#### **Review article**

# Providing prostate cancer survivorship care in Japan: implications from the US care model

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Short running title: Improving Japanese survivorship care

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#### Abstract

Introduction: Despite an increasing number of prostate cancer survivors in Japan, the current delivery of prostate cancer survivorship care is insufficient and lacks a multi-disciplinary approach. We conducted a study to characterize prostate cancer survivorship care in Japan, examine the Japanese workforce available to deliver survivorship care, introduce a conceptual framework for survivorship, and identify opportunities to improve Japanese survivorship care.

**Methods:** We systematically searched PubMed for prostate cancer survivorship care studies, including those from Japan. We also searched the internet for prostate cancer guidelines relevant to survivorship care.

**Results:** We found 392 articles, of which 71 were relevant, read in detail and reported here. In Japan, survivorship care is mostly provided by urologists. Primary care as a specialty does not exist in Japan, and there are no independent nurse practitioners or physician assistants to assist with survivorship care. Japanese quality of life studies characterize the long-term effects of prostate cancer treatment, but routine use of patient-reported outcomes is not common in Japan. In the US, in light of a growing comprehensive awareness of challenges facing survivors and their providers, the American Cancer Society prostate cancer survivorship care guidelines serve as a tool for optimizing the management of long-term treatment effects and coordination of care.

**Conclusions:** In order to deliver high-quality survivorship care in Japan, urologists need to establish collaborations with other disciplines within the delivery system. A multi-disciplinary This article is protected by copyright. All rights reserved

guideline for prostate cancer survivorship care in Japan appears warranted.

# **Keywords:**

Cancer survivor, prostate cancer, quality of life, survivorship care, workforce

#### Introduction -

With over 98,000 incident prostate cancer cases in 2015 and nearly 180,000 Japanese men alive with the diagnosis of prostate cancer, the public health burden of this disease in Japan is significant. This burden is expected to increase due to uptake of Western dietary patterns, prostate cancer screening, an aging Japanese population, and increasing effectiveness of prostate cancer treatments. With most Japanese men living with rather than dying from prostate cancer, focusing on opportunities to improve their quality of life (QOL) through better survivorship care is increasingly essential.

According to the National Coalition for Cancer Survivorship, cancer survivors include individuals diagnosed with cancer from the time of diagnosis and for the balance of life. (3) Survivorship typically refers to the phase of care following primary treatment. It has broad economic and long-term well-being implications for cancer patients and the health care system in general. The 4 essential components of survivorship care highlighted in a dedicated Institute of Medicine (IOM) report include cancer prevention, surveillance, intervention and care coordination. (4) Although most Japanese men with prostate cancer have favorable cancer-specific survival, prostate cancer treatment is often associated with lasting functional, medical, QOL, and psychosocial detriments. Prostate cancer survivorship issues are associated with the type of treatment (e.g., active surveillance, surgery, radiation, androgen deprivation therapy, chemotherapy), stage of disease, baseline function, comorbidities, and partner support, among others (Table 1). For example, men treated This article is protected by copyright. All rights reserved

surgically with radical prostatectomy may experience persistent urinary incontinence and erectile dysfunction. (5, 6) Radiation therapy may cause sexual dysfunction, irritative urinary symptoms, and bowel symptoms due to rectal toxicity. (7-9) Androgen deprivation therapy is associated with a range of adverse effects including increased fracture risk, (10, 11) metabolic syndrome, (12) cardiovascular events, (13, 14) and anemia. (15) Involving partners and caregivers in survivorship care efforts is also important as they often deal with the implications of the disease and its treatment as part of their relationship. (16-19) In general, multi-disciplinary survivorship care efforts are needed to ensure the impacts of these treatment-related side effects on prostate cancer survivor QOL are addressed and minimized.

In response to this need in the United States, the American Cancer Society (ACS) developed the prostate cancer survivorship care guidelines. These novel disease-specific guidelines, endorsed by the American Society of Clinical Oncology (ASCO), emphasize a multi-disciplinary approach to survivorship care including experts in mental health, sexual health, and physical therapy, along with primary care clinicians, urologists, and medical and radiation oncologists, to address treatment-related side effects. The focus on primary care clinicians is critical, at least in the US, given their role in the health care of prostate cancer survivors after prostate cancer treatment. While there are approximately three million prostate cancer survivors in the US, nearly 17 times more than in Japan, both countries demonstrate a significant need for survivorship care guidance to optimize the QOL and care for men with prostate cancer. (23, 24)

Although guidelines for prostate cancer screening and treatment exist in Japan, their scope of recommendations for survivorship is limited. Therefore, we first sought to summarize the current status of prostate cancer survivorship care in Japan through a narrative literature review. Next, we examined provider workforce differences, including the availability of primary care clinicians, nurse practitioners, and physician assistants in the US and Japan, each of whom could help deliver survivorship care. Finally, we introduce a This article is protected by copyright. All rights reserved

conceptual model for survivorship care, describe a survivorship care plan to assist with longitudinal Japanese prostate cancer care coordination, and offer recommendations to improve Japanese prostate cancer survivorship care.

### **Methods**

Narrative review

For our narrative review, we searched PubMed for prostate cancer survivorship care studies through September 2015. Our search terms included: prostate cancer, survivorship care, quality of life, and Japan. However, only 5 articles were identified using these search terms. We then broadened our criteria to include prostate cancer, survivorship care, and quality of life without specificity for Japanese studies. Next, we included studies involving Japanese patients, as well as supportive interventions directed at improving prostate cancer-specific QOL outcomes. Using this approach, we identified 392 articles, of which 71 were deemed relevant by the study team, read in detail and reported here. In addition, we conducted internet searches of relevant urologic and cancer websites for prostate cancer guidelines for survivorship care including those for the ACS (27), ASCO (28), and the Japanese Urological Association (JUA). (29)

Prostate cancer survivorship care workforce in Japan and the US

Because prostate cancer survivorship care is inherently multi-disciplinary, we also searched workforce sources for relevant data (e.g., number of urologists). We identified the population of both countries using the United Nations website. (25) We searched the Ministry of Health, Labor, and Welfare of Japan website to identify the number of physicians by major professional activity. (26) For the corresponding US data, we used the 2012 Physician Specialty Data Book published by Association of American Medical Colleges. (27) The number of nurses in Japan and the US were reported from the Japanese Nurse Association website (28) and the Health Resources and Services Administration Bureau of Health Professions website (29), respectively. The number of physician assistants in the US were This article is protected by copyright. All rights reserved

tallied from the National Commission on Certification of Physician Assistants website. (30)

Current state of knowledge about Japanese prostate cancer survivorship care and quality of life among Japanese prostate cancer survivors.

Several studies described QOL among Japanese men treated for prostate cancer. (31) However, most QOL studies were done in the US (47%), followed by the UK (8%), Canada (8%) and Japan (6%). (32) Therefore, most information about treatment outcomes, particularly for QOL, is based on the experience of well-educated white men and may not be as relevant for the Japanese population. (20) This is important, because prostate cancer survivors of different races may have different outcomes and needs when it comes to cancer control, expectations, general, urinary, bowel, and sexual QOL. (33-35) For example, Namiki et al. reported that Japanese men with localized prostate cancer were more likely than American men to report poor sexual desire and function at baseline. (36) As the cultural context for this difference is not fully understood and the measure used, the Expanded Prostate Cancer Index Composite (EPIC), while translated into Japanese, has not been utilized efficiently for Japanese prostate cancer survivors, it is not easy for Japanese urologists to know how to proactively address erectile dysfunction or other sexual health issues. Interestingly, a nationwide survey of breast cancer surgeons in Japan found that the discussion of sexuality issues was similarly limited in clinical encounters. (37) It is clear that there is a need for further research on how best to support Japanese survivors and their partners both before and after prostate cancer treatment in a culturally relevant manner. (38) One opportunity would be in the routine use of QOL assessment to guide clinical care. A validation study of EPIC (39) for routine QOL assessment of Japanese survivors could begin to direct care for treatment-related side-effects of prostate cancer treatment in survivorship. Implementing QOL assessment in clinical practice has been shown to not only increase physician and patient awareness of treatment-related symptoms and improve

patient-physician communication during the consultation; it also helps address these concerns in a timely manner. (40-42)

## Psychosocial issues facing Japanese prostate cancer survivors

The impact of prostate cancer and its treatment on the psychosocial, including sexual, well-being of individuals and couples cannot be overstated. (43, 44) Prostate cancer survivors make difficult decisions about which treatment to pursue and once treated, (45, 46) must learn to manage the psychological hardship of a cancer diagnosis, post-treatment complications (e.g., erectile dysfunction, incontinence), and even anticipated death. (47-49) However, the volume of Japanese research in this area remains sparse, and the psychological effect of prostate cancer on Japanese patients remains under studied. (50)

We did find three papers that reported the psychological outcome related to prostate cancer treatment in Japan. Namiki et al. assessed 340 Japanese men who had been treated for localized prostate cancer and found subgroups with high psychological distress. Fifteen percent of patients reached a high degree of anxiety. Nearly half (46%) reported a high degree of depression. Men who experienced higher psychological distress had worse urinary and bowel symptoms. Namiki et al. also reported the impact of bother with urinary and bowel dysfunction on social activities among men in Japan and the United States following radical prostatectomy or brachytherapy for localized prostate cancer. They found that the bother associated with both dysfunctions after surgery or brachytherapy for prostate cancer has a greater impact on social function in American men than in Japanese men. In another study, Taoka et al. examined Japanese localized prostate cancer patients treated with radical prostatectomy, brachytherapy, and external radiation therapy. Using validated anxiety and general health scales, they found anxiety was associated with the mental health component summary of SF-8 indicating the interplay between psychological health and well-being among treated prostate cancer survivors.

Depression and anxiety are not rare among prostate cancer survivors. Data from a meta-analysis showed clinically relevant depression to be present in 17%, 15%, and 18% of men before, during, and after treatment for prostate cancer, respectively. Similarly, clinically relevant anxiety was present in 27%, 15%, and 18% of men before, during, and after treatment, respectively. During androgen deprivation therapy for advanced stage prostate cancer, another study found one-quarter of patients might develop psychiatric illness, defined as a composite of depression, dementia, anxiety, insomnia, and psychosis. Notably, suicidal intent in prostate cancer survivors is also associated with both physical and psychological dysfunction.

Japanese urologists manage prostate cancer patients regardless of cancer stage, including those with advanced disease where one in four could develop clinically significant psychological morbidity. Despite extensive experience dealing with medical complications of prostate cancer treatment, urologists are often not proficient in managing problems such as social isolation, depression, job loss, and financial difficulties facing prostate cancer patients. Better understanding the psychological issues facing prostate cancer survivors creates opportunities for urologists to inquire and potentially address these issues, and/or refer patients to appropriate medical and supportive resources.

# Workforce limitations in Japan and the need for multidisciplinary team care in prostate cancer survivorship

Given the extent of collateral issues facing prostate cancer survivors, urologists often need the support of multi-disciplinary partners to provide optimal survivorship care. In other words, high-quality survivorship care requires urologists, in addition to pelvic floor physical therapists for continence rehabilitation, psychologists, sexual and marital counselors, nurse practitioners, physician assistants, peer-group support, dieticians and exercise physiologists. However, unlike in the US, generalist primary care clinicians are less common in Japan (Table 2). For example, the family medicine medical specialty does not This article is protected by copyright. All rights reserved

exist in Japan, and urologists, rather than oncologists, administer chemotherapy for advanced disease. This is quite different from the US where post-acute care for prostate cancer survivors is often delivered by primary care clinicians and advanced disease care is often shared with medical oncology. Broadening medical care teams in Japan to include providers other than urologists could provide some relief to these specialists and allow for more focused application of medical expertise in the care of prostate cancer survivors.

Although nurse practitioners are growing as a discipline in Japan, they are regarded as assistants for physicians and do not take independent roles in clinical practice. In addition, physician assistants as a discipline do not exist in Japan. These mid-level providers play important roles in cancer survivorship care in the US. They may staff cancer survivor clinics during and beyond prostate cancer treatment. In addition, they are often able to spend more time (e.g., 30-40 minutes) with patients and assist with treatment-related symptom management such as erectile dysfunction and urinary incontinence. (58, 59)

Other specialists who may assist in supporting prostate cancer survivor QOL are currently not available in Japan's delivery system for survivorship care. These include pelvic floor rehabilitation physical therapists who help manage urinary incontinence, and sexual health and cancer-related mental health experts who can help manage the impact of sexual symptoms on relationships and distress, respectively. Their presence would clearly benefit survivors' abilities to alleviate treatment-related long-term symptom burdens. For example, recent data from Dieperink and colleagues demonstrate the value of multi-disciplinary team interventions among prostate cancer survivors. (60) Men treated with radiation and androgen deprivation therapy were randomly assigned to a multi-disciplinary counseling program by nurses and physical therapists or usual care. The nurse counseling included psychological support and identified disease-specific problems for the survivor and their spouse. Physical therapists helped improve pelvic floor muscle function and general physical activity. At twenty week follow up, urinary and hormonal domains of the EPIC QOL survey significantly This article is protected by copyright. All rights reserved

improved in the intervention versus control groups. The availability of a multi-disciplinary program for surgical patients that included nurse practitioners, a sexual health therapist and physical therapists improved patients' outcomes and satisfaction with care. (42) Thus, multi-disciplinary programs have the potential to improve survivors' QOL.

# Conceptual model for prostate cancer survivorship care and care planning

While comprehensive prostate cancer survivorship care includes addressing cancer-specific issues (e.g., PSA surveillance), it also needs to address general health concerns and areas of functional, QOL, and psychosocial impairment. For example, most men with prostate cancer die of conditions that are modifiable through lifestyle changes (e.g. cardiovascular and respiratory diseases) or screening (e.g. other cancer). (61, 62) As a result, care for general and preventive health issues are of similar importance to care for the index cancer. In fact, primary care clinicians are often more effective than other specialists in altering survivors' attitudes and behavior, because they are more familiar with behavioral counseling. (63) In the US, family physicians who follow patients in the long term are specialists ideally suited to promote healthy lifestyles for prostate cancer survivors. Currently, this specialty is not yet recognized or available in Japan though the collaboration between specialists and primary care clinicians can foster quality prostate cancer survivorship care.

A robust approach to conceptualizing prostate cancer survivorship care is to link short and long-term care as shown in Figure 1a.<sup>(4)</sup> However, emerging appreciation of the complex problems facing prostate cancer survivors transitioning into long-term survivorship care is currently not reflected in the availability of services and relevant specialists in the Japanese model, and several areas likely need to be expanded as illustrated in Figure 1b.

The US Institute of Medicine and American College of Surgeons Commission on Cancer has recognized that in order to provide complex services in a seamless manner, linkage between services is needed. It has recommended the creation of survivorship care plans to fulfill this function. (4) Survivorship care plans can help coordinate care transitions, This article is protected by copyright. All rights reserved

engage patients and other providers in disease management, and support comprehensive long-term care. A best practice use of the care plan means that every cancer patient be given a record of all care received and important disease characteristics upon discharge from cancer treatment, including recommended treatment of recurrences and side effects of treatment to share with healthcare providers in survivorship (Supporting Data 1). As a result, this survivorship care planning has the potential to both improve the quality of cancer survivorship care as well as address anticipated problems with care coordination across providers.<sup>(64, 65)</sup>

# Challenges and potential solutions in Japanese prostate cancer survivorship care

We found several challenges to providing more comprehensive, multi-disciplinary prostate cancer survivorship care in Japan. First, there are limited general practitioners or Family Medicine specialists to assist urologists in addressing general health issues for survivors. Most internal medicine physicians in Japan tend to focus on specialty diseases rather than on general wellness. However, the Japanese Medical Specialty Board plans to rearrange the primary boards to include a general practice/Family Medicine specialty among the new 19 primary boards. (66) This effort will also increase the number of family physicians. Second, there are no independent nurse practitioners in Japan to provide survivorship care support as outlined above. However, there is a Certified Nurse Specialist system in Japan that could have increasing roles in survivorship care. These nurses provide meticulous care for patients and families dealing with complicated health care challenges as in cancer survivorship. They do have specialty designations such as Cancer Nursing and Psychiatric Mental Health Nursing. At this time they only represent 0.1% of all nurses in Japan indicating more are needed. In addition, unlike their US counterparts, they cannot prescribe medication nor staff independent survivorship clinics, but could be trained to do so. While there are dedicated survivorship clinics in the US, they tend to reside at major cancer centers and their implications for cancer-related outcomes including spending remain unclear. Third, This article is protected by copyright. All rights reserved

according to World Health Statistics, Japan has some of the greatest longevity in the world, highlighting the long-term care needed for cancer survivors. (67) One of the reasons for this longevity involves a traditional lifestyle and dietary habits. Japanese tend to eat a diet rich with fish and plant foods and low in refined carbohydrates and animal fat. This appears to have been quite effective for decreasing lifestyle-related disease including the incidence of prostate cancer. (68) This is supported by the Multiethnic Cohort Study in which first- and second-generation Japanese migrants to Hawaii were found to have higher prostate cancer incidence compared to native Japanese. (68) Recent obesity, physical inactivity, and unfavorable dietary habits (high calorie, high fat, and low vegetable) trends in Japan could trigger an increase the risk of prostate cancer creating even more survivors. (69, 70) Last, there are several clinical guidelines for diagnosis and treatment of prostate cancer available to Japanese urologists. These include JUA guideline, a Japanese version of The National Comprehensive Cancer Network (NCCN) Prostate Cancer Guidelines, and a Japanese version of the Physician Data Query (PDQ). However, we found no clinical guidelines specific to prostate cancer survivorship care in Japan. This lack of Japanese-specific guidance necessitates efforts to translate other survivorship resources as discussed below.

### Prostate cancer survivorship resources to help guide care in Japan

Given the multiple treatment options and numerous adverse effects associated with prostate cancer treatment, addressing late and long-term effects has the potential to improve prostate cancer survivor QOL. (71) We found the number of post-treatment resources for cancer survivors in Japan (e.g. health promotion) to be limited compared to the US indicating opportunities to enhance these resources. (72, 73) Therefore, we highlight several resources for Japanese providers in Table 3 including internet sites for treatment and survivorship care guidelines, decision support, and healthy living recommendations for prostate cancer survivors.

While there is a JUA clinical guideline for prostate cancer, it does not cover many of the issues facing long-term prostate cancer survivors highlighted in Table 4. The recently published ACS Prostate Cancer Survivorship Guidelines can help fill this gap. (20) This comprehensive disease-specific guideline was endorsed by the American Society of Clinical Oncology, (21) and targeted to post-treatment prostate cancer survivors and their providers. The guidelines addresses (1) health promotion, (2) surveillance for recurrence, (3) screening and early detection of second primary cancers, (4) assessment and management of physical and psychosocial long-term and late effects, and (5) care coordination and practice implications. (20)

The ACS guideline goes beyond typical urology-related issues (e.g., management of incontinence and erectile dysfunction, disease-specific QOL) to address other critical health promotion and psychosocial issues discussed above (e.g., dietary advice, physical activity, nutrition, sexual health, anxiety and depression). For example, there are recommendations for 1) use of a post-treatment patient-reported measure of side effect burden (e.g., EPIC for Clinical Practice (EPIC-CP)) (74) to facilitate longitudinal self-management and medical management\_efforts, and 2) at least annual assessment of late and long-term QOL effects (e.g., Sexual Health Inventory for Men) including the psychosocial effects of the cancer diagnosis. (75) Another rich resource offering self, medical, and surgical management for prostate cancer treatment and side effects comes from the Michigan Cancer Consortium recommendations for prostate cancer survivorship care (Supporting Data 2). Although primary care clinicians rarely follow prostate cancer survivors in Japan, these guidelines can assist urologists and radiation oncologists following prostate cancer survivors, as well as other specialists engaged in treatment such as physiotherapists and psychologists. They also offer prostate cancer survivors insight into the opportunities to engage in self-management, diet and other health promotion activities.

Although self-management, diet and other health promotion approaches for cancer survivors are not well-recognized in Japan, lifestyle modification and behavioral change can improve both physical and psychological well-being. Jones and Demark-Wahnefried conducted an extensive literature review regarding health promotion for cancer survivors. (76) They highlighted weight management, nutrition and diet, exercise, smoking cessation, limited alcohol use, sunscreen use, complementary and alternative therapies, osteoporosis prevention, and immunizations. Although controversies exist regarding the intensity, length, and timing of interventions as well as patients' preferred delivery channel, many interventions aimed at lifestyle modifications enhanced the survivors' QOL, and some interventions, especially physical activity, increased survival. (76-80) Furthermore, Yang et al. recently offered insight on how diet may help improve survivorship for the patients diagnosed with prostate cancer in the US. Men eating a mostly Western diet (those in the highest quartile of the Western dietary pattern) had two-and-a-half times higher risk of prostate cancer-related death—and a 67% increased risk of death from any cause—than those ate mostly a "prudent" diet (higher consumption of vegetables, fruits, fish, legumes, and whole grains). (81) Taken together, evidence suggests lifestyle modification and behavioral change recommendations for prostate cancer survivors can improve quality and quantity of life.

# Summary

While comprehensive prostate cancer survivorship care includes addressing cancer-specific issues (e.g., PSA surveillance), it also needs to address general health concerns and areas of functional, QOL and psychosocial impairment. In order to provide high-quality prostate cancer survivorship care, Japanese urologists need to cooperate with a variety of multi-disciplinary providers including pelvic floor physical therapists for continence rehabilitation, psychologists, sexual and marital counselors, peer support, dieticians and exercise physiologists. Although the Japanese health care system is far different from the This article is protected by copyright. All rights reserved

US health care system, efforts to enrich the current approach to long-term survivorship care can improve disease-specific QOL as well as psychosocial and sexual well-being of individuals and couples. In addition, there is increasing QOL research in Japanese men with localized prostate cancer. However, Japanese urologists should also strive to incorporate QOL assessment into routine clinical care and use discussion of outcomes to improve patient-physician communication and address unmet need. Prostate cancer survivorship care guidelines and self-management materials can be especially helpful for providers and patients although translation into Japanese appears warranted.

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#### **Conflict of interest**

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#### Figure Legends

Figure 1. Conceptual models for prostate cancer survivorship care. (4)

1a- An ideal conceptual model of follow up care and cancer survivorship. (Hewitt M et al. The national Academics press 2006.) 1b- A real practice model of cancer survivorship care in Japan. (Continuous circle: real fraction, dashed circle: ideal fraction in Japan)

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#### A list of Supporting Information

**Supporting Data 1:** The Institute of Medicine survivorship care plan. (National Academies Press, Washington, DC 2005.

**Supporting Data 2:** The Institute of Medicine survivorship care plan. (National Academies Press, Washington, DC 2005: Michigan Cancer Consortium Recommendations for Prostate Cancer Survivorship Care.

Table 1: Physical and Psychosocial Long-Term and Late Effects (19)

TREATMENT TYPE	LONG-TERM EFFECTS	LATE EFFECTS			
	Urinary dysfunction	Disease progression			
	<ul> <li>Urinary incontinence (stress)</li> </ul>				
	<ul> <li>Urinary symptoms (urgency,</li> </ul>				
+	frequency, nocturia, dribbling)				
Surgery (radical	Urethral stricture formation (scarring				
prostatectomy: open,	at the urethra)				
laparoscopic,	Sexual dysfunction				
robotic-assisted)	• ED				
	<ul> <li>Lack of ejaculation</li> </ul>				
	Orgasm changes (without erection,				
	associated with incontinence)				
	Penile shortening				
	Urinary dysfunction	Urinary dysfunction			
_	Urinary incontinence	Urethral stricture			
	<ul> <li>Urinary symptoms (dysuria,</li> </ul>	Hematuria due to small blood vessel			
	urgency, frequency, nocturia,	changes			
	dribbling)	Sexual dysfunction			
	Hematuria	• ED can be delayed in onset 6 to 36			
Radiation (external	Urethral stricture	mo after therapy			
beam or	Sexual dysfunction	Bowel dysfunction			
brachytherapy)	Progressive ED	<ul> <li>Rectal bleeding secondary to</li> </ul>			
_	Decreased semen volume	thinning/small blood vessel changes			
	Bowel dysfunction	of anterior rectal wall mucosa			
	Fecal urgency, frequency,	Disease progression			
	incontinence				
	Blood in stool				
	• Rectal inflammation, pain				
+	Sexual dysfunction	Osteoporosis, fractures			
	• Loss of libido	Metabolic syndrome			
	• <b>E</b> D	Cardiovascular disease (possible			
	Other	increased risk of myocardial			
Hormone (androgen	Hot flushes/sweats	infarction)			
deprivation therapy)	Weight gain, abdominal obesity	Diabetes; decreased sensitivity to			
	Change in body image	insulin and oral glycemic agents			
	• Excessive emotional reactions and	Increased cholesterol			
	frequent mood changes	Increased fat mass and decreased			
	Depression	lean muscle mass/muscle wasting			

- Fatigue/decreased activity
- Gynecomastia
- Anemia
- Body hair loss
- Dry eyes

- · Venous thromboembolism
- Vertigo
- · Cognitive dysfunction
- Disease progression



Expectant
management (active surveillance or

watchful waiting)

- Stress, anxiety, worry
- Risks associated with repeat biopsy (active surveillance), PSAs and DREs
- Symptoms associated with disease progression

Disease progression

#### GENERAL PSYCHOSOCIAL LONG-TERM AND LATE EFFECTS

- · Depression, depressive symptoms
- Distress (multifactorial unpleasant experience of psychological, social, and/or spiritual nature)
- · Worry, anxiety
- Fear of recurrence
- Pain-related concerns
- End-of-life concerns: death and dying
- · Changes in sexual function and/or desire
- Challenges with body image (secondary to surgery, hormonal therapy)
- · Challenges with self-image
- · Relationship and other social role difficulties
- Return to work concerns and financial challenges

ED, indicates erectile dysfunction; PSA, prostate-specific antigen; DRE, digital rectal examination.

† According to the National Cancer Institute Dictionary of Cancer Terms, active surveillance indicates a treatment plan that involves closely watching a patient's condition but not giving treatment unless there are changes in test results that show the condition is getting worse. Active surveillance may be used to avoid or delay the need for treatments such as radiation therapy or surgery, which can cause side effects or other problems. During active surveillance, certain exams and tests are done on a regular schedule. It may be used in the treatment of certain types of cancer, such as prostate cancer. It is a type of expectant management. Watchful waiting indicates closely watching a patient's condition but not giving treatment unless symptoms appear or change. Watchful waiting is sometimes used in conditions that progress slowly. It is also used when the risks of treatment are greater than the possible benefits. During watchful waiting, patients may be given certain tests and exams. Watchful waiting is sometimes used in prostate cancer. It is a type of expectant management.

Table 2. Comparison of health care providers involved in prostate cancer survivorship care in US and Japan.

Provider characteristics	US	Japan		
Number of Doctors <sup>a</sup>	798,398	288,850		
Density per 1000 population	2.5	2.3		
Internal Medicine (% in doctors) b	108,817 (13.6%)	61,177 (21.2%)		
Family Medicine/General Practice (% in doctors)	106,391 (13.3%)	-		
Urology (% in doctors)	9,824 (1.2%)	6,754 (2.3%)		
Hematology and Oncology <sup>c</sup>	12,724 (1.6%)	-		
Medical oncology d	-	1,050 (0.3%)		
Number of Nurses <sup>e</sup>	1,427,497	1,470,421		
Density per 1000 population	4.4	11.5		
Number of nurse practitioner (% in nurses)	158,348 (11.1%)	-		
Certified Nurse Specialist (% in nurses)	-	1,466 (0.1%)		
Number of physician assistant <sup>f</sup>	95,108	-		
Density per 1000 population	0.3	-		

<sup>&</sup>lt;sup>a</sup> US (2010), Japan (2012)

(http://www.jsmo.or.jp/authorize/lists.html)

<sup>&</sup>lt;sup>b</sup> This number does not include internal medicine subspecialists

<sup>&</sup>lt;sup>c</sup> Hematology and oncology are separated in Japan.

<sup>&</sup>lt;sup>d</sup> The number is from the report from Japanese society of medical oncology (September 2015). Medical oncology is subspecialty board in Japan.

<sup>&</sup>lt;sup>e</sup> US (2010), Japan (2010)

Table 3: Prostate cancer resources for health care providers and patients in US and Japan

# US JP Treatment guidelines for urologists NCCN clinical practice guideline for prostate Japan Urological Association, Clinical guideline for cancer, prostate cancer, http://www.nccn.org/professionals/physician\_gls/f http://minds.jcqhc.or.jp/n/medical\_user\_main.php guidelines.aspquideline PDQ Prostate Cancer Treatment-for health Japan Society of Clinical Oncology, Clinical professionals, practice guideline for prostate cancer, http://www.cancer.gov/types/prostate/hp/prostate-t http://www.jsco-cpg.jp/guideline/26.html reatment-pdq#section/\_1 Up To Date for health professionals, NCCN guideline, Japanese translation, http://www.uptodate.com/ http://www.tri-kobe.org/nccn/guideline/urological/ PDQ Prostate Cancer Treatment- for health professionals, Japanese translation, http://cancerinfo.tri-kobe.org/

#### Treatment decision guidance for patients

NCCN guideline for patients,
http://www.nccn.org/patients/

American Cancer Society Fact sheet for
professionals, http://www.cancer.org/
Up to date for patient information,
http://www.uptodate.com/
Cancer patient education network,

http://www.cancerpatienteducation.org/

Public service (Information for prostate cancer),
http://ganjoho.jp/public/cancer/prostate/treatment\_
option.html
Private network (Senyu-Net; Prostate cancer
support network), http://pros-can.net/index.html

Private network (Senyu-Net), http://pros-can.net/01/01-1.html

#### Prostate cancer survivorship care guidelines for health providers

American Cancer Society Prostate Cancer Survivorship Guidelines, http://onlinelibrary.wiley.com/enhanced/doi/10.332 2/caac.21234/

None

Michigan Cancer Consortium, http://prostatecancerdecision.org/index.htm MD Anderson Cancer Center,

http://www.mdanderson.org/education-and-resear ch/resources-for-professionals/clinical-tools-and-re sources/practice-algorithms/survivorship-algorithm s.html

# Post-treatment resources for cancer survivors including healthy living issues

NCCN Clinical Practice Guidelines in Oncology,
Survivorship: www.NCCN.org
ASCO Guidelines for Survivorship Care,
http://www.asco.org/asco-releases-first-three-guid
elines-cancer-survivorship-care
Up to date for patient information,

NPO project, http://kibou.jp/survivorship.html

Pharmaceutical company sponsored service, http://www.gan-guide.jp/

Private network (Senyu-Net; Prostate cancer support network), http://pros-can.net/index.html
Official network related to work opportunities,
http://survivorship.info/index.html

Private Network related to work opportunities, http://workingsurvivors.org/

# Post-treatment resources for cancer survivors and partners regarding sexual health

Michigan Cancer Consortium,

http://www.uptodate.com/

http://prostatecancerdecision.org/index.htm

American Association of Sexuality Educators,

Counselors and Therapists,

https://www.aasect.org/

Society for Sex Therapy and Research,

http://www.sstar.org/

Sexual Medicine Society of North America,

http://www.smsna.org/V1/index.php

International Society for Sexual Medicine,

http://issm.org/

None

Author M

Table 4 Comparison between American Cancer Society (ACS) prostate cancer survivorship guidelines and the Japan Urological Association (JUA) clinical guideline for prostate cancer

Guideline	Anemia	Bowel dysfunction	Cardiovascular and metabolic effects (ADT)	Distress, depression, PSA anxiety	Fracture risk, osteoporosis (ADT)	Sexual dysfunction, body image	Sexual intimacy	Urinary dysfunction	Vasomotor symptoms ( ADT)
ACS prostate cancer survivorship guidelines	•	•	•	•	•	•	•	•	•
JUA clinical guideline for prostate cancer	O*1		O*1		O*1	○*2		•	

<sup>\*1</sup> Only mention risk

ADT: Androgen deprivation therapy

<sup>\*2</sup> Recommendation of penile rehabilitation using PDE5