

Prostate Cancer Survivorship Care

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Improving the quality of prostate cancer survivorship care has the potential to transform the national efficiency and effectiveness of cancer specialty care delivery.

rostate cancer is the most common cancer diagnosis among U.S. veterans.1 More than 12,000 veterans will be diagnosed with prostate cancer in 2014, to join more than 200,000 veteran survivors.1 Because its incidence increases with age and nearly half of veterans are aged ≥ 65 years, the clinical and economic burdens of prostate cancer are expected to increase.² Fortunately, > 80% of these men will have local disease with 5-year cancer-specific survivals of 98%.3 Even among the small population of veterans whose disease returns after treatment, < 1 in 5 will die of prostate cancer within 10 years.4

Thus, most men live with prostate cancer and its sequelae rather than die of it, similar to other chronic diseases. In 2003, the VHA outlined a National Cancer Strategy, indicating priorities for quality cancer care and access to care for all veterans with cancer.⁵ Importantly, this directive recognized prostate cancer as a service-connected condition for men exposed to the herbicide Agent Orange.⁶ For all these reasons, understanding the delivery of prostate cancer survivorship care has tremendous cost and quality implications for the VHA.

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SURVIVORSHIP CARE

Due to the extensive focus on screening and initial treatment, very little prostate cancer survivorship research exists either within or outside VHA. In fact, a 2011 literature review found that < 10 prostate cancer survivorship studies were published annually. Because long-term survival is increasingly common after any cancer diagnosis, better understanding cancer survivorship (ie, the chronic care following diagnosis and treatment) and the distinct needs of cancer survivors are central to cancer care quality. 8,9

A 2005 breakthrough report from the Institute of Medicine, *From Cancer Patient to Cancer Survivor: Lost in Transition*, emphasized the distinct issues facing cancer survivors and called for an increased emphasis on cancer survivors and their care from both clinical and research perspectives (Table).¹⁰

Due to the expanding population of veteran prostate cancer survivors, this report has increasing relevance to VHA.¹¹ For prostate cancer survivors in particular, up to 70% have persistent symptoms (eg, incontinence, impotence) with some symptoms persisting 15 years after treatment, indicating the need for ongoing care and similarity to other chronic diseases.^{12,13}

Despite this growing need and the universal provider access to electronic

medical records, VHA, like most other integrated delivery systems, does not have a systematic organizational approach to deal with its prostate cancer survivors, indicating a tremendous opportunity.

One recent proposal for supporting survivorship care in the VHA is a Patient-Aligned Specialty Team for oncology to provide comprehensive cancer care through tumor boards, multispecialty clinics, care coordinators/navigators, and patient education.¹⁴

SYMPTOM BURDEN

The 3 usual approaches to treatment of prostate cancer are (1) surgery (radical prostatectomy); (2) radiation therapy (brachytherapy or external "beam" radiation); and (3) observation (watchful waiting and active surveillance). 15-18 While some men do choose observation initially, ultimately many undergo some form of surgical or radiation treatment.¹⁹ Unfortunately, long-term adverse effects (AEs) of these treatments are common and vary by treatment type. Men may experience ongoing problems with urinary control (eg, urinary incontinence), sexual function (eg, impotence), hormonal (eg, fatigue, depression), and bowel function (eg, diarrhea and fecal incontinence) far beyond that of age-matched controls. 13,15,20-27

Up to 75% of men report prob-

lems with erectile dysfunction after prostatectomy, compared with 25% who receive brachytherapy, and 40% who receive brachytherapy plus external beam radiation. 20,22,26,28 Urinary problems include both incontinence and pain with urination, which may improve over time with medical and nonmedical management approaches.^{26,27} Among patients treated with radiation therapy, between 40% and 55% report urinary problems as long as 8 years posttreatment (incontinence and/or pain). 26,27,29,30 Unlike surgery, radiation therapy is also associated with bowel problems posttreatment, including rectal urgency and diarrhea.^{25,31}

Although the greatest symptom burden and associated reduction in quality of life (QOL) occurs initially following treatment, many prostate cancer survivors experience considerable symptom burden for years following treatment. 21,22,26,32-35 This persistence of symptoms is documented among thousands of patients after prostate cancer treatment, most of which are nonveterans. For example, among men with prostate cancer and no sexual, urinary, or hormonal problems at baseline, 9% to 83% reported severe problems in at least 1 domain 3 years after treatment with surgery or radiation.36

Gore and colleagues demonstrated persistent symptoms among 475 prostate cancer patients for up to 48 months following initial treatment.²⁷ The Michigan Prostate Cancer Survivor Study, a registry-based survey of 2,500 prostate cancer survivors responding about 9 years postdiagnosis, found that up to 70% reported ongoing problems with AEs, some of whom were more than 15 years removed from primary treatment.¹² Addressing these symptoms through

medical and self-management approaches is one way to reduce their impact and improve QOL among prostate cancer survivors.

Despite the size of the veteran prostate cancer survivor population, most research documenting symptom burden and reduced OOL is from nonveterans. Because veterans often experience greater disease burden than that of the general population, their symptom burden would be expected to be similar or greater than that reported among nonveterans. Although there has been no comprehensive assessment of symptom burden across the VHA as a whole, research to understand optimal approaches to support veteran prostate cancer survivors with self- and medical management of their treatment related symptoms seems warranted.

SELF-MANAGEMENT

Though there have been no comprehensive self-management interventions directed to help survivors limit the impact of prostate cancer treatment sequelae in everyday life, evidence suggests that such an intervention is likely to have a positive

impact.37 For example, urinary symptoms can be self-managed through a variety of approaches, including emptying the bladder at regular intervals before it gets too full and pelvic floor (ie, Kegel) exercises to help decrease urinary leakage episodes. In fact, a randomized trial demonstrated a 50% decrease in incontinence episodes among prostate cancer survivors who used pelvic floor muscle training and bladder control strategies.³⁸ A recent systematic review suggests that exercise, another self-management strategy, improves incontinence, energy level, body constitution, and QOL after treatment for prostate cancer.37 Exercise among prostate cancer survivors is also associated with decreased prostate cancer-specific and overall mortality.39

For sexual function after prostate cancer treatment, minimizing tobacco and excessive alcohol use and communicating with partners about feelings and sex are self-management strategies for improving sexual relationships. ⁴⁰ Avoiding spicy and greasy foods, coffee and alcohol, and staying well-hydrated may help limit the adverse bowel effects of radiation (ie,

Fast Facts...

- ➤ The burden of prostate cancer among veterans is substantial with more than 200,000 survivors and 12,000 new diagnoses annually
- Symptom burden after prostate cancer treatment can be substantial, last well into survivorship, and lead to reduced quality of life and greater use of services
- Unclear roles and regional variation in the VHA cancer specialist workforce can complicate delivery of quality survivorship care
- ➤ The design and implementation of tools to facilitate the delivery of optimal cancer survivorship care in VHA rests on understanding how responsibility for survivorship care is managed and the barriers to quality survivorship care

Recommendation	Description
1	Raise awareness of the needs of cancer survivors, establish cancer survivorship as a distinct phase of cancer care, and act to ensure the delivery of appropriate survivorship care.
2	Patients completing primary treatment should be provided with a comprehensive care summary and follow-up plan (survivorship care plan) that is clearly and effectively explained.
3	Health care providers should use systematically developed evidence-based clinical practice guidelines, assessment tools and screening instruments to help identify and manage late effects of cancer and its treatment.
4	Quality of survivorship care measures should be developed through public/private partnerships and quality assurance programs implemented to monitor and improve the care that all cancer survivors receive.
5	The Centers for Medicare and Medicaid Services, National Cancer Institute, Agency for Health-care Research and Quality, the Department of Veterans Affairs, and other qualified organizations should support demonstration programs to test models of coordinated, interdisciplinary survivorship care in diverse communities and across systems of care.
6	Congress should support the Centers for Disease Control, other collaborating institutions and the states in developing comprehensive cancer control plans that include consideration of survivorship care, and promote the implementation, evaluation, and refinement of existing state cancer control plans.
7	The National Cancer Institute, professional associations and voluntary organizations should expand and coordinate efforts to provide educational opportunities to health care providers to equip them to address the health care and quality of life issues facing cancer survivors.
8	Employers, legal advocates, health care providers, sponsors of support services, and government agencies should act to eliminate discrimination and minimize adverse effects of cancer on employment, while supporting cancer survivors with short-term and long-term limitations in ability to work.
9	Federal and state policy makers should act to ensure that all cancer survivors have access to adequate and affordable health insurance with the assistance of insurers and health care payers.
10	The Centers for Medicare and Medicaid Services, National Cancer Institute, Agency for Health-care Research and Quality, the Department of Veterans Affairs, Centers for Disease Control, voluntary organizations such as the American Cancer Society, and private health insurers and plans should increase funding support of survivorship research and expand mechanisms for its conduct to better guide effective survivorship care.

radiation proctitis) among prostate cancer survivors.⁴¹ However, there are no systematic mechanisms to share these strategies with veterans or nonveterans.

MEDICAL MANAGEMENT

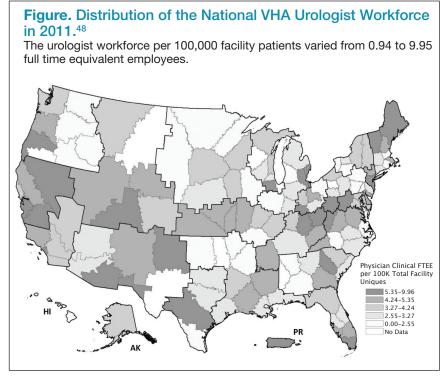
Recommendations for the medical management of prostate cancerrelated AEs have recently been updated by the Michigan Cancer Consortium's Prostate Cancer Action Committee and are available at www .prostatecancerdecision.org. ⁴² Originally developed in 2009, these recommendations were directed toward the management of common posttreatment problems to minimize their impact on men who have been treated for prostate cancer, their families, caregivers, partners, and primary care providers (PCPs).

The recommendations combine expert opinion and evidence-based strategies for identifying recurrence and managing specific symptoms, including erectile dysfunction, urinary incontinence, bowel problems, hot flashes, bone health, gynecomastia, relationship issues, and metabolic syndrome. The increasing recognition that comprehensive, point-of-care resources are needed to direct survivorship care is fueling tremendous efforts targeting primary and specialty care providers from many major cancer stakeholder organizations (ie, American Cancer Society, National Comprehensive Cancer Network, etc).⁴³⁻⁴⁵

Primary care providers often consult prostate cancer specialists (urologists and radiation and medical oncologists) for assistance in managing prostate cancer survivors.46 However, it is not clear whether the supply of cancer specialists is capable of meeting the increasing needs of cancer survivors and their PCPs. 47 VHA urologists vary tremendously in their regional availability from < 1 per 100,000 patients in Little Rock, Arkansas, to > 10 urologists per 100,000 patients in New York City.48 Similar variation exists for medical oncologists in the VHA. For prostate cancer, the urologist workforce impacts screening rates and cancerrelated mortality. 49,50 Yet how this workforce variation influences quality of survivorship care, particularly among PCPs dependent on specialist expertise, is unknown.

A better understanding of these relationships will help inform whether interventions to improve survivorship quality of care need to target PCPs with less access to prostate cancer specialists (eg, rural providers through telemedicine initiatives); survivorship care coordination at sites with more cancer specialists; or other potential barriers, such as knowledge gaps pertaining to AE evaluation and management. Each of these barriers to optimal care would be addressed through different interventions.

The long natural history of prostate cancer coupled with the number of survivors basically ensures that PCPs are faced with managing these men and their symptom burdens.⁵¹ However, it is often undecided who has primary responsibility for survivorship care.^{52,53} When queried regarding responsibility for prostate cancer survivorship care, about half of PCPs from one state-based survey felt that



it was appropriate for either the cancer specialist or themselves to provide such care. 12 Another study revealed high discordance among cancer specialists and PCPs regarding who should provide follow-up care, cancer screening, and general preventive care. 54 Without clear role identification, poor communication between primary and specialty care fosters fragmented, expensive, and even poor quality survivorship care. 55

Optimizing the delivery of survivorship care among cancer specialists and PCPs is also difficult, because comprehensive prostate cancer survivorship guidelines that might delineate responsibilities and recommend referral practices are just becoming available. In fact, the American Cancer Society just released its Prostate Cancer Survivorship Guidelines in June 2014. 10,56,57 Primary care providers may be willing to take on increased responsibility for survivor-

ship care with appropriate specialist support, including timely access to specialist evaluation. ^{54,58} Moreover, PCPs are usually better at supporting cancer survivors' general health as well. ^{51,58} Therefore, defining the interface between PCPs, their medical home (ie, Patient-Aligned Care Team), and the limited supply of cancer specialists is necessary to streamline information exchange and care transitions. ⁵⁹

Understanding symptom management (eg, incontinence, impotence) across this interface is also critical to the design and implementation of survivorship quality improvement interventions. Promoting clear responsibilities for prostate-specific antigen surveillance, symptom management, and bone density testing for men treated with androgen deprivation therapy across the primary-specialty care interface is a potential starting point.

TRANSFORMATIVE TOOLS

Whether targeting cancer care or not, quality improvement interventions often lack insight into the causal mechanisms by which they effect change. 60-62 This is particularly true for interventions targeting clinician behavior change, such as improving uptake of evidence-based practice. 63,64 For example, the effectiveness of audit with feedback interventions to improve guideline adherence ranges from 1% to 16%.65-69 The same intervention can vary in its effectiveness, depending on context.70-72 Barriers and enablers that vary by provider, facility, and other contextual factors (eg, workforce, location) contribute to this variable effectiveness.73-79 For this reason, a guiding theoretical framework is useful to understand an intervention's transferability among different settings, as well as to ensure comprehensive assessment of the factors that can prevent uptake of evidence-based practice.80-83 For example, a theoretical framework might provide insight into how causal mechanisms of an intervention to improve cancer survivorship care might vary in a community-based outpatient clinic vs a tertiary center.84-86

A guiding theoretical framework is even more useful when used to design quality improvement interventions. 82,83,87,88 Mapping barriers to theoretical constructs, and theoretical constructs to interventions to facilitate clinician behavior change can assist in planning strategies for effective implementation across a range of settings.88 While psychological theories like the Theoretical Domains Framework and Theory of Planned Behavior are pertinent for individual behavior change, understanding how best to implement interventions targeted at the facility level requires a broader perspective focused on context.^{83,88-92}

The Consolidated Framework for Implementation Research (CFIR) provides a comprehensive, practical taxonomy for understanding important organizational, individual, and intervention characteristics to consider during an implementation process.75,76 The CFIR framework provides the broader contextual milieu contributing to the quality of survivorship care at the facility level across 5 domains: (1) intervention characteristics—evidence, complexity, relative advantage; (2) outer setting—peer pressure, external policies; (3) inner setting structural characteristics, readiness for implementation, culture; (4) individual characteristics-knowledge about intervention, self-efficacy; and (5) process-planning, engaging stakeholders, champions, execution.

Using both individual and organizational constructs to effectively characterize the relationships, needs, intentions, and organizational characteristics of primary and cancer care providers throughout VHA will be key to designing successful interventions to broadly ensure quality survivorship care. The best interventions to improve survivorship care will likely vary across facilities based on contextual factors such as cancer specialist availability, facility characteristics, and the current delivery system for survivorship care.

Intervention modalities currently being used by the VHA Office of Specialty Care Transformation to improve access to specialty care are indeed transformative tools to optimize the quality of survivorship care. The latter builds on a successful approach developed and widely used in New Mexico, which makes the expertise of academic specialists at the

University of New Mexico available throughout the state, using video tele-conferencing. 93,94 The opportunities for video-enabled interaction between specialists and PCPs in VHA, both in consultation about specific patients and in educational sessions to enhance PCP knowledge and self-efficacy in managing patients requiring specialty knowledge, are revolutionary for cancer care. 93,95

CONCLUSIONS

Due to the expanding population of veteran prostate cancer survivors, improving their QOL by ensuring proper cancer surveillance, effectively managing their treatment complications and transitions of cancer care will reduce risk and provide timely management of symptoms and disease recurrence.

Understanding how variation in the VHA cancer specialist workforce impacts the quality of cancer survivorship care is a critical step towards optimizing veteran cancer care. Through this understanding, communication between PCPs, PACT, and cancer specialists can be improved via theory-based quality improvement tools to address gaps in the quality of prostate and other VHA cancer survivorship care. Interventions designed to enhance PCP self-efficacy in delivering high-quality prostate cancer survivor care may improve job satisfaction among PCPs and specialists.

Clarifying issues in the delivery of optimal prostate cancer survivorship care may inform models for other cancer survivorship care in the VHA. The contextual factors contributing to a VHA facility's performance for prostate cancer survivorship care may be very relevant to the facility's performance for other types of cancer survivorship care. A facility's pri-

mary care organizational structure, cancer specialist workforce, and oncology-specific facility characteristics vary little across cancer types, suggesting that a better understanding of how to improve PSA surveillance for prostate cancer, the most common cancer treated in the VHA, should apply to carcinoembryonic antigen surveillance for colon cancer, hematology studies for lymphoma, and the surveillance of other malignancies in the VHA.^{96,97}

The VHA National Cancer Strategy stressed the importance of meeting or exceeding accepted national standards of quality cancer care. Therefore, understanding the relationship between quality of cancer survivorship care and the cancer specialist workforce and its interface with primary care is critical to this goal, as is elucidation of the other barriers preventing optimal care. Last, embracing VHA's latest telemedicine initiatives, including video teleconferencing to improve prostate cancer care, has the potential to transform this system into a national leader in prostate cancer survivorship care.

Author disclosures

The authors report no actual or potential conflicts of interest with regard to this article. Dr. Skolarus is supported by a VA HSR&D Career Development Award - 2 (CDA 12-171). Drs. Hawley (PI) and Skolarus (Co-I) are supported by VA HSR&D IIR (12-116).

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PROSTATE CANCER SURVIVORSHIP CARE

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PROSTATE CANCER SURVIVORSHIP CARE

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