particular cancer is embedded in a more comprehensive process than dealing with a single cancer site.

Through the dedication of the Basic Lexicon Committee and the collaborative efforts of the various MCC partner organizations, much has been accomplished over the past few years. Baseline data on reporting practices for breast, colorectal and prostate cancer specimens were obtained from facilities that reported more than 250 cancer cases annually. A consensus was reached on the data elements to include in a standardized template. A draft template was developed for dissemination and pilot use among various facilities throughout the state. Regional meetings were held to educate professionals on the importance of the project, to recruit pathologists to participate in the pilot phase and to initiate a forum for further discussion. To enhance the information obtained in the pilot phase and to contribute to the evaluation of this project, a survey was developed to collect data regarding the usability of the template in actual practice settings and to assess the likelihood of users adopting this type of reporting format into their facility. The Lexicon Synoptic Templates that were drafted and pilot tested by the Lexicon Advisory Committee were approved by the MCC at the September 21st, 2005 MCC Board meeting. The Lexicon templates, which include most cancer sites, are now posted and available for download on the MCC website at: www.michigancancer.org/OurPriorities/StandardizedLexicons_InformationForProviders.cfm