Prostate Cancer Survivorship: Implementation of Survivorship Care Plans to Meet the Mandate and Enhance Urologic Practice Through Collaborative Care

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Prostate cancer is the most common malignancy among the male survivorship population in the United States, representing 44% of approximately 7 million survivors. In the era of modern medicine and value-based care, successfully treating only the cancer is not sufficient. The cancer survivor represents an individual in need of restoration and protection against future events. A well-designed and well-supported survivorship program not only meets a mandate for accreditation, it logically translates into better patient care. This review summarizes the history of the survivorship movement, outlines some key elements of a survivorship program, and highlights the opportunity to apply these principles to improve cancer-related care, develop relationships with colleagues that may allow increased identification of men at risk, and expand both the experience and outcomes of individual specialists within men's health.

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KEY WORDS

Prostate cancer • Survivorship care plan • Cancer surveillance

n 2016, prostate cancer (PCa) will comprise 21% of all new cancer diagnoses.¹ Of these, 92% will consist of local-only disease, for which 5-year survival rates have improved over the past 40 years.¹ Data from the Surveillance, Epidemiology, and End Results (SEER) database found the 5-year survival rate following diagnosis of localized disease to be as low as 68% from 1975 to 1977, with improvement to 83% in 1987 to 1989, and to 99% from 2005 to 2011.2 The current 10- and 15-year survival rates of 98% and 95%, respectively, further emphasize the importance of understanding the needs of PCa survivors.² PCa is the most common malignancy among the male survivorship population in the United States, representing 44% of approximately 7 million survivors.¹ Thus, developing comprehensive survivorship programs should be a priority for both cancer centers and large urology group practices.

The National Coalition for Cancer Survivorship, founded in 1986, maintains a focus on life after a cancer diagnosis. Their initial definition of a cancer survivor was "someone who remained disease-free for 5 years," whereas 30 years later it is defined as one "living with, through, and beyond a cancer diagnosis."³ Issues facing survivors may be physical, financial, mental, and/or social. Comprehensive care should facilitate efficient communication from physician to patient, physician to family, and physician to physician.

Over the past decade, cancer survivorship has received greater attention among policy makers, oncology care advocates, and national accrediting organizations. At present, mandates are in place regarding survivorship resources for comprehensive cancer centers to maintain accreditation. Although the added requirements may initially seem onerous, tools have been developed to render this requirement stress free. Additionally, the survivorship model creates a more supportive environment for patients, and it (ASCO), established a task force to determine a course for cancer survivors and to establish a framework for long-term care. A total of 10 recommendations were published

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History of Survivorship

In 1985, Fitzhugh Mullan, a physician, offered personal insight into stages of survival after his successful battle with cancer.⁴ He eloquently discussed needs of oncology patients such as physical limitations following treatment, changes in body image, and difficulty within the survival phase associated with diminishing support from healthcare providers.⁴ He wrote, "for better and for worse, physically and emotionally, the experience leaves an impression."⁴ Mullan was one of the founding

in the report From Cancer Patient to Cancer Survivor: Lost in Translation.⁵ These recommendations included direct patient-related topics such as monitoring for and treating consequences of oncology therapies, surveillance for recurrent or new cancers, and ensuring patient access to employment and healthcare insurance without discrimination. Additionally, recommendations were made for evaluating survivorship care models, provider education, and ongoing research within the field. An additional recommendation involved provision of survivorship care plans (SCPs), to allow for a comprehensive review of treatment with ongoing goals.

Survivorship Care Plans

Following primary treatment of PCa, patients may transition back to their primary care providers without a firm understanding of the role of the urologist, medical oncologist, radiation oncologist, nutritionist, or psychosocial provider, paving the way for incomplete and poorly coordinated care. SCPs are intended to avoid this

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members of the National Coalition for Cancer Survivorship, and a pioneer in advocacy of survivorship. In 2005, the Institute of Medicine, in combination with the American Society of Clinical Oncology

situation, and to encourage a successful multidisciplinary approach for long-term benefit. These documents are to include type and stage of disease, as well as specifics related to the types of therapy received. Additional components include surveillance schedules, information regarding adverse effects of treatments received, resources available for support, and general health review.6 These plans are to be discussed by patients and their cancer care providers. This process involves assigning responsibilities among involved providers for the different components of follow-up, which is important because one study determined that more than one-third of patients were unsure of which physician was leading this charge.7

Research on SCP design has shown a common desire among patients and providers to have a concise and easy-to-read product.8 In terms of content, patients found information related to health promotion, psychosocial support, and financial resources to be most valuable, whereas providers preferred a streamlined version focused on components of care.9 Although the SCP may seem to be only a simple document, it sets the framework for important conversations between patients and their providers, as well as with their loved ones, especially because a substantial number of patients report a lack of knowledge of their received treatments.¹⁰ Although creating such a document seems like a daunting task, Boston Scientific (Marlborough, MA) has introduced customizable templates for men treated for PCa. Versions exist across the spectrum of treatment modalities and were created with input from practicing urologists. These are unbranded and freely available to interested physicians (Figure 1).

Meeting the Mandate

The American College of Surgeons Commission on Cancer (ASC CoC) has mandated implementation of SCPs as part of the accreditation review process, which was updated for 2016.11 Specifically, SCPs are to be given within 1 year of diagnosis, and no later than 6 months after completion of adjuvant therapy. Expectations for implementation involve provision of SCPs to 25% of eligible patients by 2016, 50% by 2017, 75% by 2018, and all eligible patients by 2019.12 Several barriers to effective implementation of SCPs have been suggested.13 Of these, one of the most concerning to providers involves time expenditure, with inadequate reimbursement for the time and resources required. A test run by ASCO13 found that these documents can be completed in as little as 10 minutes, typically by nursing staff.

In addition to SCPs, the ASC CoC mandates triennial assessments of healthcare disparities and following radical prostatectomy (RP) found 53% of participants experienced distress or cancer-related anxiety.¹⁷

Cancer Surveillance

Cancer surveillance is a critical aspect of survivorship and can be spearheaded by the patient's cancer care provider. Considering the additional men's health needs often present in these patients, the urologist seems best suited to fill this role. Existing guidelines and timing of assessments can be built into the SCP. ASCO provided recommendations for PCa survivorship for primary care providers in 2014 to help guide survivorship care across various provider settings.18 Within these guidelines, serum prostate-specific antigen (PSA)

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barriers to care such as transportation, language, cultural differences, financial resources, and child care.11 Another component of survivorship stressed by the ASC CoC program standards includes assessment of psychosocial needs. This is in response to a 2007 Institute of Medicine report that called for screening patients for distress, connecting patients and families with appropriate services and resources, and coordinating such care.14 Such distress can include feelings of vulnerability to depression, panic, and social isolation.15 Various screening instruments exist, such as the Distress Thermometer created by the National Comprehensive Cancer Network® (NCCN), which allows patients to use a visual scale along with yes/no questions related to various practical, family, emotional, and physical problems.¹⁶ A study utilizing the NCCN Distress Thermometer among 197 men levels should be checked every 6 to 12 months for the first 5 years and then annually thereafter, with digital rectal examinations performed in coordination with cancer specialists to avoid duplication.18 The NCCN guidelines are the same in regard to frequency of PSA testing, but state that digital rectal examinations can be omitted if PSA is undetectable.¹⁹ PSA testing among those with metastatic disease is more frequent at every 3 to 6 months.19 Evaluation for PSA anxiety should be assessed as part of ongoing psychosocial assessments. Abnormalities in PSA, as defined by the NCCN per treatment modality, should prompt a visit between the patient and his primary cancer care provider.¹⁸ Additionally, screening for secondary malignancies is especially important in those previously treated with radiation therapy, considering the increased risk of bladder and colorectal cancers.²⁰ Blood

9. Follow Up Appointment Follow Up Appointment Date: 12. Follow Up Appointment Date: 10. Follow Up Appointment Date: Date: Date: PSA: PSA. PSA: PSA II. Follow Up Appointment Date: Follow Up Appointment Date: Follow Up Appointment 5. Follow Up Appointment Radical Prostatectomy (Surgery) Point of Contact Date: Date PSA: PSA: PSA: PSA imaging Results (CT, MRI, etc., If Applicable): 9 1 œ Survivorship Care Plan Radical Prostatectomy (Surgery) Pathology Results/Gleason Score Nurse/Nurse Practitioner/PA-C **Diagnostic Information** Cancer Type: Adencarcinoma Treatment Information 3. Follow Up Appointment 4. Follow Up Appointment Date: 2. Follow Up Appointment 1. Follow Up Appointment **Prostate Cancer** Health Care Providers Primary Care Provider Radiation Oncologist Medical Oncologist Diagnosis Date: **Other Providers** Bone Scan: + / -Care Team Clinical Stage Your Name: DRE: + /-Hospital: Date: Surgeon Date: PSA Date PSA PSA PSA PSA. Survivorship Radical Prostatectomy (Surgery) **Care Plan** Prostate **CARE Team Member Name** Cancer Clinic Name Clinic Address City, State 12345 XXXX-XXX (XXX

in the urine or stool should result in appropriate referrals for evaluation.

Health Maintenance

A survivorship program should also evaluate the patient's status regarding routine health maintenance. Discussion may be required related

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to lifestyle modifications involving diet, exercise, smoking, and immunizations. Patients should be counseled regarding how their diagnosis characterizes risk for other family members. Patients receiving androgen deprivation therapy (ADT) may be at risk for various systemic effects. Accordingly, ASCO recommends an annual complete blood count for evaluation of anemia. SEER data demonstrated that ADT is associated with a greater incidence of cardiovascular disease after 5 years of followup.^{21,22} An advisory panel from the American Heart Association, American Cancer Society, and the American Urological Association recommended assessment of blood pressure, lipid profile, and blood glucose level prior to initiation of therapy, 3 to 6 months after first treatment, and annually thereafter.23 Patients receiving ADT should also be screened with dualenergy radiographic absorptiometry scan and treated appropriately.¹⁸

Anatomic Restoration

The prostate is linked to both urinary and sexual health and treatment for PCa can impact quality of life. Even when an operation such as RP is done in similar fashion in two similarly appearing patients, subsequent sexual function and continence may differ. These situations should not be viewed as complications of surgery per se, but likely reflect the unique potential for recovery among patients. It is important to recognize that erectile function declines over time even in patients who are not treated for PCa, so it would be unsurprising for subsequent function to be lower than baseline after

a window of recovery. Urinary symptoms can be observed subsequent to all treatment modalities for PCa. One study of nearly 200 patients found that 88% noted changes in their voiding or sexual function.¹⁷ The spectrum of manifestation may reflect the variable nature of the healing process between individuals.

ASCO guidelines include a recommendation for discussion of urinary symptoms such as nocturia, frequency, urgency, and incontinence, and a suggestion for primary care providers to refer affected men to a urologist for additional evaluation.¹⁸ Male stress

undergone some modifications to improve continence control and durability, but the basic design remains relatively unchanged and consists of three separate components, including a circumferential urethral cuff, pressure regulating balloon, and pump-control assembly.27-29 It remains the gold standard for stress incontinence in men, and long-term data verify that the majority of patients have satisfactory results of zero to one pad per day usage, low infection rates, and long-term durability.²⁹ Depending on the degree of incontinence, a synthetic male urethral sling, first introduced by American Medical Systems in the late 1990s, may also be considered in select men.³⁰ Within the context of survivorship, it is prudent to discuss correction of stress incontinence in affected patients with appropriate referrals to high-volume specialists to achieve optimal outcomes.

Sexual health concerns, including libido, erectile function, and body image, should also be discussed in follow-up care. It is

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incontinence negatively affects quality of life and has variable incidence with reports of 2.5% to 87% following RP for localized disease, with increased rates reported by patients relative to that reported by providers.^{24,25} At 5 years after treatment of localized disease, 28% and 4% of men use pads after RP and radiotherapy, respectively.²⁶ Management of persistent and properly evaluated stress incontinence may involve placement of a male urethral sling or artificial urethral sphincter.

Initially released in 1983, the AMS 800[™] (American Medical Systems, Minnetonka, MN) has

essential to address the medical and psychosocial aspects of sexual health in the PCa survivor, as 60% are 70 years or older, and many remain interested in sexual activity.³¹ Rates of erectile dysfunction (ED) have been reported to be 20% to 40% for men 60 to 69 years of age and 50% to 100% in men over age 70.32 Considering all men between the ages of 40 and 70 years, the Massachusetts Male Aging Study found that the majority had at least some degree of ED.33 Thus, based on age alone, the typical patient diagnosed with PCa is likely to have some form of sexual dysfunction. Assessment and documentation of erectile function prior to treatment can help set expectations, influence portions of the customized survivorship plan, and may have implications for in-global reimbursement for care provided relative to sexual health. ED is reportedly as high as 60% to 70% in men following radiation and surgery for PCa, thus representing a large population in need of restoration.^{34,35}

ASCO guidelines call for use of validated instruments to monitor erectile function, such as the Sexual Health Inventory for Men (SHIM). Interventions for interested patients may involve oral, injectable, or surgical therapies, and referral to an appropriate specialist should be made when indicated. Surgical restoration has been found to have higher patient and partner satisfaction compared with oral or intracavernosal therapies.³⁶ The modern era of the penile prosthesis began in the late 1960s, with the original inflatable device launched in 1973 by American Medical Systems.³⁷ Inflatable devices are now considered the gold standard in the United States and have seen drastic improvements in infection prevention over time, thanks to measures such as the InhibiZone[®] coating introduced by American Medical Systems in 2001. Satisfaction rates relative to penile prostheses for patients and partners are reported as 98% and 96%, respectively.^{38,39} Despite these impressive figures, a review of SEER data found that only 0.78% of patients treated with RP or radiation therapy for localized PCa receive a penile implant.⁴⁰ A commitment to optimize quality of life within a survivorship program should likely foster an increased awareness of the restoration afforded through prosthetic urology. Comprehensive care should also include counseling services designed to address issues of intimacy related to a cancer diagnosis and subsequent treatment.

It Takes a Village

A multidisciplinary approach lends itself to improved delivery of care in multiple disease states, and PCa is no exception. Employment of the survivorship model encourages collaboration across several laboratory evaluations. In addition to maximizing efficient use of clinical resources, incorporation of the shared medical appointment model can encourage participation from advanced practice providers (physician assistants, nurse practitioners). Chains of collaboration also create opportunities for valuable data collection, which can be used for both quality improvement

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specialties. We have already discussed the critical role of the primary care provider as recognized by the ASCO guidelines and the need for routine health maintenance. Developing a relationship with a cardiologist is also prudent, given the risks of ADT and the recognized relationship between ED and cardiovascular disease.41 Once the program is in place, the value will be apparent to all parties involved, and this creates an important resource for men in the community. Medical oncologists, radiation oncologists, specialists involved in treating secondary malignancies, physical therapists, nutritionists, counselors, and even financial planners add to the visibility of such a communal effort.

Collaboration between those specializing in urologic oncology and those involved primarily in prosthetic urology, either within the same group or across groups, should serve to improve patient outcomes and foster a team approach that may increasingly identify men at risk for undiagnosed malignancy or untreated impotence and/or incontinence. Also, building relationships with providers actively involved with testosterone replacement offers them an outlet for referring those men found to have abnormal PSA values on the requisite serial

initiatives and research endeavors. Also, SHIM-based identification of preoperative ED, even if mild, may allow appropriate modifier-based reimbursement for care delivered by a patient's designated sexual health expert within the global period following RP.

Conclusions

In the era of modern medicine and value-based care, successfully treating only the cancer is not sufficient. The cancer survivor represents an individual in need of restoration and protection against future events. A well-designed and well-supported survivorship program not only meets a mandate for accreditation, it logically translates patient into better care. Additionally, it elevates and expands the sphere of influence of a urologic practice, maximizes its use of resources, and creates channels of communication and collaboration with other providers to construct a symbiotic multidisciplinary team. This process is simplified by use of an available SCP template that can be customized to any practice and administered in minutes. In addition to overall health maintenance and surveillance for recurrent or secondary malignancies, anatomic restoration should be offered to

those men with persistent stress incontinence or refractory ED.

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MAIN POINTS

- Over the past decade, cancer survivorship has received greater attention among policy makers, oncology care
 advocates, and national accrediting organizations. At present, mandates are in place regarding survivorship
 resources for comprehensive cancer centers to maintain accreditation. The survivorship model creates a more
 supportive environment for patients, and it can enhance a given urology practice via increased collaboration
 with other providers.
- Following primary treatment of prostate cancer, patients may transition back to their primary care providers without a firm understanding of the role of the urologist, medical oncologist, radiation oncologist, nutritionist, or psychosocial provider, paving the way for incomplete and poorly coordinated care. Survivorship care plans are intended to avoid this situation.
- A survivorship program should evaluate the patient's status regarding routine health maintenance, and address psychosocial needs. In addition, comprehensive care should include counseling services designed to address issues of intimacy related to a cancer diagnosis and subsequent treatment.