Prostate Heidelberg

cancer support group

Information, Education and Support for men and their families

Newsletter No. 183 **Next Meeting Tuesday 16th April 2019**

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Prostate Heidelberg provides information, education and support for those affected by prostate cancer.
At the meetings, we:

Show respect to Members, Speakers, and Guests.
Allow people to speak and the other attendees to listen.
Respect confidentiality.

Our speaker this month is A/Professor Miranda Xhilagha

Miranda will be speaking on "Current research that is exciting me"

The Research Advisory Committee is coordinated by Miranda Xhilaga, Director, Research programs at PCFA since 2009.

In addition, she has a honorary adjunct associate professor position at the School of Health and Social Development, Deakin University. Miranda holds an MBBS from Tirana University and a PhD in molecular biology from Monash University. She has an interest in global health and knowledge translation (KT) and has trained as KT Specialist at the University of Toronto.

As Director, Research Programs at PCFA, she is responsible for the implementation and development of strategies that increase coordinated prostate cancer research activities nationwide, research evaluation and knowledge transfer.

Vale Patrick Woodlock

It is with much sadness that we advise that Patrick died peacefully on Monday 25th March. Over the last 9 years Patrick contributed to Prostate Heidelberg in many ways, with his knowledge, as Treasurer, and as the editor of this newsletter until 6 months ago.
His contribution to the group was enormous and touched the lives of many people. He will be sadly missed.
Prostate Heidelberg was represented at the funeral service by 7 members of your Steering Committee

Rest in peace Patrick

2019 SUBSCRIPTIONS $20

The 2019 annual subscriptions are due from 1st January 2019. The rate is **$20 per individual, couple or family**. Pay at your next meeting, by mail or directly into the Prostate Heidelberg bank account: BSB 083-256; Account 583244292 (include your name in the details).

This is our only source of income so if you have not already paid please do so now

Androgen deprivation therapy for prostate cancer and the risk of autoimmune diseases

We conducted a population-based nationwide cohort study of 17,168 patients newly diagnosed with PCa between 1996 and 2013 using the National Health Insurance Research Database (NHIRD) of Taiwan. Cox proportional hazards models with 1:1 propensity score-matched analysis were used to investigate the association between ADT use and the risk of autoimmune diseases. The duration of ADT use as a time-dependent variable was also examined for its association with autoimmune diseases. We also performed six secondary analyses.

Results

Of the 17,168 selected PCa patients, 14,444 patients met all the inclusion and exclusion criteria. After propensity score matching, 5590 ADT users and 5590 non-ADT users were included in the study cohort. A propensity score-matched analysis demonstrated a significantly decreased risk of autoimmune diseases in ADT users. A significant decrease in the risk of autoimmune diseases with increasing ADT duration was also demonstrated

Conclusions

We observed that ADT use in patients with PCa was associated with a decreased risk of autoimmune diseases. These novel findings provide a potential role for androgen deprivation therapy in the modification of inflammation and autoimmunity in Asian patients with prostate cancer.

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Increased saturated fat intake linked to aggressive prostate cancer

Eating a diet higher in saturated fat, a type of fat found commonly in foods such as ***fatty beef and cheese, was linked to more aggressive prostate cancer,*** a study by University of North Carolina Lineberger Comprehensive Cancer Center researchers and collaborators has found. The preliminary results were presented Monday, April 18 at the American Association for Cancer Research Annual Meeting in New Orleans.

"We show that high dietary saturated fat content is associated with increased prostate cancer aggressiveness," said Emma H. Allott, PhD, a research assistant professor in the UNC Gillings School of Global Public Health. "This may suggest that limiting dietary saturated fat content, which we know is important for overall health and cardiovascular disease prevention, may also have a role in prostate cancer."

The results were drawn from a survey of 1,854 men who were diagnosed with prostate cancer between 2004 and 2009 in North Carolina and in Louisiana as part of a larger study called the North Carolina-Louisiana Prostate Cancer Project.

Men were asked a series of questions about their diet and other factors at the time of diagnosis with prostate cancer, and then researchers examined the association between saturated fat intake and the aggressiveness of the men's tumor at diagnosis. They adjusted dietary saturated fat for total fat intake in their statistical models in order to tease apart the effects of saturated fat from total fat intake. They gauged aggressiveness using the results of the patients' prostate cancer-specific antigen, or PSA, tests, as well as the clinical stage of their cancer and Gleason grade.

They found that higher saturated fat intake was linked to increased prostate cancer aggressiveness. Allott said that high saturated fat content in the diet contributes to raised blood cholesterol levels, and the researchers also found in the study that men taking statins, which are drugs used to control cholesterol levels, had weaker associations between saturated fat intake and prostate cancer aggressiveness. These findings may suggest that statins counteract, but do not completely reverse, the effects of high saturated fat intake on prostate cancer aggressiveness. In addition, they found that ***higher levels of polyunsaturated fats, which are found in foods such as fish and nuts, were linked to lower levels of prostate cancer aggressiveness.***

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Prostate Cancer Support Groups, Canada-Based Specialists' Perspectives

American Journal of Men's Health
John L. Oliffe, PhD, RN,1 Suzanne Chambers, PhD,2 Bernie Garrett, PhD, RN,1 Joan L. Bottorff, PhD, RN,3 Michael McKenzie, MD,1,4 Christina S. Han, MA,1 and John S. Ogrodniczuk, PhD1

Abstract

To understand prostate cancer (PCa) specialists' views about prostate cancer support groups (PCSGs), a volunteer sample of **Canada-based PCa specialists** (n = 150), including urologists (n = 100), radiation oncologists (n = 40), and medical oncologists (n = 10) were surveyed.

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The 56-item questionnaire used in this study included six sets of attitudinal items to measure prostate cancer specialists' beliefs about positive and negative influences of PCSGs, reasons for attending PCSGs, the attributes of effective PCSGs, and the value of face-to-face and web-based PCSGs.

In addition, an open-ended question was included to invite additional input from participants. Results showed that PCSGs were positively valued, particularly for information sharing, education and psychosocial support. Inclusivity, privacy, and accessibility were identified as potential barriers, and recommendations were made for better marketing PCSGs to increase engagement.

Findings suggest prostate cancer specialists highly valued the role and potential benefits of face-to-face PCSGs. Information provision and an educational role were perceived as key benefits. Some concerns were expressed about the ability of web-based PCSGs to effectively engage and educate men who experience prostate cancer.

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Make Sure Your PSA is as Accurate as Possible

December 19, 2018 | By JANET FARRAR WORTHINGTON

The PSA is never meant to be a one-shot reading; it's not a constant number, forever set in stone like the Ten Commandments. Instead, it's more like a Polaroid snapshot – a quick capture of one moment in time. PSA fluctuates; that's why it's good to follow the general trend of the number over time, instead of just looking at one reading and saying with absolute confidence that a man definitely does or does not have prostate cancer.

That said, if you're getting a PSA test, let's make sure it's as accurate as possible. Here are some things that can artificially raise or lower your PSA. A couple of these can be avoided; as for the rest, be sure to tell your doctor.

Don't get your PSA tested if you have a urinary tract infection. "This will cause your PSA level to be elevated," says New York University urologist Stacy Loeb, M.D. "Urinary retention (when you cannot urinate) will also cause an elevation in PSA."

Don't ejaculate for at least two days before you get the PSA test. This can send more PSA into the bloodstream and can artificially raise your PSA level.

Don't get the PSA test after your rectal exam. Your doctor should know this, but sometimes it happens. The rectal exam, which stimulates the prostate, can also cause PSA to be released into the bloodstream. This is an avoidable cause of unnecessary worry!

Don't work out right before your PSA test. Vigorous exercise can cause a "bump" in PSA, with bicycle riding being the biggest culprit.

Do tell your doctor if:
You are taking Proscar or Avodart for BPH (benign prostate enlargement), or Propecia for hair loss. All three of these drugs can throw off your PSA level, making it seem lower than it actually is.

"To correct for this, if you have been on one of these drugs for two years, your PSA level should be multiplied by 2.0," says Johns Hopkins urologist Patrick C. Walsh, M.D., co-author of Patrick C. Walsh's Guide to Surviving Prostate Cancer. "Then for the next five years, it should be multiplied by 2.3, and after seven years, by 2.5. Fortunately, these drugs do not affect measurements."

You have had surgery for BPH. A transurethral resection (TUR) or laser procedure for BPH can make your PSA much lower, because there isn't as much tissue inside the prostate as there used to be. This, too, can give a false impression that everything's okay, when it might not be.

You have had recent manipulation of the urinary tract. "Catheter placement and other procedures in the urinary tract could cause the PSA level to go up and give a false impression," says Loeb. Vigorous bicycle riding is the biggest culprit of a PSA "bump."

You have liver problems. Liver cirrhosis can lower PSA, and so can liver fibrosis (scar tissue in the liver, which develops as the liver attempts to fix cells damaged by disease). "If you have a liver disease, talk to your doctor about how it might affect the PSA, and if you are a Baby Boomer (born between 1945 and 1965), consider a one-time check for hepatitis C virus infection," says Johns Hopkins epidemiologist Elizabeth Platz, Sc.D., M.P.H.

The safest bet, says Walsh, is this: "If your PSA begins to increase steadily, even if this increase is very small, you should see a urologist.

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Anxiety, Depression in Prostate Cancer: Managing Psychosocial Effects in Male Patients

Although prostate cancer is highly treatable, men with prostate cancer frequently experience significant anxiety and depression.
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A person receiving a cancer diagnosis is likely to experience a wide range of emotions; fear, anxiety, sadness, and depression are among the most prevalent. The type of cancer, stage, and treatment modality may affect a patient's emotional state. A logical conclusion is that men with prostate cancer — which is generally regarded as highly treatable — would suffer a relatively lower rate of psychosocial distress than people receiving diagnoses that typically have poorer prognoses and outcomes. However, men with prostate cancer commonly feel significant anxiety and depression.

CancerCare and Us TOO International surveyed 633 men with prostate cancer regarding their feelings of anxiety and depression: 77% of the respondYou have had surgery for BPH. A transurethral resection (TUR) or laser procedure for BPH can make your PSA much lower, because there isn't as much tissue inside the prostate as there used to be. This, too, can give a false impression that everything's okay, when it might not be.
normal for patients with prostate cancer; and 97% felt there was a need to help patients recognize the symptoms and find treatment.
Men tend to avoid seeking help for psychosocial issues — notably more than women. This is borne out by survey results that suggest men with prostate cancer would benefit from support groups, yet they seldom attend them.1 Other data show that women outnumber men by 3 to 1 in cancer support groups.1 There are myriad reasons for this.

PERCEPTION OF WHAT IS A MAN

Typical qualities that define the role of a man in society are the projection of power, physical strength, dominance, control, and toughness. Neediness or asking for help are considered signs of weakness. Men do not like to appear emotionally vulnerable; instead, they often expect that the task of feeling emotions should fall to a spouse, partner, or relative. Stereotypically, men are expected to be logical and make decisions based on the analysis of information. When they do reach out to their doctors and nurses, it is often for informational — rather than emotional — support.

Because prostate cancer affects the reproductive, urinary, and gastrointestinal systems, there are often feelings of embarrassment and shame attached to this diagnosis. Already feeling shamed by his status as a patient (and therefore in a weakened state), adverse effects such as incontinence and erectile dysfunction may exacerbate a man's anxiety over future levels of functioning in these areas. All of these factors may lead a man with prostate cancer to hide his feelings even more deeply from medical staff and to refrain from divulging his feelings to his family and loved ones.

Clinicians need to create an environment where men feel comfortable sharing their concerns. One way to do this is to simply reassure a man with prostate cancer that feeling a certain amount of anxiety and sadness is normal, and these feelings can be mitigated by psychosocial support such as counseling and support groups. In addition, study data have shown that patients who receive strong emotional support may benefit from a protective effect on health outcomes.3 These patients are more likely to follow their treatment plans, whereas patients who are depressed might be inclined to feel treatment is useless or give up on it altogether.

WHEN FEELINGS BECOME PHYSICAL SYMPTOMS

An important first step to helping a patient with prostate cancer cope with emotional issues is to help him identify his feelings. He needs to determine whether he is experiencing anxiety, depression, or both. Importantly, anxiety and depression are not the same, and they may require different interventions and/or treatments.

A certain amount of anxiety occurs in daily life for most of us. "Situational anxiety" occurs frequently for cancer patients before undergoing a medical test, such as a scan, or a treatment, such as radiation. This anxiety is different from continual, pervasive anxiety that interferes with daily functioning and manifests as gastrointestinal distress, chest pains, elevated heart rate and blood pressure, or suddenly breaking into a sweat.

Depression is a medical disorder characterized by feelings of sadness and/or a loss of interest in activities once enjoyed and may be characterized by hopelessness, despondency, abnormal sleep or eating habits, loss of interest in sex, feelings of worthlessness, the desire to harm oneself, and/or suicidal thoughts

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.Men with prostate cancer may already feel as if he is diminished in the eyes of others, and subsequently, may reject the interventions that can help mitigate anxiety and depression. Support groups, individual counseling, or a prescription for antianxiety or antidepressant medications may be highly useful, but men sometimes perceive these as further signs of weakness. Nevertheless, these options should be explained, reassuring them that their innate distaste for these interventions is normal as well. However, clinicians also need to make clear that these interventions are often helpful and may lead to better quality of life and improved medical outcomes.

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Prostate Optimal Care Pathway Update

This is work of Lena Elkman from NEMICS who visited the group many times

North Eastern Melbourne Integrated Cancer Services undertook work in the prostate tumour stream for optimal care pathways (OCPs) in 2018, focussing on multidisciplinary team meetings (MDMs).

A core component of OCPs is to discuss all newly diagnosed patients in a multidisciplinary team meeting prior to beginning treatment. A baseline audit of the Austin Health Urology MDM revealed only 52% of patients diagnosed with prostate cancer were being presented (n=25, Jan–July 2017). It also identified that patients were being added to the MDM agenda in a non-systematic and ad-hoc manner.

After discussions with the Austin Health urology team, the quality improvement methodology of 'Plan, Do, Study, Act' (PDSA cycle) was used to test and implement a process for systematically adding newly diagnosed patients to the prostate MDM agenda. This involved collecting data and meeting with clinicians to understand processes of how cases are added to the MDM agenda. Multidisciplinary team meetings were attended to look for opportunities to streamline processes.

The new process, requiring the urology intern to gather all post-biopsy confirmed urological cancer cases from pathology reports, was implemented. Outcomes from the process were monitored for five meetings, and the documentation for intern training on the MDM software system was updated.

The results showed an increase from an average of three prostate patients to six prostate patients discussed per week, where 100% (n=33) of newly diagnosed patients with prostate cancer had a prospective MDM discussion (July–September 2018). Continued monitoring also demonstrated that 15% of urological patients had their initial treatment plan changed after discussion at an MDM.

This new process has now been embedded as standard practice at Austin Health. MDM attendees have reported high satisfaction with the new process, particularly for non-surgical team members including radiation oncology and nursing staff.

CALENDAR 2019

Meetings: **10:00am -12:30pm**
3rd Tuesday each month except January

April 16th **General discussion**

June 18th ***Associate Professor Nik Zeps***
Group Director of Research and Development, Epworth Hospital

"Negotiating your way through the medical system and life for cancer patients"

July 16TH	**General discussion**
August 20th	**Speaker to be advised**
September 17th	**General discussion**
October 15th	**Speaker to be advised**
November 19th	**General discussion**
December 21st	**Speaker to be advised**

STEERING COMMITTEE

Barry Elderfield	**Treasurer**
David Bellair	**Website**
Janis Kinne	**Membership**
Max Shub Ph 0413 777 342	**Facilitator**
Spiros Haldas	**Library**
Michael Meszaros	

Use of the internet is to find your questions to ask your specialist. ***It should not be trusted to find answers for your personal case.*** The web is general. Your specialist specifically knows you. The following are web sites members have found useful:

Organisation	Details	Website
Prostate Cancer Foundation of Australia	*For guides and help.*	www.PCFA.org.au
Prostate Cancer Foundation (USA)	*Guide for men newly diagnosed with prostate*	www.pcf.org/guide/
Us TOO International PC Education	*USA Prostate Cancer support groups and information*	www.UsToo.org/Read-Educational-Materials
Cancer Council Victoria	*For general help and to understand services supporting men with cancer.*	www.CancerVic.org.au
Ex MED Cancer program	*A best-practice exercise medicine program for people with cancer.*	www.EXMedCancer.org.au/
Prostmate	*The companion for those impacted by Prostate Cancer*	www.ProstMate.org.au
Beyond Blue	*For help with depression or anxiety.* HELPLINE – 1300 22 4636	www.BeyondBlue.org.au
Continence Foundation of Australia	*For assistance with incontinence and for aids (such as pads). HELPLINE – 1800 33 0066*	www.Continence.org.au/
Australian Advanced Prostate Cancer Support Group	*For men diagnosed with advanced metastatic prostate cancer.*	www.JimJimJimJim.com
Commonwealth site for palliative care	*Government information on palliative care.*	www.Health.gov.au/PalliativeCare
Banksia Palliative Care	*Specialist home based community palliative care service for people living in the north east suburbs of Melbourne*	www.BanksiaPalliative.com.au
University California San Francisco	*One of the leading Prostate Cancer Research centres*	www.urology.ucsf.edu/patient-care/cancer/prostate-cancer

Useful Newsletters

PAACT Newsletter	**www.paact.help/newsletter/**
PCRI Prostate Digest	**www.pcri.org/insights-blog/2018/04/prostate-digest-volume21-issue1**
US TOO Hotsheet	**www.ustoo.org/Read-the-HotSheet-Newsletter**