

Prostate Cancer Control Recommendations for Survivorship

Goal, Progress Markers, Rationale, Objectives, Strategy Options

Prostate Cancer Survivorship Goal

By 2010, practice guidelines and educational materials will be available for professionals and survivors/families that address prostate cancer symptom management across the survivor continuum to decrease morbidity.

Progress Markers

How will the MCC know if progress is made toward achieving this prostate cancer priority? The following markers will be utilized:

- Tools to track morbidity indicators in populations have been developed or adapted.
- Practice guidelines for prostate cancer symptom management have been developed for providers.
- Educational materials for prostate cancer symptom management have been developed for survivors and families.

Why This Priority Is Important

National Cancer Institute (NCI) publications define a person as a cancer survivor from the time the individual is diagnosed with cancer through the balance of his or her life. The director of the NCI stated, “We are beginning to view cancer not only as an acute disease to be eradicated, but as a disease that people live with and don’t die from.”²⁰ Additionally, NCI has defined cancer prevalence as “...the numbers of people alive today who have been diagnosed with cancer which includes individuals who are newly diagnosed, in active treatment, have completed active treatment, and those living with progressive symptoms of their disease”.²¹ Historically, people diagnosed with cancer that lived 5 years or more, post-diagnosis, were considered ‘cured’ of cancer. In 2004, the NCI in partnership with Centers for Disease Control (CDC) reported that the prevalence of cancer survivors living in the United States had increased from 3.0 million (1.5% of the U.S. population) in 1971 to 9.8 million in 2001 (3.5% of the U.S. population).²² A national health objective for 2010 was identified to increase, to 70%, the proportion of cancer patients who are living 5 years or longer after diagnosis.²³

²⁰ Hightower, D., & Vaughn, P. (2003) Survivorship and the changing role of palliative care. *Benchmarks* (e-journal). U.S. National Institutes of Health, National Cancer Institute, 3(4), Retrieved from www.nci.nih.gov/newscenter/benchmarks-vol3-issue4.

²¹ U.S. National Institutes of Health, National Cancer Institute (NCI). Estimated U.S. cancer prevalence counts: definitions. Retrieved July 19, 2005 from <http://dcccps.nci.nih.gov/ocs/prevalence/definitions.html>.

²² Centers for Disease Control and Prevention (CDC). (2004) Cancer survivorship—United States, 1971-2001. *MMWR Morbidity Mortality Weekly Report*, 53(24), 526-529.

²³ Centers for Disease Control and Prevention (CDC) and Lance Armstrong Foundation. (2004) A national action plan for cancer survivorship: advancing public health strategies. Retrieved from www.cdc.gov/cancer/survivorship/survivorpdf/plan.pdf.

The CDC reported in 2004 that men who had a primary diagnosis of prostate cancer were the second largest group of cancer survivors, representing 17% of all cancer survivors in the United States. At the beginning of 2003, there were an estimated 81,417 prostate cancer survivors living in Michigan, and an additional 8,540 Michigan men were diagnosed with new cases of prostate cancer in 2004. The American Cancer Society reported that prostate cancer incidence rates between 1988 and 1992 "...increased dramatically due to earlier diagnosis..." African American men, in the U.S. and in Michigan, experienced both the highest incidence and mortality rates for prostate cancer.^{24,25}

Although the number of prostate cancer survivors is increasing and considerable progress has been made in the treatment of prostate cancer, little information is available to assist men and their families with survivorship issues. One of the most troubling aspects of survivorship, identified by prostate cancer survivors and their families, is managing symptoms that have resulted from the disease or the treatment for it. Available research indicates men experience erectile dysfunction, urinary incontinence, rectal incontinence, and hormonal imbalance *in varying degrees* as a result of prostate cancer and/or treatment. These symptoms can extend for a number of years following treatment and are associated with lower quality of life and more emotional distress among men and their partners. However, men with prostate cancer typically are followed for only six months by their cancer specialist and then referred to primary care providers. Primary care providers are often unaware of cancer survivor issues or lack time in their brief provider-patient encounter to address survivor issues.

What Needs To Be Done

The experience of prostate cancer can have long-term effects on the health related quality of life (HRQOL) of the men and their families that include physical, functional, psychological, and social changes. At this time there are no prostate-specific practice guidelines in Michigan to assist health care professionals to provide ongoing care to survivors and their family members. Health care professionals who interact with survivors and their families across the continuum of care at the time of diagnosis, before and after treatment, as well as during active surveillance with 'watchful waiting' are in key positions to assess and address HRQOL concerns for prostate cancer survivors and their partners. HRQOL endpoints are being included in clinical trials for prostate cancer treatment to measure changes in physical, functional, psychological, and social health.²⁶

In addition to practice guidelines, there is also a need for professionals, survivors and families to have access to the latest educational materials on prostate cancer symptom management. To date, information is lacking on the number of prostate cancer survivors/families who have received culturally appropriate educational materials on prostate cancer symptom management or been informed about community resources to address their needs. Since provider-patient encounters are typically very brief, there is little time for teaching especially in areas related to

²⁴ Centers for Disease Control and Prevention (CDC). 2004 Cancer Burden Data Fact Sheets Michigan.

²⁵ Michigan Public Health Institute. The Cancer Burden in Michigan: Selected Statistics 1985-2002. December 2004.

²⁶ Wei, J.T., Dunn, R.L., Sandler, H.M., McLaughlin, P.W., Montie, J.E., Litwin M.S., Nyquist, L., & Sanda, M.G. (2002) Comprehensive comparison of health-related quality of life after contemporary therapies for localized prostate cancer. *Journal Clinical Oncology*, 20(2), 557-566.

prostate cancer survivorship issues (e.g., incontinence, erectile dysfunction, hormone imbalance). In order for survivors to participate fully in maintaining their own well being and quality of life following the diagnosis and treatment of prostate cancer, they need access to well-developed, evidence-based educational materials. These materials need to be culturally appropriate and at a reading level Michigan residents can comprehend. Because family members, especially partners, are the primary source of physical and emotional support to prostate cancer survivors, educational materials also need to be family-centered and address issues relevant to family caregivers.

Objective

By 2010, develop and distribute *practice guidelines* for prostate cancer symptom management to Michigan primary care providers and pertinent specialists.

Prostate cancer symptom management practice guidelines will help clarify the standard of care in the State of Michigan. It is important that all health care providers know the practice guidelines and can implement them. It is also important that patients and their families be informed about the practice guidelines so that they can know the expected standard of care.

Strategies

- Identify the content essential to symptom management for the different phases of prostate cancer survivors.
- Develop provider practice guidelines for prostate cancer symptom management that are age-specific and culturally appropriate.
- Develop strategies to facilitate ongoing implementation of the prostate cancer symptom management guidelines during the critical transition from specialty care to follow-up care by primary care providers.
- Develop a process to distribute the practice guidelines to health care providers as well as to survivors and families in Michigan.
- Develop a method to evaluate the effect of the practice guidelines on the health related quality of life of survivors and families in Michigan.

Objective

By 2010, develop and distribute *educational materials* for prostate cancer symptom management to prostate cancer survivors and their families that are culturally sensitive, age-specific, and at an appropriate reading level.

Strategies

- Identify the needs of prostate cancer survivors through a review of the literature and the use of focus groups.
- Identify existing educational materials relevant to prostate cancer survivors/families that will address their information needs.
- Identify gaps in existing prostate cancer educational materials.
- Adopt, adapt, or develop patient educational material for prostate cancer survivors and their family members.

- Develop a process to distribute prostate cancer symptom management educational materials to providers and survivors/families in Michigan.
- Develop a method to evaluate how the utilization of educational materials affects the health related quality of life of survivors and families in Michigan.

Additional References

1. Althof, S.E. (2002) Quality of life and erectile dysfunction. *Urology*, 59(6), 803-810.
2. American Cancer Society. Man to Man Program. Retrieved from www.cancer.org/docroot/CRI/content/CRI_2_6X_ACS_Man_to_Man_Program_Background_36.asp?sitearea=&level.
3. Aubin, S. (2005) Sexuality and Intimacy. *ASCO Prostate Cancer Symposium, General Session X: Survivorship, Supportive Care, and Complications of Therapy*. Retrieved from www.asco.org/ac/1,1003,12-002514-00_18-0037-00_19-0013,00.asp.
4. Bantia, R., Malcarne, V.L., Varni, J.W., Ko, C.M., Sadler, G.R., & Greenbergs, H.L. (2003) The effects of dyadic strength and coping styles on psychological distress in couples faced with prostate cancer. *Journal of Behavioral Medicine*, 26(1), 31-52.
5. Bertero, C. (2001) Altered sexual patterns after treatment for prostate cancer. *Cancer Pract*, 9(5), 245-251.
6. Bokhour, B., Clark, J.A., Inui, T.S., Silliman, R.A., & Talcott, J.A. (2001) Sexuality after treatment for early prostate cancer: exploring the meanings of erectile dysfunction. *Journal of Gen Internal Medicine*, 16(10), 649-655.
7. Carlson, L.E., Bultz, B.D., Speca, M., & St. Pierre, M. (2000) Partners of cancer patients part I: impact, adjustment, and coping across the illness trajectory. *Journal of Psychosocial Oncology*, 18(2), 39-63.
8. Galbraith, M.E., Arechiga, A., Ramirez, J., & Pedro, L.W. (2005) Prostate cancer survivors' and partners' self-reports of health-related quality of life, treatment symptoms, and marital satisfaction 2.5-5.5 years after treatment. *Oncology Nursing Forum*, 32(2), E30-41.
9. Higano, C.S. (2005) Neurocognitive Effects". *ASCO Prostate Cancer Symposium, General Session X: Survivorship, Supportive Care, and Complications of Therapy*. Retrieved from www.asco.org/ac/1,1003,12-002514-00_18-0037-00_19-0013,00.asp.
10. Jacobsen, P.B. (2005) Exercise: benefits for prostate cancer patients. *ASCO Prostate Cancer Symposium, General Session X: Survivorship, Supportive Care, and Complications of Therapy*. Retrieved from www.asco.org/ac/1,1003,12-002514-00_18-0037-00_19-0013,00.asp.
11. Jakobsson, L., Hallberg, I.R., & Loven, L. (2000) Experiences of micturition problems, indwelling catheter treatment and sexual life consequences in men with prostate cancer. *Journal of Adv Nursing*, 31(1), 59-67.
12. Kronenwetter, C., Weidner, G., Pettengill, E., Marlin, R., Crutchfield, L., McCormac, P., Raisin, C.J., & Ornish, D. (2005) A qualitative analysis of interviews of men with early stage prostate cancer: the prostate cancer lifestyle trial. *Cancer Nursing*, 28(2), 99-107.

13. Malcarne, V.L., Banthia, R., Varni, J.W., Sadler, G.R., Greenbergs, H.L., & Ko, C.M. (2002) Problem-solving skills and emotional distress in spouses of men with prostate cancer. *Journal of Cancer Education*, 17(3), 150-154.
14. Maliski, S.L., Heilemann, M.V., & McCorkle, R. (2001) Mastery of post prostatectomy incontinence and impotence: his work, her work, our work. *Oncology Nursing Forum*, 28(6), 985-992.
15. Miller, D.C., Sanda, M.G., Dunn, R.L., Montie, J.E., Pimentel, H., Sandler, H.M., McLaughlin, W.P., & Wei, J.T. (2005) Long-term outcomes among localized prostate cancer survivors: health-related quality-of-life changes after radical prostatectomy, external radiation, and brachytherapy. *Journal of Clinical Oncology*, 23(12), 2772-2780.
16. Moyad, M. (2005) Complementary medicine: use, trends, and benefits. *ASCO Prostate Cancer Symposium, General Session X: Survivorship, Supportive Care, and Complications of Therapy*. Retrieved from www.asco.org/ac/1,1003,12-002514-00_18-0037-00_19-0013,00.asp.
17. Oeffinger, K.C., Mertens, A.C., Hudson, M.M., Gurney, J.G., Casillas, J., Chen, H., Whitton, J., Yeazel, M., Yasui, Y., & Robison, L.L. (2004) Health care of young adult survivors of childhood cancer: a report from the childhood cancer survivor study. *Annual Family Medicine*, 2(1), 61-70.
18. Penson, D.F., & Litwin, M.S. (2003) Quality of life after treatment for prostate cancer. *Curr Urol Rep*, 4(3), 185-195.
19. Schover, L.R., Fouladi, R.T., Warneke, C.L., Neese, L., Klein, E.A., Zippe, C., & Kupelian, P.A. (2002) The use of treatments for erectile dysfunction among survivors of prostate carcinoma. *Cancer*, 95(11), 2397-2407.
20. Schwarts, A.L. (2004) *Cancer fitness: exercise programs for patients and survivors*. New York: Simon and Schuster.
21. Smith, M.R. (2005) Bone complications and their treatment. *ASCO Prostate Cancer Symposium, General Session X: Survivorship, Supportive Care, and Complications of Therapy*. Retrieved from www.asco.org/ac/1,1003,12-002514-00_18-0037-00_19-0013,00.asp.
22. Sunga, A.Y., Eberl, M.M., Oeffinger, K.C., Hudson, M.M., & Mahoney, M.C. (2005) Care of cancer survivors. *American Family Physician*, 71(4), 699-706. Review 713-714.
23. Williams, C.R., & Williams, V.A. (2003) *That black men might live: my fight against prostate cancer*. Roscoe: Hilton Publishing Company.
24. Wilson, I.B., & Cleary, P.D. (1995) Linking clinical variables with health-related quality of life. A conceptual model of patient outcomes. *JAMA*, 273(1), 59-65.
25. Wei, J.T., (2005) What is health related quality of life? *University of Michigan Cancer Update Conference*, Petosky, MI.