



Seminar article

Enhancing prostate cancer survivorship care through self-management

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Abstract

The lack of clear roles for prostate cancer survivorship care providers places prostate cancer survivors at significant risk of inappropriate use of services delivered piecemeal by different providers, persistent bothersome symptoms, and silent suffering. Optimizing quality of care for prostate cancer survivors hinges on decreasing fragmentation of care, and providing quality symptom management. This is achieved through comprehensive, appropriate medical, surgical, pharmacological and psychosocial care, coupled with self-management, as highlighted in several recent resources addressing long-term and late effects of treatment. Although further study is warranted, prostate cancer survivors engaging in self-management may reduce the negative impact of prostate cancer in their lives through better quality of care (better symptom management and efficient use of services) and quality of life. Published by Elsevier Inc.

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Burdens of prostate cancer survivorship

For most men diagnosed with prostate cancer, long-term and late effects of both diagnosis and treatment can lead to impairments in quality of life [1–4]. Up to one-third of prostate cancer survivors undergo a medical intervention to evaluate or manage the consequences of the disease (e.g., incontinence and bowel symptoms) [5]. For survivors undergoing expectant management with active surveillance or watchful waiting, periodic prostate-specific antigen testing, physical examination, and prostate biopsy may lead to anxiety, depression, out-of-pocket costs, and relationship and coping challenges [6,7]. Partners of prostate cancer survivors may experience more distress than the survivors

themselves [8,9], exacerbating the implications of living with a prostate cancer diagnosis, even when it is cured.

Implications of poorly managed prostate cancer-related symptoms

Until recently, there has been limited guidance with respect to which providers should manage which prostate cancer-related symptoms, increasing the likelihood that survivors and their partners will experience fragmented care that fails to meet their needs [10]. The variety of specialists providing follow-up care of survivors includes urologists, radiation and medical oncologists, and even gastroenterologists for bowel-related treatment effects [6,10,11]. However, because of its protracted clinical course and an increasing number of prostate cancer survivors, much of survivorship care falls upon primary care clinicians (PCC) [12]. Approximately half of PCCs in one study reported it was equally appropriate for them or the specialist to provide survivorship care, though their comfort managing common urinary and sexual side effects was

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limited, indicating real-world challenges for the longitudinal care of prostate cancer survivors [13].

The lack of clear roles for survivorship care providers, addressed at least to some degree through recently mandated survivorship care plans [10], and the lack of availability of experts able to address enduring symptoms (e.g., sexual) [9], places prostate cancer survivors at significant risk of inappropriate use of services, delivered piecemeal by different providers. The resulting care fragmentation is not patient-centered, and can lead to overuse and duplicate care (e.g., repetitive prostate-specific antigen testing) [14]. Cancer survivors already use health services at a higher rate than nonsurvivors [15], including overuse of specialty care to address symptom management and intensive surveillance testing for local recurrence or metastatic disease [16].

Perhaps due to fragmentation, although high service use exists, studies show that many prostate cancer survivors still “suffer in silence,” not seeking primary or specialty care when indicated to address their well-being [12,17]. Many survivors may not know which providers to access for which issue. Furthermore, repeated requests to manage certain symptoms from multiple providers without resolution may arguably cause survivors to give up on seeking care. Postponement of care can lead to worse long-term quality of life, and even increasing costs. For example, without timely surgical correction of persistent urinary incontinence or sexual health counseling aimed at adjustment to a new normal in survivorship, survivors may keep on spending on hygiene products, may feel distressed due to urinary incontinence, or may experience worsening relationship satisfaction.

Increasing focus on self-management to enhance prostate cancer survivorship care

Symptom self-management is a successful approach to activating survivors to use services based on understanding their symptoms and rehabilitation strategies [18,19]. As such, it can mitigate the overuse and inappropriate use of costly medical interventions via a targeted pursuit of strategies to palliate bothersome symptoms. In fact, suffering could be alleviated when patients feel competent they can manage their symptoms and are able to seek medical care from their PCC or an appropriate specialist [20].

It is useful to define self-management in the context of cancer survivorship. One relevant definition comes from Barlow and colleagues who define self-management as, “a person’s ability to manage the symptoms and consequences of living with a chronic condition, including treatment, physical, social, and lifestyle changes” [21]. Self-management support interventions can improve self-care behaviors and outcomes among patients with a variety of chronic medical conditions, and lead to more efficient use of primary and specialty care [20]. To the extent that cancer

survivorship represents a chronic disease (e.g., diabetes and hypertension), applying the Chronic Care Model can also help promote high-quality care [20,22,23]. A critical component for quality care in this model is effective self-management. Although the model is rarely used in cancer survivorship, it seems highly relevant to supporting prostate cancer survivors manage the biopsychosocial implications of their disease, particularly through self-management [10].

Self-management support typically involves assisting patients to understand expectations related to their illness, and offering direction for management of side effects and other disease-related issues. Effective self-management approaches educate patients regarding managing their own health, how to implement different approaches, and indications for seeking care [21,24]. Ideally, systems for self-management facilitate interactive assessments of patient needs over time, providing feedback and reassessment to understand evolving or resolving needs [22,23,25].

Self-management efforts for cancer survivors generally focus on periods following treatment to achieve cure or remission, such as chemotherapy administration, not necessarily on chronic issues such as persistent treatment side effects as in cancer survivors [20]. Self-management support interventions among cancer survivors have included nurse-initiated telephone calls, home visits, small group seminars, take-home materials with call-back information, and automated telephone response systems [26–30]. In general, these interventions have helped reduce survivors’ symptom burdens, improve quality of life, and even survival, though no one approach appears superior to others.

Although further study is warranted, prostate cancer survivors engaging in self-management may reduce the negative impact of prostate cancer in their lives. For example, a randomized trial indicated a 50% reduction in urinary incontinence episodes with pelvic floor physical therapy and bladder management approaches among prostate cancer survivors [31]. Evidence also suggests that exercise as a self-management approach is associated with decrease in urinary leakage, fatigue, and improved quality of life after prostate cancer treatment, not to mention increased survival [32–35]. Minimizing tobacco and excessive alcohol use, and communicating with partners about feelings and sex are each important self-management approaches for improving sexual well-being among survivors and partners [9,36]. Finally, avoidance of greasy, spicy foods, excess coffee, and alcohol can help minimize bowel symptoms from radiation therapy [37].

Prostate cancer survivorship guidelines and resources address biopsychosocial needs

Recognizing a growing need to support PCCs, specialists, and patients in survivorship care, several organizations have gathered evidence and expert opinion to create

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