



PROSTATE CANCER SURVEY REPORT:
A CANADIAN PERSPECTIVE

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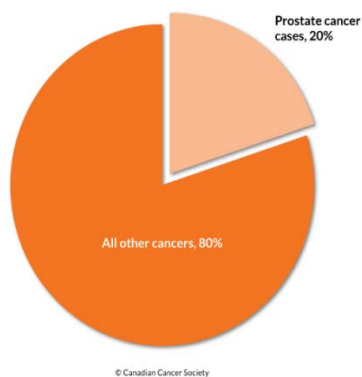
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(i) ABOUT PROSTATE CANCER IN CANADA

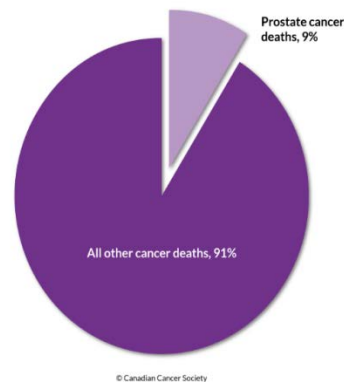


Prostate cancer is the most commonly diagnosed cancer among Canadian men. 22,900 men were diagnosed with the disease in 2019¹ which accounted for approximately 1 in 5 or 20% of all new cancer cases in men. Sadly, it is the 3rd leading cause of death from cancer in men in Canada, accounting for 10% of all cancer death.¹

Percentage of All Estimated New Cancer Cases in Men in 2019



Percentage of All Estimated Cancer Deaths in Men in 2019



1 in 9 males is expected to be diagnosed with prostate cancer in their lifetime.²



According to the Canadian Cancer Statistics,² almost all prostate cancers (99%) are expected to occur in men 50 years of age or older. There is a dramatic variation in prostate cancer incidence across the country, likely largely due to differences in the use of prostate-specific antigen (PSA) testing rather than differences in risk.²

Survival rates for men with prostate cancer have indeed increased over the years, resulting from improved screening and treatment options. There is a subset of the prostate cancer population who acquire a no evidence of disease (NED) status after successful treatment. Others are

diagnosed with a slow-growing cancer which requires several years to progress, and these men can nevertheless lead productive, fulfilling lives after adopting the watchful waiting approach. There are, however, men whose cancer is diagnosed at an advanced stage because its biology is fast growing due to its aggressive nature. Men who undergo radical surgical procedures report long-lasting side effects which compromise quality of life, and have a need to share these treatment-induced side-effects with other men who are undergoing those same challenges in a supportive care setting or with psychosocial experts.

Regardless of the subtype of prostate cancer with which a man is diagnosed, promoting awareness of the pathology is critical in helping to prevent and/or effectively treat the disease as well as helping to empower patients and their caregivers. Generally, the earlier prostate cancer is diagnosed and treated, the better the patient's outcomes will be, and promoting awareness of the disease plays a significant role in helping to secure an early diagnosis.

The information captured through CCSN's patient and caregiver survey may assist in promoting awareness among the general population. More importantly, survey results may help prostate cancer patients and caregivers going through the journey who may benefit from the information captured, given that it reflects the perspectives, values and preferences of the patients, survivors and caregivers surveyed throughout their prostate cancer journey.

(ii) ABOUT THE CANADIAN CANCER SURVIVOR NETWORK (CCSN) & THE PROSTATE CANCER SURVEY

The Canadian Cancer Survivor Network (CCSN) is a Canadian charity and a leader in patient participation in healthcare, with a mandate to educate the public and policy makers about cancer survivorship, and engage in research on ways to alleviate barriers to optimal cancer care in Canada.

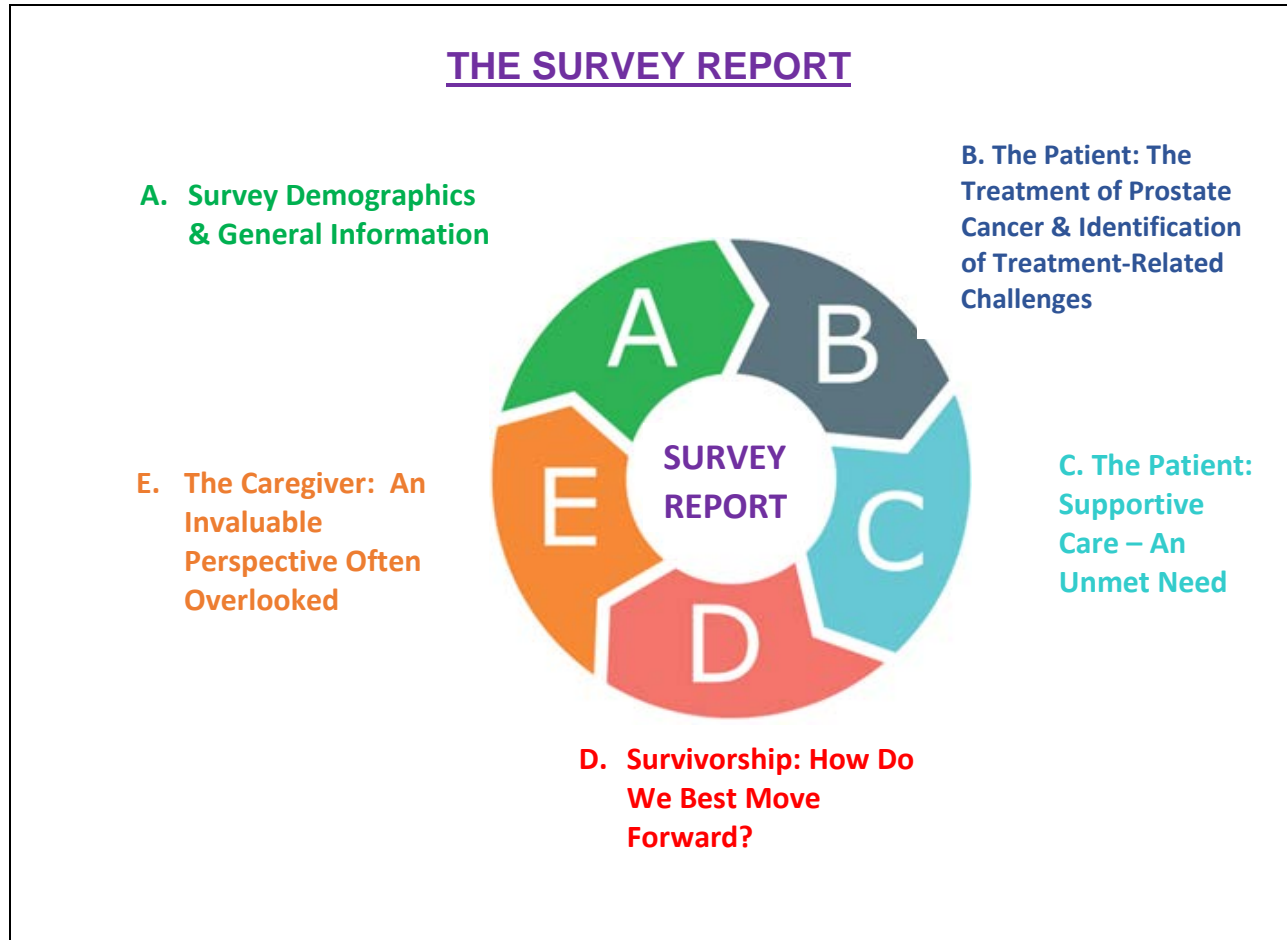
In August 2018, CCSN employed a thoughtful and comprehensive national prostate cancer survey to help capture the patient, survivor and caregiver perspective on the prostate cancer journey from diagnosis to survivorship. The purpose of this survey was to help the prostate cancer community better understand the journey that prostate cancer patients, caregivers and survivors experience during their transition from diagnosis, to treatment, to follow-up and finally to survivorship.

The survey was administered via Survey Monkey to prostate cancer patients, survivors and caregivers, and this report written to help the prostate cancer community as well as CCSN to develop key messages for future information and education campaigns. The objective of these campaigns is to improve the quality of life for prostate cancer patients, survivors and caregivers across the continuum of prostate cancer care and the journey of Canadians face after a diagnosis of prostate cancer.

The data captured in the survey results is presented in this report, which reflects the experiences, perspectives, values and preferences of those patients, survivors and caregivers who completed the CCSN's survey. We thank them for sharing their personal stories with us.

PART II: THE PROSTATE CANCER SURVEY REPORT FINDINGS

The prostate cancer report has been organized according to the following five sections:



A thorough description of each section is based on survey results and the open-ended replies furnished by patients, survivors and caregivers who completed the survey.

If you have any questions or concerns regarding the content of the Report, please contact CCSN via email at info@survivornet.ca or phone at **613-898-1871**. CCSN is happy to assist.

PART A: SURVEY DEMOGRAPHICS & GENERAL INFORMATION

To help capture the patient, survivor and caregiver perspective on the prostate cancer journey, the Canadian Cancer Survivor Network (CCSN) conducted a national online survey in 2018, surveying prostate cancer patients, survivors, and caregivers residing both within and outside of Canada. There were **134 respondents** who completed the survey, representing all provinces within Canada with the exception of the Northwest Territories, Yukon and Nunavut. Additionally, three respondents were identified from Florida, Texas, and Australia, for a total of 137 survey respondents.

The 137 respondents were identified as follows according to Question 5 (**Q5**) of the survey:

- 59 prostate cancer patients in active treatment.
- 64 survivors.
- 14 caregivers.

Total: 137

The diagnosis of prostate cancer can be challenging and often drawn out because other health conditions have to be ruled out before making a formal diagnosis of prostate cancer. Men and their partners may worry and experience feelings of anxiety, isolation and trepidation. This is a completely normal response to a set of highly stressful circumstances.

According to the survey results, **80%** of patients were diagnosed between 51 and 70 years of age (Q3), and according to the responses to **Q4**, **86%** of patients and survivors had their disease initially diagnosed through **Prostate Specific Antigen (PSA) testing**. The second most utilized method of diagnosis was a digital rectal exam performed by a healthcare professional. A biopsy then pathologically confirmed the results of both those of these methods of diagnosis. Other methods of diagnosis included:

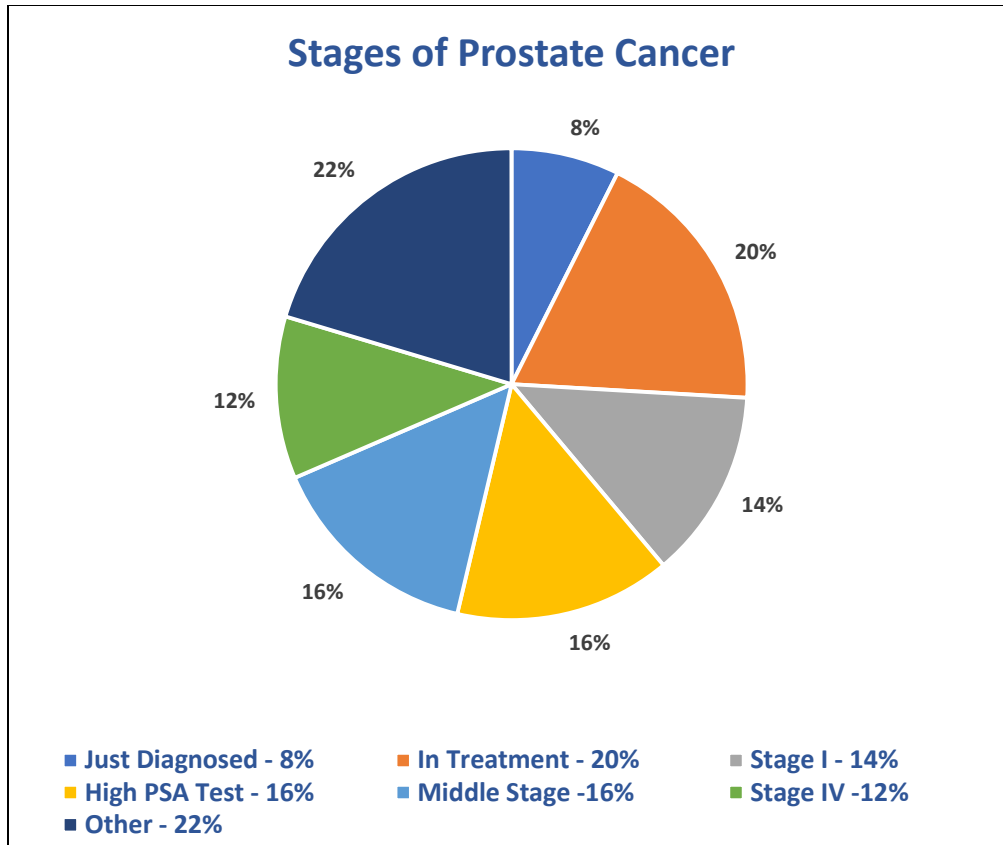
- Description of symptoms.
- Bloodwork.

The following open-ended replies were furnished in **Q4** of the survey results:

“TURP surgery. They took prostate specimens and pathologist confirmed I had high grade prostate cancer.”

“Biopsy of the prostate (confirmed cancer).”

Q6 stratified patients according to where they were in their disease journey. 50 patients responded to the question from a possible 59 patients. Disease stage distribution captured in the survey results were as follows:



The “*Other*” category (22%) identified patients who experienced a recurrence of their disease as well as patients who assumed a watchful waiting approach for their cancer:

“5 years after radical prostatectomy, PSA has reappeared and started to rise.”

“10 years after my diagnosis, despite 4 urologists (except 1) saying I needed surgery, I changed my diet (to vegan) and followed a course of watchful waiting. I’ve never had a high PSA reading since my initial diagnosis. All is well. I wish the medical community would talk more about prevention via diet.”

“I underwent radical prostatectomy in September 2016. Recent blood tests showed increasing PSA. Am awaiting radiology treatment.”

“Biopsy revealed low-grade cancer several months ago. Gleason score of 6 (3+3); 1 of 12 cores 40% positive. MRI in less than week to see if this gets upgraded.”

PART B

THE PATIENT: THE TREATMENT OF PROSTATE CANCER & THE IDENTIFICATION OF TREATMENT-RELATED CHALLENGES

Improvements in the management of prostate cancer have favorably affected patient outcomes such that the death rates have declined in the past 20 years (2.8% per year since 1994).³ The decline likely reflects improved treatment following the introduction of hormonal therapy for early and advanced-staged disease as well as advances in radiation therapy.³ This is wonderful news for the prostate cancer population.

However, a high proportion of patients with advanced stage disease will nevertheless succumb to the disease. The five-year relative survival rate is 28% for Stage IV patients⁴ whose cancer has spread to distant organs. Additional therapeutic options are clearly required for this subset of the population.

For those patients who do survive the disease, there may be other challenges they face, such as treatment-induced toxicities, coping with long-term side-effects of the treatments, fear of recurrence, self-esteem issues, and more. These issues were addressed in CCSN's survey, and patients provided thoughtful and compelling open-ended responses, which are discussed below.

Patients were asked about any issues they may have faced during their prostate cancer treatments (Q9). The majority (36%) selected **Significant Side Effects of Treatment** followed by **Psychological Health Issues** (24%). They provided the following open-ended replies to support their selection:

"I feel fatigued ALL the time."

"Side effects of treatment while not severe are nevertheless impactful on quality of life and mental health."

"I find that the system, at least in New Brunswick, is not adapted, support wise. You get info from the urologist, but then, after that, you are left alone without any formal support group."

"Treatment wait times are the issue – way too long."

"Waiting one-and-a-half months for MRI at Ottawa Hospital."

"Was lucky, had minimal side effects from the chemo, but started getting medications to counteract the side effects of other medications. Trying to keep meds to a minimum. Am a person who took five or six Tylenol a year to taking up to 18 pills a day."

"Side effects of treatment, while not severe, are nevertheless impactful on quality of life and mental health."

When patients who were actively undergoing treatment were asked to rate their Quality of Life (QoL) in the past 12 months on a scale of 1-10, where 1 represents poor and 10 represents very good, **76%** selected between 7 and 10. They furnished the following open-ended replies (**Q7**), which identified **sexual function, fatigue and incontinence** as the most notable treatment-related issues:

“I feel good but my sex life is not.”

“I suffer from involuntary urinary incontinence and I must change my Depends diapers at least 4-5 times daily. My bones ache, especially hips, thighs and lower back. I suffer from ED. I haven’t had an erection since February 2017. I also suffer from mood swings. I have gained 20 pounds since I am on hormone therapy. In reality, it’s chemical castration. I will have my bone scan this month or the latest, next month. If the results are good, my uro-oncologist will take me off of hormone therapy. Thank god - it will be 2 years that I have been on it.”

“Following treatments: issues with bowels, bladder and sexual function.”

“Feel very good, except get the sweats every so often, mostly in the evening.”

“My prostate cancer has not really bothered me, just the treatments. But I understand the need for them. Reason I am not a 10 is occasional depression and stress as well as some negative impact from chemotherapy.”

“Able to continue most activities, other than sex, albeit with less energy than previously.”

Q13 asked patients to specifically list the main issues they faced once their treatments were completed. For those patients who had undergone treatments, the majority selected **significant or long-term physical side effects of treatment (34%)**; **psychological/mental issues** also scored high (**14%**). Patients furnished the following open-ended replies to support their choice:

“The impact of sexual health (and by extension quality of life and mental health) is not adequately recognized by healthcare system. There is no public coverage of erectile dysfunction drugs for men with prostate cancer – this needs to be addressed.”

“Severe urinary and bowel issues continuing 17 months after completing treatment. Very significant (excruciating pain) urinary issues right after treatment that were not adequately addressed.”

“Side effects of ADT: depression, loss of sex drive, loss of muscle mass, weight gained as fat, etc. A lot of serious stuff that I wasn’t prepared for.”

“Hot flashes and loss of sex drive.”

“Effects on bowels, bladder, and sexual function.”

“ED and incontinence. Fatigue.”

∴

Responses to **Q14** identified **anxiety (48%)** as the most readily identified psychological/mental health issue faced during a patient's diagnosis and treatment. It was followed by **fear (14%)**, **depression (12%)**, **uncertainty/destabilization**, and **frequent mood changes**. There was a subset of the population who said they had a **positive mental attitude about it all (20%)** but no anecdotal replies were provided reflecting their selection. Instead, open-ended replies highlighted issues of anxiety, depression and fear:

"Other than ADT causing me to get more emotional about sad things."

"Initially anxiety and fear...even though my doctor recommended watch & wait up front, it took over 6 months of info gathering to be comfortable with the program...now I am pleased with this choice."

"Occasional anxiety, but I've been kept very well informed and that helps a lot."

"Low point reached in Jan 2018. Had cry and then improved. Couldn't eat, not spouse's fault, I couldn't eat."

Patients were asked if they encountered any issues with the healthcare system prior to their diagnosis. While **46%** of patients selected **I encountered no issues**, the majority of patients (46%) had an issue with **length of time before diagnosis** and **identification of health issue**. The following provocative replies were provided by patients in **Q8**:

"I have what could be considered a very low grade prostate cancer...It has been stable after 10 years following 3 biopsies and a scan...My main complaint is that initially it took me over 6 months to obtain the info I need (including a 2nd consult) to feel comfortable with my program..."

"Although my PSA test was up to 4.42 from 1.46 a year earlier, my family doctor never did any follow up. I found out that my PSA was up to 8.51 following a request for my yearly checkup. If I hadn't called, I wouldn't have found out about it."

"PSA test not paid for until you have cancer."

"Waiting time for MRI and biopsy."

"After having an MRI and being told I needed a biopsy – it would have taken much too long so I saw a urologist privately and did get results much faster, which was good, because although the biopsy showed only 5 pieces of the 12 were cancerous, the urologist was concerned about the "aggressivity." My Gleason score was 9/10."

"I was proactive, you have to push sometimes."

"I paid for my own biopsy and have waited almost five weeks to hear when I start treatment."

“Amount of time lost to not having a doctor. Family doctor retired, my specialist died, I waited three years to get a nurse practitioner so I could continue follow-up monitoring on my prostate cancer from 12 years ago. Once PSA test was completed and we saw that my PSA had spiked, the health system worked well, and I started treatment in under a week.”

“My PSA test was positive two years earlier than I was told. If I had not called my doctor for a PSA test, I would not have known for a longer period. It is one thing to tell people to get tested, but if the doctor doesn’t follow up when the test is positive, what is the point?”




“Lack of information regarding possible side effects and poor (wrong) dietary information given during radiation treatment.”

“My initial urologist insisted that I did not have prostate cancer BUT an enlarged prostate that was blocking my urethra and that’s why I couldn’t pee. He assured me that after my TURP surgery I would be able to pee like a 25-year-old. I asked him, are you sure I don’t have prostate cancer and he said that I worry too much. I explained to him that my father is a prostate cancer survivor of 23 years. My dad is now 88 years old. I also mentioned that I have sharp pains in my pelvis area and my rear end. I strongly feel that my initial urologist was not a good listener. He was shocked when my pathology results confirmed I had a high grade form of prostate cancer.”

These replies highlight the need for timely and improved access to care and treatment throughout the care pathway. This would reduce the patient’s anxiety and doubt, allowing them to move forward with a greater degree of ease and confidence in their care path.

Watchful Waiting (also known as **Observation**) is a management option for patients with prostate cancer. It is intended for older men or men with other serious health problems AND/OR men who are not likely to benefit from treatments such as surgery or radiation therapy. Watchful waiting is also a way of monitoring prostate cancer that isn’t causing any symptoms or problems. The aim is to keep an eye on the cancer over the long term and avoid treatment unless the patient becomes symptomatic.

Prostate cancer can grow slowly and may not cause any symptoms as a result. In that asymptomatic setting, employing treatments (such as radiotherapy or surgery such as radical prostatectomy) can cause unpleasant side effects which may include the following:

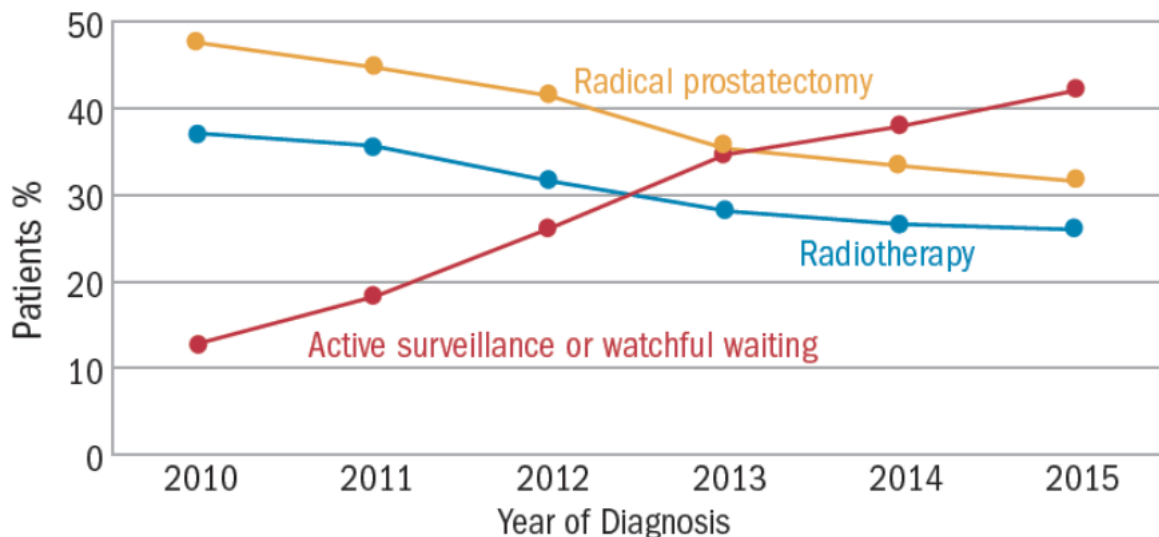
	<p>PROBLEMS ACHIEVING OR MAINTAINING AN ERECTION (ERECTILE DYSFUNCTION)</p> <p>Erectile dysfunction means not being able to get and keep an erection firm enough to have sex. It can result from prostate cancer treatments, including surgery and hormonal therapy.</p>
	<p>LEAKING URINE (URINARY INCONTINENCE)</p> <p>Urinary incontinence is a loss of bladder control. It can happen when a tumour in the prostate grows, presses on the urethra and blocks the flow of urine from the bladder. Surgery or radiation therapy for prostate cancer can also damage the nerves or muscles that control the bladder or the release of urine.</p>
	<p>BOWEL PROBLEMS, SUCH AS DIARRHEA, OR ABDOMINAL DISCOMFORT</p> <p>Men treated with radiation therapy may develop bowel problems, such as irregularity, excessive flatulence, cramping or diarrhea.</p>

For some men, these side effects may be long lasting and may have a significant impact on their daily lives, which is why the Watchful Waiting approach may be suggested.

Watchful Waiting should not be confused with Active Surveillance, which is a management option for patients whose cancer is unlikely to spread or progress in the near term. It consists of strict, regular monitoring of the cancer by the doctor. It allows men to avoid potentially life-altering side effects of treatment while retaining the option to treat the cancer with curative intent should the tumour show signs of progression.

According to a recently-published paper in the *Journal of the American Medical Association*, more men are choosing Active Surveillance or Watchful Waiting to manage their low-risk prostate cancer.⁵ The illustration appearing below nicely highlights how Active Surveillance combined with Watchful waiting are surpassing conventional therapies.⁶

Popularity of prostate cancer treatments



More men are choosing active surveillance or watchful waiting to manage their low-risk prostate cancer.

Source: JAMA, February 19, 2019.

The CCSN surveyed population were asked if they assumed a Watchful Waiting approach to the management of their care (Q11). **46%** responded **Yes**, and then went on to describe any downfalls they see in assuming such an approach to their disease:

“Always on your mind. Concern of it getting worse while waiting.”

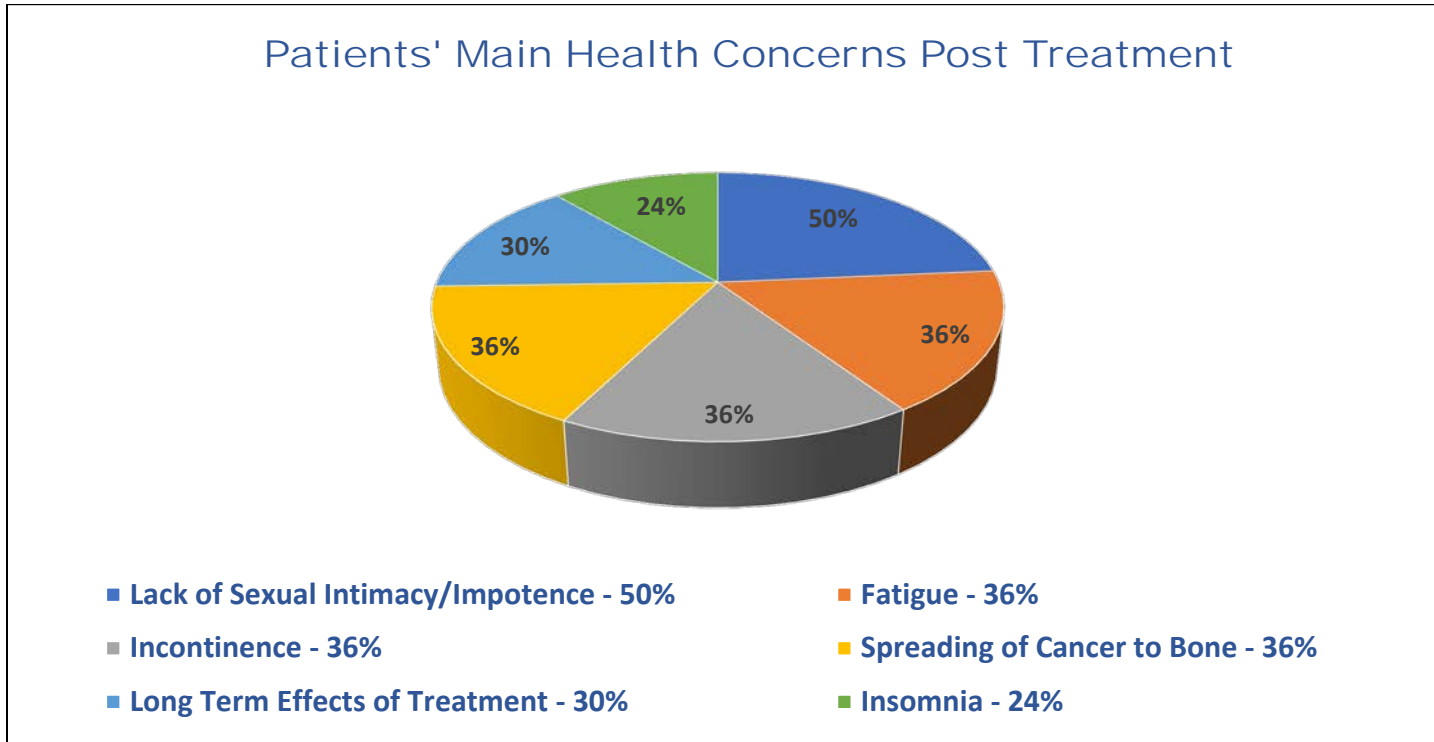
“The first year is difficult waiting for the PSA results, but the more it is stable the more relaxed I became.”

“Always wondering if it is getting worse or spreading.”

“Just knowing that you have this little time bomb.”

Patients were also asked about any barriers in their return to work after treatment (Q19). For those patients who returned to work, **fatigue** was cited as the most commonly experienced barrier preventing patients from returning to work at full capacity, followed by **difficulty concentrating**. **Bowel and bladder functions** followed. For patients who assumed a Watchful Waiting approach for their disease, the barriers which impacted their ability to return to work were psychological in nature, such as **worry, stress and difficulty concentrating** (Q20).

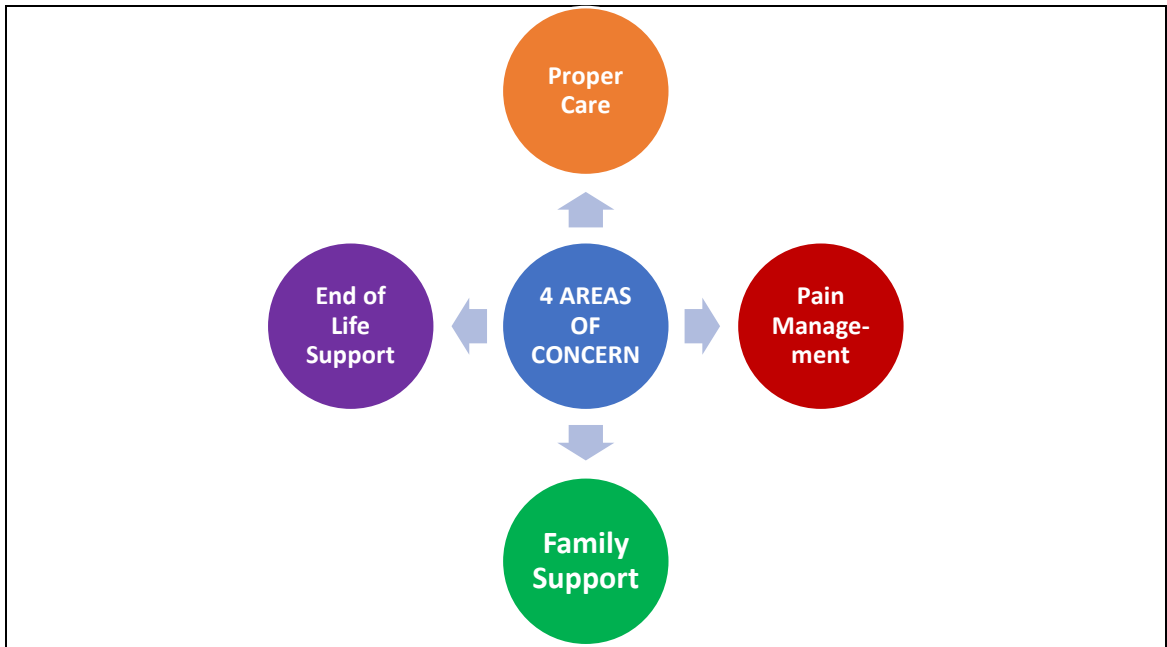
When patients were asked to stipulate their main health concerns post treatment (**Q21**), the following health concerns were identified as highlighted in the pie chart below:



And the following thoughtful open-ended reply was provided:

“Future treatments when necessary will severely impact sexual health. hormone treatments kill libido and result in impotence (irreversible after extended treatment), among other significant adverse effects.”

The advanced stage patient population was asked what their key concerns were in terms of the management of the disease (**Q22**). As per the graphic appearing below, the four areas of concern that were highlighted were:



Patients went on to provide the following input:

“No pain now, but worry about it being in the future. Also not sure how far spousal care will continue in the future towards end of life.”

“How to accept all of this and still plan for future without giving up, and having someone that loves you has helped me live.”

“A difficult question. I hope that chemo and hormone treatment will help in the long run or give me a chance of living out my days in peace of body and mind.”

“I just wonder what is available to me after I finish the current treatment I am on.”

Wives, partners, friends and family members are significant sources of support for men living with prostate cancer. Exhausting that support is always top of mind for patients. Issues surrounding palliative care, the goals of which typically include pain management and end of life support, were also top of mind for the advanced prostate cancer patient. Their objective is to have their quality of life improved while managing their symptoms in the most comprehensive and holistic manner possible.

Q22 identified the areas of concern for the advanced prostate cancer patient. A diagnosis of advanced prostate cancer is difficult to hear, stressful to endure, and for many patients challenging to navigate and to discuss with their loved ones. Thoughtful dialogues with the patient’s healthcare team can help to alleviate some of the burden and anxiety associated with an advanced prostate cancer diagnosis, for these cancer care professionals have special skills, experience and knowledge to support patients and their families throughout this part of the journey.

PART C

THE PATIENT: PROVISION OF SUPPORTIVE CARE – AN UNMET NEED

Patients who are diagnosed with prostate cancer may face a host of treatment-induced issues that can impact quality of life. Some of these treatments include:

- Radical prostatectomy (surgical removal of the entire prostate gland plus some of the tissue around it, including the seminal vesicles).
- Radiation therapy, in the form of brachytherapy or external beam radiation.
- Systemic therapy such as Androgen Deprivation Therapy (ADT).

These treatments can impact a patient both physically and psychosocially. Two frequently reported treatment-induced side effects are:

- Sexual dysfunction (an inability to achieve or maintain an erection).
- Urinary incontinence.

Prostate cancer patients struggle with these side effects and more. The burden of sexual dysfunction, for example, is responsible for the single greatest impact on patient and partner health-related quality of life; even more so than the concern for cancer recurrence (Crowe & Costello, 2003).⁷ Supportive Care Programs may help patients meet the physical, emotional and practical challenges associated with prostate cancer.

Information-based support can provide:

- Information to newly-diagnosed patients on treatment options.
- Information that focuses entirely on the sexual side effects of treatments and sexual rehabilitation.
- Information on the identification and management of all treatment-induced side effects.
- Information on how to assume a healthy lifestyle during and post treatment.

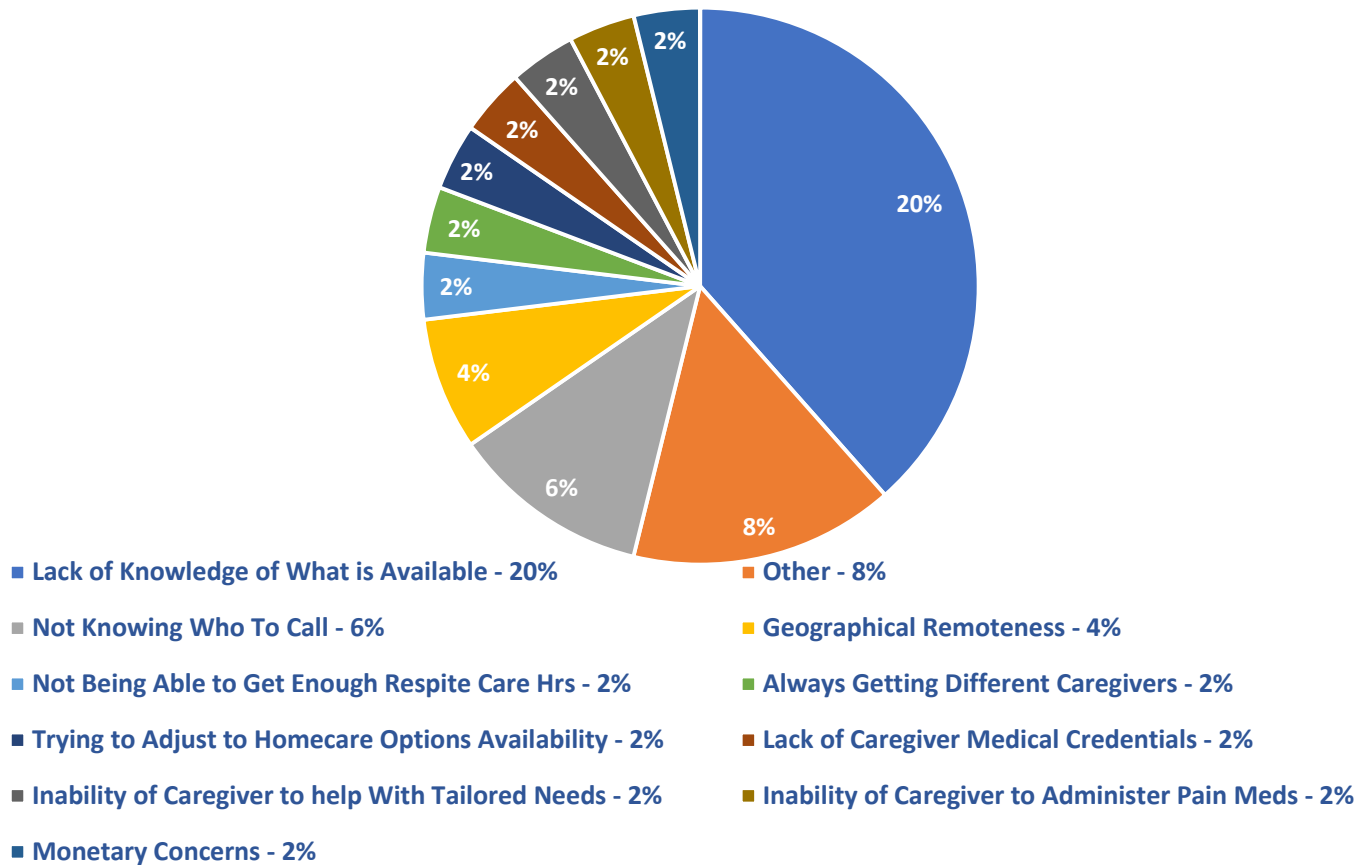
Psychosocial-based support can provide:

- Psychosocial support for patients experiencing anxiety, fear, isolation and distress resulting from a diagnosis of prostate cancer or side effects from prostate cancer treatments.

Questions 23-29 of the survey focused on the provision of supportive care for patients.

54% of patients identified lack of **knowledge of what is available (20%)** as the most important issue. Other issues were identified as follows:

Issues Experienced By Patients Trying to Secure Support



The **Other** category included the following replies from patients:

“I have a family doctor whom I must line up for, sometimes two weeks, and then I see a volunteer lately. One month of stomach issues and my doctor still can’t answer why and she leads my treatment team???”

“I have contacted local support group but none has had my kind of treatments, so got no response. Met with BC Cancer Agency counsellor; he only suggested I journalize feelings – I did not find that to be remotely useful.”

“In my case, if it was not for access to the local Prostate Cancer Support Group and my family doctor’s support to arrange a 2nd consult, it would have taken much longer for me to come to terms with my situation....”

“Once again, the ADT educational program is the most valuable thing I found for dealing with advancing prostate cancer after learning that my surgery and radiation therapy had not controlled the disease. Your organization could be helping thousands of men at little cost by supporting the ADT educational

program. Please check it out at www.LIFEonADT.com and/or look at their Canadian Urological Association endorsed book on ADT.”

“Not knowing who to call.”

“Geographical remoteness.”

“Not being able to get enough respite care.”

“Trying to adjust to homecare availability.”

“Monetary concerns.”

Q24 asked if rehabilitation services were offered during patients’ treatments, and **64% responded No**. One patient offered the following comment:

“I had to go find it myself. It is out there, but not a primary concern of medical staff. Need more emphasis on exercise oncology.”

For those patients for whom rehabilitation services were offered, the following services were listed as having been accessed by patients (**Q25**), and only a fraction (2.1%) paid for those services out of pocket (**Q26**):

- *Physiotherapy.*
- *Psychology.*
- *Counselling.*
- *Follow-up care.*
- *Secondary treatment.*
- *Exercise and sleep counselling.*
- *Dietary counselling.*
- *Bathing & Housecleaning.*

Q27 specifically asked patients if they have any unmet needs they would wish to have addressed through cancer rehabilitation. Patients provided the following open-ended replies, which, once again, dealt with treatment-induced side effects:

“Maintaining physical fitness.”

“Rehab management of symptoms.”

“Would be nice to have more local support from people having gone through the same cancer. There is a local support group, but it is highly insignificant.”

“Management of symptoms – primarily pain management and urinary side effects.”

“Managing ADT side effects.”

“Management of symptoms, sexual health.”

As mentioned above, treatment-induced side effects (specifically, sexual dysfunction and urinary incontinence) were the two most commonly reported unmet needs that patients would wish to see addressed through cancer rehabilitation. Patients expressed a need for support and management of these life-altering side effects.

Q28 asked if there were any additional issues impacting prostate cancer patients. The provision of supportive care for patients was a recurring theme as well as access to accurate information on the management of the disease, as noted below. The provision of information can empower patients and help them feel more in control of their disease – a control they surrendered the day they were given their diagnosis. Information can facilitate increased understanding of their disease and how it is treated. That information can be delivered by their health care providers, nurses and charities.

“Because men are less inclined to seek support and create supporting networks, we have to rely on our physicians to get maximum info. As most of them are over extended and busy, it is very difficult to get proper info and support.”

“Are you aware of any peer navigator programs?”

“Have your prostate checked from your 40s using PSA test and bloods. Of course it would help if you have a family doctor!”

“Sexual health, impotence, coverage of erectile dysfunction drugs.”

“Advice to sons about possible risk.”

“Having access to someone initially to put the situation in perspective...Hearing you have cancer and then waiting to obtain good reliable info is difficult...I can just imagine someone with a more serious case that would be life threatening – very scary!!!”

“1. How to decide which treatments to have; and 2. What to expect during treatments.”

“Education about the disease and its ideopathology.”

It is not surprising that the theme of supportive care came up several times throughout this portion of the survey. Patients have highlighted the need for supportive care to:

- Handle treatment-induced side effects (i.e. sexual dysfunction and urinary incontinence).
- Include accurate information regarding the management of the disease. Patients can feel empowered and in control of their disease through the acquisition of a better and thorough understanding of content. One patient commented:

“I think people today rely on Google to find out the information they think they

want and it is not always the best information.”

- Gain access to emotional support or psychosocial services to help address or alleviate the fears, anxiety, and distress surrounding prostate cancer therapies.

PART D

SURVIVORSHIP: HOW DO WE BEST MOVE FORWARD?

Each year, more Canadian men are surviving prostate cancer and winning back their lives due to better screening and treatment options. Many men having undergone treatment will be cured of their disease after five years even if the cancer has spread to a distant organ(s) of the body. While this is certainly encouraging news, survivors of prostate cancer are often faced with the daunting task of having to manage lingering side effects from the treatments they endured for their disease. The most commonly reported treatment-induced side effects by survivors following prostate cancer treatment are erectile dysfunction and urinary incontinence.

The chance of erectile dysfunction after treatment depends on a number of factors:⁸

- Age.
- Health.
- Sexual function prior to treatment.
- Stage of disease.
- Whether the nerves that control erection were damaged after surgery or radiation.

Men who are treated for prostate cancer will experience erectile dysfunction for at least a short time. For some men, this problem is temporary, but for some men it may be longer. But treatments may be available. A thoughtful discussion with your doctor about which treatment is right for you will help you to learn more and to move forward in a confident and reassured manner.

Urinary incontinence is urine leakage without your control, and may result from prostate cancer treatment. There are essentially four types of urinary incontinence that may result after prostate cancer surgery:⁸

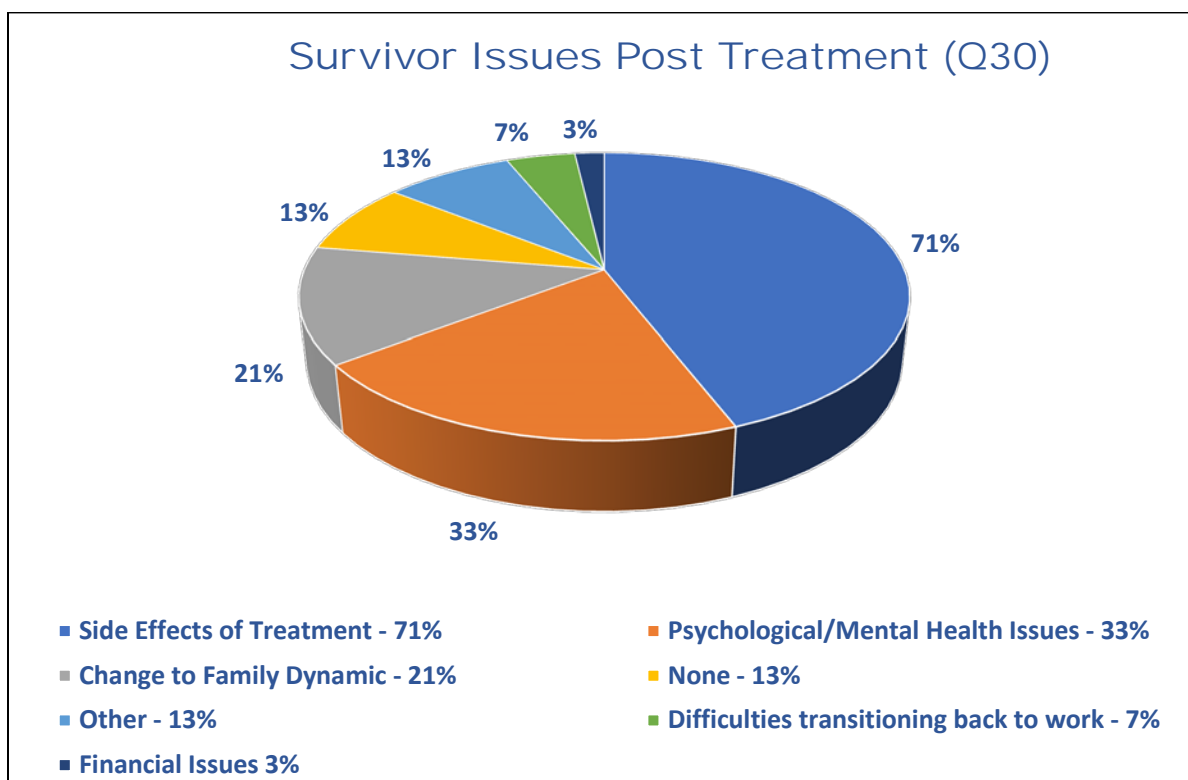
- **Stress Incontinence:** Coughing, laughing, sneezing or exercising can cause urine to leak. This is the most common type of incontinence.
- **Urge Incontinence:** Feeling a sudden, urgent need to go to the bathroom, even when the bladder is empty. This is typically due to an overly sensitive bladder, which is also known as an overactive bladder.
- **Urinary Frequency:** Urinating very often. Going to the bathroom 1-2 times every hour.
- **Mixed Incontinence:** Having more than one type of urinary incontinence.

Urinary incontinence is often short lived and may resolve within 6-12 months.⁸ Treatments are available and choices should be discussed with your treating physician.

Survivors may also feel quite emotional post-treatment as well as fearful that the cancer may recur, or that another type of cancer may develop altogether. These are perfectly normal and anticipated emotions. Survivors and their families will experience a wide range of emotions, from relief and hopefulness to anxiety and fear.

The short-or long-term side effects may impact several areas of a patient's life, causing a whirl wind of emotions that give way to constant trepidation and eventual depression. Whenever possible, turning to family, friends, other men who have or had prostate cancer, and their medical team for support is a helpful coping mechanism in the continuous battle post treatment. The months and years after treatment – known as the **survivorship period** – may present a new set of challenges and support is required for men as they move forward confidently and courageously.

The CCSN Survey Report results identified a number of key issues identified by prostate cancer survivors post treatment as per the pie chart below:



Q30 identified the following **main issues** faced by prostate cancer survivors once treatment was completed:

- **Side Effects of Treatment (71%).**
- **Psychological/Mental Health Issues (33%).**

Both of these are consistent with the evidence in the literature⁸ reported above. Survivors provided the following open-ended responses as well:

“Minor urinary incontinence. Erectile dysfunction.”

“Because radiation virtually destroyed my prostate, I am impotent and no longer able to maintain an erection.”

“Urinary control – dripping when seating in certain positions and when sneezing.”

“Having sex.”

“Extreme incontinence. Changed pads 3-4 times daily. Concerned to stain places I was sitting.”

Survivors identified the following psychological or mental issues they faced after completing treatment of their prostate cancer (**Q31**):

- Anxiety (25%).
- Depression (23%).
- Fear (21%).
- Anger (9%).
- Grief (9%).
- Loneliness (7%).
- Other (13%).

The replies captured in the **Other** category included:

“Feeling like less of a man due to the complications brought on by ED.”

“Impatience general but I also think this comes with age, by the time you have reached my age you have seen a lot. You see people making the same mistakes and you think “come on,” this is not just men, I think women feel the same way.”

“Questioning whether I should have had surgery due to the side effects.”

“Relief, gratitude, survivor’s guilt.”

Q32 asked if the family dynamic had changed for survivors after prostate cancer treatment. While only **2%** responded **Yes**, **47%** of the respondents provided several thoughtful open-ended replies as to how the family dynamic had been impacted. Below are a few of the replies provided:

“Uh boy, its poor dad, maybe we should leave him alone, but get invited to visit the kids who are in their forties, and visit the grand children, etc.”

“No longer interested in intimacy with my partner after surgery.”

“It’s like they are afraid to talk to me about me getting cancer (prostate).”

“I am frustrated, and my wife shows no interest in sex.”

“Lack of sex due to incontinence and ED post operation.”

“Sexuality, in that spouse fails to understand that sex life is not like it was before.”

“Loss of intimacy with my spouse.”

“Sex has ceased to be spontaneous. It requires planning around consuming a Pill first.”

“Lack sexual drive.”

“Loss of sex life.”

“More edgy. We try to laugh about our relationship.”

Survivors identified the following barriers which impacted their ability to return to work in **Q33**:

- Fatigue (15%).
- Difficulty Concentrating (7%).
- 41% of respondents identified other barriers, including:

“Side effects of radiation, i.e. toileting on demand.”

“Leakage of urine.”

“Leakage.”

“Incontinence.”

Not surprisingly, the majority of survivors identified **impotence (62%)** as their main current health concern currently in **Q34** followed by fear of cancer returning (**49%**), Other (**29%**), fear of cancer spreading to other parts of the body (**25%**), and fatigue (**15%**). The “**Other**” category included replies primarily dealing with urinary incontinence issues, i.e. “*Frequent urination, particularly at night.*”

When survivors were asked what they found most helpful in the healthcare system during and post-treatment (**Q35**), the themes that emerged in **PART B** (according to the patient’s perspective) were echoed in this section and equally relevant to the survivor population. The open-ended results clearly highlight the survivor’s need for:

- Information provision on treatment and side effects to help empower patients to feel more in control of their disease through increased understanding.
- Supportive care to deal with treatment-induced side effects post treatment: changes in sexual function and urinary incontinence and more.
- Supportive care services for emotional/psychosocial support surrounding fear of disease recurrence, onset of another cancer, anxiety, and depression.
- Thoughtful, meaningful relationships with healthcare professionals to foster positive outcomes.

Survivors provided the following open-ended replies to support the above:

“Going to PCCN meetings in the West Island of Montreal for discussions and info sessions.”

“Prompt treatment by cheerful nurses and technicians. A doctor with great bedside manner that I had confidence in.”

“Great urologist who provided various treatment options, recommendations and guidance to after treatment support.”

“Local support group.”

“Good doctor, prostate awareness group.”

Survivors were provided with the opportunity to respond to **Q36**, which asked, “What would survivors change about the healthcare system to make it better for either themselves or other patients in the future?”

Survivors acknowledged they had difficulties communicating either with their primary care physician or their treating oncologist/urologist about vital issues in the management of their prostate cancer. Treatment-induced side effects may not have been managed optimally, leaving patients feeling lost, uncertain, unsupported and depersonalized. Survivors felt there was a lack of empathy demonstrated by their treating physician which in turn made it difficult to:

- Ask questions that were psychosocial in nature.
- Seek emotional support services through his treating physician, who showed little interest in his emotional welfare.

Several replies highlighted the need for emotional and psychological support for treatment-induced side effects, primarily urinary incontinence and erectile dysfunction. The need to be supplied with relevant and up-to-date information can help empower patients to feel more in control of their disease through an increased understanding. Accessing that information as well as testing and treatment was also a concern for survivors, as they highlighted in their replies. Below are the eight replies which were representative of the input captured through the 51 responses supplied by survivors:

“Where do I start? A lot of the health system is not bad but like everything else, it can definitely be improved. A lot of the medical staff are not trained very well in two ways: Knowledge, and being civil. Some personalities are abrasive and domineering. When I was in the automotive repair business, we had HR training. But sometimes when left alone to deal with customers or patients, I wish that I had recorded them. This kills our confidence in some of the health system, especially when the same hospital is guilty of it a lot of the time. A sick person, even if miserable due to their circumstances, does not deserve to be treated poorly or badly. Cameras in the different sections of the building that record voices will in a short period of time show which of the staff need to be complimented or dealt with.”

“The side effects of the surgery were not explained sufficiently by my urologist. Far more attention must be given to these effects. For example, I was told that

recovery would take eight weeks. After eight months, I am still recovering. It was only through my own efforts that I found that physiotherapy could be a useful treatment to incontinence.”

“A therapist to talk to about sex after surgery.”

“Increase awareness, more information and shorter waiting time for treatment.”

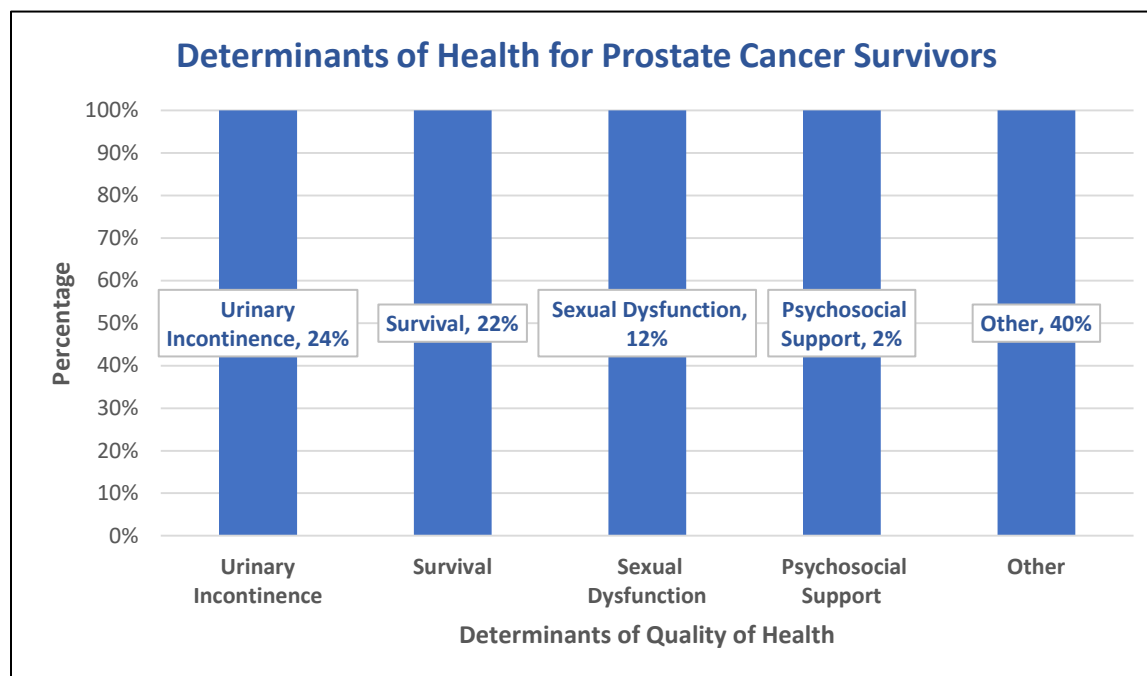
“A clearer, more realistic explanation of the side effects of treatment. And, more proactive assistance with the psychosocial aspects of recovery and living with side effects.”

“Better road maps of the various treatment options.”

“Faster biopsy results.” and “Shorter wait times to see specialists.”

“I don’t believe that some of our GPs are sufficiently well trained. They are reactive rather than pro-active. Also, they tend to be bound by outmoded medical models from the nineteenth century.”

Survivors identified the following determinants of Quality of Life when living with prostate cancer in Q37:



Not surprisingly, urinary incontinence, sexual dysfunction and longevity (overall survival) ranked among the top three responses. **33%** of survivors were offered cancer rehabilitation services according to Q38 during and/or after their treatment for prostate cancer. According to the open-

ended replies, some survivors had to find these services on their own and found great benefit, while others were referred to the local chapter of the Prostate Cancer Canada Network (PCCN). This Network is intended for all prostate cancer survivors who can benefit from the experiences of men having gone through the journey of prostate cancer and are willing to share their story and valuable perspective with others newly diagnosed or new to the supportive care setting. The Support Groups attempt to demystify and destigmatize the disease experience and eliminate the isolation and loneliness for those men and their families undergoing the experience by providing support and information.

Q39 asked survivors what rehabilitation services were offered to them and the following replies were provided:

“Home care.”

“Local services were available.”

“Counselling.”

“Support Group.”

“Hope and Cope Services.”

“Services of a physiotherapist to help with incontinence.”

“Prostate cancer support group.”

“Some psychosocial counselling, some therapies to recover erectile function, all of which failed.”

“Various instructional classes such as sex after cancer etc lots of newsletters from prostate cancer groups.”

A small subset of the survivor population (**16%**) were required to pay out of pocket for their rehabilitation services, according to **Q40**. When asked if there were any specific needs they would wish to see addressed through cancer rehabilitation, the following thoughtful replies were furnished in **Q41** by survivors:

“Cancer support group is important for emotional support.”

“Someone to talk to concerning sex after surgery and include my partner.”

“Emotional support. I did not know where to turn. My side effects were and are still quite prevalent and it's been over two years since my last radiation session.”

“ED support.”

“Much more attention has to be given to the side effects, specifically impotence and incontinence.”

“Better physical rehabilitation, more thorough exploration of alternative therapies for both incontinence and erectile dysfunction.”

“I paid out of my own pocket for “pelvic floor physiotherapy” which greatly helps to reduce my incontinence, to “mild stress incontinence” to the present day, and this is something that all men in these situations require. I also feel that all hospitals that deal with prostate cancer require a significant nurse with tremendous experience in the impact of prostate cancer treatment such as ED and its psychological impact available to its patients. Currently, some of the even larger hospitals such as Sunnybrook Health Sciences Centres do not have this.”

“Group sessions among cancer survivors would have been helpful.”

“An exercise programme to counteract the upper body muscle loss and bone density loss due to long term androgen deprivation therapy.”

The mention of the specialist nurse above echoes the sentiments of patients throughout the survey results. Access to a specialist nurse may permit patients to discuss aspects of their disease/care with someone who is highly skilled and trained in this disease site. Nurses may serve as patient and caregiver advocates, furnishing referrals, providing explanations and providing support during critical times in the trajectory of the disease. They can be a positive experience in an otherwise difficult and challenging cancer journey.

Q42 asked if there were any particular issues they felt impacted survivors of prostate cancer that had not been covered in the survey. Survivors identified issues with respect to:

- Trying to obtain life insurance once diagnosed with prostate cancer.
- Bowel function and changes in bowel habits.
- Awareness of prostate cancer and how important it is to obtain regular PSA testing.
- Incorporating nutritional information into the clinical management of the disease to improve patient outcomes.
- Living life to its fullest and thriving despite the possibility of disease recurrence.

PART E:

THE CAREGIVER – AN INVALUABLE PERSPECTIVE OFTEN OVERLOOKED



A prostate cancer diagnosis can be equally frightening for the caregiver, who can be a spouse, family member, friend or loved one. The caregiver may take on many roles in the course of the prostate cancer patient's journey. They will assume the role of medical translator, information specialist, financial advisor, psychosocial expert, and much more. Quite often the caregiver's function is overshadowed or under-valued, in large part because the focus is typically on the patient, thus discounting the essential role played and meaningful contribution delivered by the caregiver.

There is, however, much to glean and learn from the caregiver perspective. The role commands respect as they undergo enormous challenges supporting a man with prostate cancer, regardless of disease stage. The CCSN Prostate Cancer Survey sought to capture the caregiver perspective from Q44-49. Appearing below are the results and open-ended replies from those questions administered.

Caregivers were asked if they encountered any issues while caring for someone with prostate cancer (Q44). Thirteen caregivers responded to the question and **77%** selected:

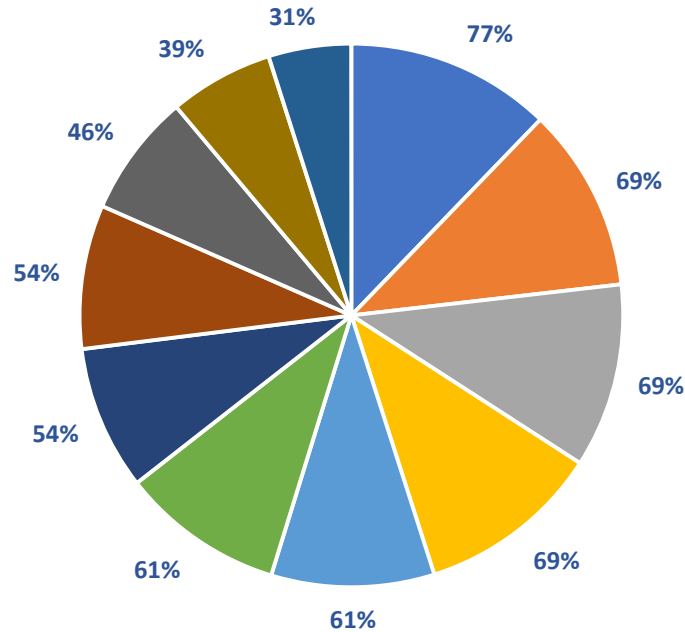
“Emotional drain and/or trauma for the caregiver.”

This selection is in keeping with the stress a caregiver undergoes once a prostate cancer diagnosis is delivered to a patient and his loved ones. It tends to impact more than the patient for whom the diagnosis is intended. The diagnosis can be stressful and a confusing time for the caregiver – fraught with emotional turmoil and trauma. Speaking to doctors, understanding various treatment options, providing support to the patient while taking care of the family, and often maintaining a full-time job can be quite onerous and taxing on the caregiver's emotional state.

Caregivers selected the following issues while caring for patients with prostate cancer and inserted two relevant open-ended comments:

“Lack of intimacy” and “Connection to a social worker and psychosocial support.”

Issues Faced By Caregivers While Caring For Patients



- Emotional Drain and/or Trauma For Caregiver - 77%
- Hours Spent in Medical Appointments - 69%
- Physical Fatigue - 61%
- Management of Side Effects - 54%
- Hours Spent on Medical Information Seeking - 46%
- Lack of Medical Know-How - 31%
- Insomnia - 69%
- Lifestyle Changes - 69%
- Ongoing Worry about Prognosis - 61%
- Inability to Plan Ahead - 54%
- Weekly Volume of Hours Needed from a Caregiver - 39%

Living with prostate cancer implies adapting to a new norm, not only by the patient, but by the caregiver as well. The cancer journey, however, can be a difficult one as expressed repeatedly by patients and their caregivers. Caregivers can be reticent to request help, for they may feel a sense of weakness in so doing or a burden to the person to whom they are turning. Caregivers may feel compelled to do everything on their own. They may feel that since the patient is enduring such a difficult journey, they as the caregiver are, therefore, responsible for assuming the entire burden of care. It is painful for them to admit that they cannot do it all while continuing to maintain their own health and sanity intact. They will strive to meet every challenge for their loved one and if they fall short, feelings of depression and waves of helplessness often overwhelm them.

In those times, the support of friends and family is key.

Q45 asked where does the caregiver seek support for themselves? **54%** of the respondents selected “**Through Friends & Family**” and “**Reading Books and/or Websites.**” Caregivers also selected:

- Visits with a psychologist or other mental health professional (**23%**).
- Through my faith (**15%**).
- Local Support Group (**7%**).
- Online Support Group or Forum (**7%**).

But no one selected a patient organization. There are many kinds of support programs, including one-on-one or group counselling and support groups. A support group can be a powerful tool for both people with cancer and those who care for men with prostate cancer. Speaking with others who are in similar situations can be empowering, and may help to ease the isolation and loneliness experienced by caregivers. Tips may be shared, lessons learned may be pooled, and useful ideas can help other caregivers move forward in a confident and courageous manner.

Q46 of the Survey asked caregivers what support services could be improved upon for caregivers of individuals with prostate cancer. The most popular open-ended reply was (**62%**):

“To be made aware that there are organizations and support groups.”

The need for supportive care services was clearly top of mind for caregivers.

“I wish there was a support group for caregivers, close to where I live.”

“Prostate cancer group meeting at the hospital...”

“Meetings with other caregivers.”

Support services are required for caregivers to stay healthy, be good caregivers, and allow them to stay in the caregiving role. Access to social support can lower distress and allow not only patients but also caregivers to feel less burdened.⁹ The importance of social support and the role it plays in promoting quality of life cannot be underestimated in cancer patients or in caregivers, and it is well illustrated in the literature.^{10 11}

When asked what issues they encountered in securing support for themselves or for the patient, **46%** of caregiver respondents identified “*a lack of knowledge of what is available*” and **23%** identified “*Not knowing who to call*” (**Q47**).

“Aside from the doctor in charge, there were no specific prostate cancer resources in my city. I reached out to Prostate Cancer Canada and got some resources and was to get a call back but that never happened. Luckily, I had family and friends who were there to support me.”

Caregivers provided the following thoughtful input (**Q48**) on issues that could be further explored regarding the caregiver’s role and how the prostate cancer journey impacts them significantly:

“How to support the man devastated by his ‘manhood taken away from him’. He is like a changed person.”

“When dad passed away, I was not followed up on for my own health needs. I sought it myself. Perhaps a phone call or information package with support options would be helpful.”

“Lack of information from doctors about what to expect...”

Q49 gave caregivers the opportunity to share additional information. Five additional themes emerged in this last question of the survey which were meaningful and likely applicable to the caregiver and patient alike.

The first theme dealt with the inadequate provision of information by the treating specialist. Treatment options were NOT presented, nor was the patient told he had a confirmed diagnosis of cancer.

“We were never given any options as to how we wanted to deal with this and the word cancer was never mentioned and we were not told that he was being given chemo.”

The second theme revolved around the adoption of a healthy lifestyle, including a healthy diet void of red meat and dairy, according to the respondent. The evidence is evolving, but a diet low in red meat and animal products and high in plant-based foods such as vegetables and fruits, may help to slow down the progression of prostate cancer and reduce tumor growth. Good nutrition may also help reduce the recurrence of the disease.^{12 13}

“I think the focus on a healthy diet for prostate cancer patients needs to be emphasized. It is a factor that patients have control over, and I think doctors really need to emphasize the importance of diet, such as avoiding meat and dairy.”

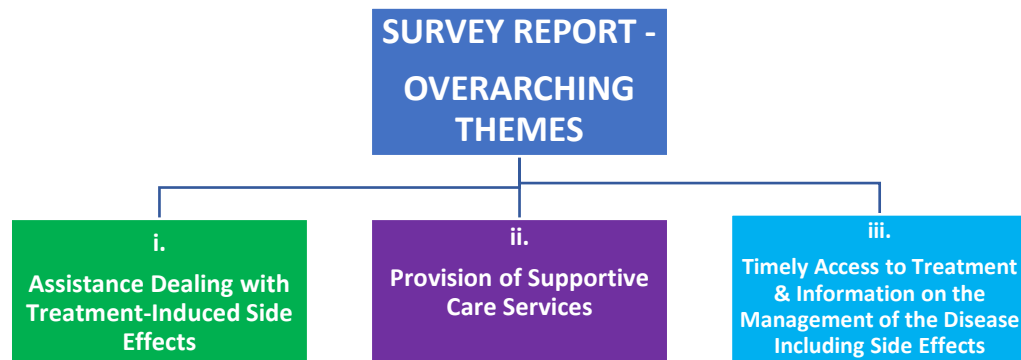
Caregivers highlighted the importance of accessing online Prostate Cancer Forums for moral support for women (third theme). They found this form of support quite helpful.

The fourth theme focused on the need for more prostate cancer awareness, particularly in smaller cities and towns – rural areas. Remote geographical location may present challenges in so far as awareness and education of cancer for the general population. It may place the cancer patient and their caregiver in a less than privileged position. According to the literature, rural living may be associated with delays in diagnosis, challenges of travelling long distances to urban centres, limited access to oncology services, economic disparities, and treatment decisions that are made based on geographic location.¹⁴

The fifth and last theme dealt with furnishing the caregiver with a superior knowledge base/understanding of palliative care services and equipping them with a bereavement support group post their loved one’s passing – a theme which was also highlighted in PART B.

“Better knowledge of palliative care. Bereavement group support.”

PART III: CONCLUSION – OVERARCHING THEMES



The CCSN Survey Report captured three overarching critical themes that resonated consistently throughout the Survey Results, as provided by patients in active treatment, survivors of prostate cancer and caregivers alike.

i. Assistance Dealing with Treatment-Induced Side Effects

The first and most frequent theme to emerge was the respondents' perceived lack of assistance dealing with treatment-induced side effects, specifically, as it relates to their sexual dysfunction and urinary incontinence. Both these side effects are life-changing side effects, which can reduce quality of life, and increase anxiety if not properly dealt with in a timely and informed manner. Survey respondents expressed a need for information on the management, severity and duration of incontinence and erectile dysfunction, in addition to practical support involving these treatment-induced side effects. Patients and survivors referred to not being properly supported by their treating healthcare professionals and wished for additional therapeutic options to be made available for these life-altering side effects. This could in turn help to empower these patients who are feeling lost, isolated and quite vulnerable. Patients also underscored the need for improved access to cancer specialist nurses throughout the care pathway as well as psychosexual support for treatment side effects.

The need to address treatment-induced side effects resonated quite vigorously in the second theme, as well.

ii. Provision of Supportive Care Services

The provision of supportive care services was a recurring theme throughout the entire survey. Patients have highlighted the need for supportive care to handle treatment-induced side effects, include accurate information regarding the management of the disease, and gain access to emotional support or psychosocial services to help address or alleviate the fears, anxiety or distress surrounding prostate cancer therapies.

Patients, survivors and caregivers highlighted the need for emotional and psychosocial support for treatment-induced side effects, primarily urinary incontinence and erectile dysfunction. Seeing that patients face a myriad of issues associated with treatments that can significantly impact their quality of life, it is not surprising that patients, survivors and their caregivers would wish to seek out supportive care services to reduce distress and anxiety in response to issues, such as erectile dysfunction, and subsequently improve their quality of life.

Caregivers reported the need to access supportive care services because sexual dysfunction has psychosocial implications on the patient's partner wherein poor spousal communication may result in addition to intimacy loss. Hence, it is not surprising that both patients and their caregivers identify requiring more psychosocial support than is typically provided. Additionally, caregivers are often overlooked as recipients of care for psychosocial support. They too experience challenges throughout the trajectory of their loved one's disease due to caregiver burnout. By focusing on themselves, they do not wish to appear unsupportive of the patient. Hence, they suffer in silence with an increasing amount of distress and anxiety. This can in turn negatively impact the prostate cancer patient. Supportive care services are required for the caregiver as well.

The Survey Results highlight access to support via a vis one-to-one peer support, support from patient advocacy support groups and support from health care professionals. Some of the open-ended replies furnished within the Survey Results showed that men perceived support groups to have two different roles:

- Provision of information (led by a patient expert or health professional).
- Emotional sharing (peer to peer support).

The goal of supportive care is *"to prevent or treat as early as possible the symptoms of a disease, side effects caused by treatment of a disease, and psychological, social, and spiritual problems related to a disease or its treatment"*.¹⁵ According to the survey results, patients, caregivers and survivors feel there is a lack of appropriate support services for prostate cancer.

iii. Timely Access to Treatment & Information on the Management of The Disease, Including Side Effects

The third theme revolved around the provision of information in a timely manner and access to treatment in an expedited fashion. Men felt they were not provided with enough information about prostate cancer treatment options from their healthcare professionals, while prostate cancer experts assumed patients had acquired enough content than was the case. Men felt ill at ease dealing with the treatment options, or rushed through their treatments, and felt unprepared for the severity and duration of treatment side effects.

This third theme highlights the need for information to be provided in a timely and comprehensive way. This is critically important, for it will permit not only the patient to proceed in a competent and confident manner throughout his cancer journey, but will also allow his caregiver to do precisely the same. Making more disease-related information available at or shortly after diagnosis is important, but so is interpreting that information, especially the information that relates to extent and severity of treatment side effects and prognosis. Reducing the patient's anxiety and doubt can allow him to move forward with a greater degree of ease.

Proceeding to a timely consult is also imperative, according to the survey respondents. Men felt they were lost in the system, and did not know to whom they could turn while waiting for their first appointment. The anxiety experienced during this time while waiting for that first consult is unimaginable.

The need for more timely and accurate information and resources to help manage daily living impacted by treatment side effects resonated in all three themes. Also, in view of the significant role played by caregivers, there is a need for healthcare professionals to acknowledge the care burden on caregivers and provide access to support.

In conclusion, the CCSN Prostate Cancer Survey Report suggests respondents had unmet information and supportive care needs, including physical, psychological, sexual and the healthcare system itself. Providing men with supportive care services can bring them out of a sense of isolation and loneliness and provide them with the tools to speak about their disease with ease and confidence. They can then share information and exchange ideas and tips with others going through the journey.

It behooves all stakeholders to come together to support the prostate cancer patient and his caregiver in a meaningful and productive manner. The hope is that the CCSN Prostate Cancer Survey Report will serve as the impetus in helping to achieve this endeavour.

PART IV: FOOTNOTES

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