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Is there Scientific Benefit to PCa Survivors from Groups like Prostaid?

The Role of Prostate Cancer Support Groups in Health Promotion

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Men are living longer with PCa, and the death rate continues to be significantly lower than the incidence rate. In the absence of a known cause or cure, the number of men diagnosed with PCa will increase with the aging population, and for many men it will become a chronic, long-term illness. Diverse health issues are encountered by men and their families as a result of PCa and its treatments, many of which influence gender roles and gender relations, and quality of life. Health and illness information are integral to the well-being of men who have PCa, and prostate cancer support groups (PCSGs) have emerged as important community-based resources. Underpinned by the basic premise that PCSGs have much to offer, we designed a study to better understand how groups operate as a means of describing their role in health promotion. Previous studies of Canadian PCSGs indicated that men derive a sense of meaning and purpose through attending support group meetings. A survey of men attending a professionally-led Montreal-based PCSG indicated that the sharing of PCa experiences with others gave men reassurance, helped alleviate anxiety, and provided a more positive outlook and a perception of being actively involved in their treatment.

Health promotion and illness demotion There is strong evidence that men are reluctant to engage with health promotion programs; typically men react to severe symptoms rather than attempt to maintain their health, and are more likely to deny than discuss illness-related

issues. Men at PCSGs revealed an intriguing exception to these longstanding commentaries by routinely discussing ordinarily private illness experiences and engaging with self-health. We observed how an environment conducive to men's talk was established to normalize PCa, and to promote individuals and the collective health of group members. Group members often focused on the facts (e.g., the latest biomedical research) and figures (e.g., Prostate Specific Antigen [PSA] and Gleason biopsy scores) and this enabled many men to objectify and position their PCa as a manageable disease.

Living examples of healthy men Participants drew reassurances from survivors who attended the meetings. Many men explained how they observed the practices and progress of other men as a means to engage with and, in some cases, assess their own health. This was due, in part, to the complexities and ambiguities associated with the science of PCa. As such, the presence of healthy men at the groups provided important "proof" and "hope" that survival was possible, regardless of the specificities of men's PCa biomarkers.

Mixing health and illness information Opportunities were available for the men to promote their health and well-being rather than to remedy or ruminate on an existing PCa. Many men detailed specific dietary supplements or strategies for modifying the consumption of potentially beneficial (i.e., fruits/vegetables) and detrimental (i.e., sugar, alcohol, coffee) foods.

Trajectory and problem-specific information

Information was solicited by and tailored to individuals to counter specific problems based on where they were within the illness trajectory. The most common example of tailored information related to treatment decision-making for newly diagnosed men who were deciding if and what treatment they would have. Group members were quick to share their perspectives, but careful to be impartial about the treatment options. Some larger PCSGs formed treatment subgroups (i.e., prostatectomy, radiation therapy, brachytherapy, etc.)

Prostaid Calgary's next monthly meeting will be held at

7:30 PM on Tuesday

October 13th 2009
In the auditorium at Foothills Hospital with Dr. Dean Ruether And Cheryl Scott, RN

"What's new for men with prostate cancer in Southern Alberta"

Come meet other prostate cancer survivors, share stories, and enjoy coffee and snacks.

Our next regular meeting of "Women And Prostate Cancer" (WAPC) will be at 7:30PM, on Tuesday October 27 in room 1001, South Calgary Health Centre.

A peer meeting for men will be held at the same time in room 1014 at South Calgary Health Centre. at 31 Sunpark Plaza South East.

Our first "Women and Prostate Cancer" (WAPC) for those in the north will be held on Tuesday October 20 at 7:30 PM at Wellspring 1404 Home Road NW

which newly diagnosed men could access to discuss specific information.

The function of humour Psychosocial benefits, including improved mood and mental health, and increased quality of life, have been reported among men who routinely attend PCSG meetings.³³⁻³⁶ We noticed that humour was frequently a part of the groups' interactions, and this prompted us to formally examine the function of humour at PCSGs. The study findings revealed how humour could disarm men's stoicism and mark the boundaries for providing and receiving mutual help.

Women and prostate cancer support groups

Women influence their spouses' experiences of PCa, and are also significantly affected by living with a partner who has PCa. So much so, that PCa has emerged as a "couple's illness" in which the disease, as well as its treatments, affect gender identities and relations across the entire illness trajectory. We focused our analysis to better understand how PCa was situated and negotiated as a 'couple's illness', by describing women's participation at PCSGs. The reasons why women attended the groups and the roles they played at group meetings are detailed below. **Reasons for attending** Despite feeling anxious and wondering whether they would fit in at a men's group meeting, most women decided to attend group meetings as a means to support their husbands. In addition, attending groups allowed the women to obtain much needed information about PCa treatments and access the experiences of other women. Continued attendance centered on the women's need to manage their experience of their partner's illness, as well as to give back to the group as a couple. **Women's roles** Within the groups we examined, women assumed three roles that were strongly influenced by the composition of the group and the length of time they had been attending. Most commonly, women were **social facilitators**, establishing and sustaining social connections within the group by welcoming new members and serving refreshments, or organizing social events. Although these women downplayed their contributions, they were vital to the social. Women also operated as **background supporters**, wanting to be there for their husbands without disrupting the men's ownership of the group because they believed this would inhibit men's support for each other. Positioning themselves in this way helped minimize the women's anxiety about attending a men's group, and provided a way to encourage men's self-disclosure. Conversely, some women explicitly positioned the experience of PCa as a couple's illness and adopted the role of a **cancer co-survivor**. These women shared and solicited psychosocial support, and did not downplay their involvement in the group, realizing that it's just not a man's disease, it's their disease too. It was also clear that PCSGs offered important opportunities for women to access much needed support.

This article can be viewed in its entirety at <http://nexus.ubc.ca/documents/PCSG%20ES%20Revise%20Final.pdf>

The Gleason Behind the Gleason Score

If you have had prostate cancer, you probably know that the Gleason score is the most important factor in predicting your current state of prostate cancer and its probable outcome. The score is based on tumor grade -- an indication of the tumor's aggressiveness. Tumor grade reflects how far the cancer cells deviate from normal, healthy cells, which are highly organized, with well-defined structures.

Cancer cells display various degrees of disorganization and distortion and could be likened to a Jackson Pollock painting. Cancers whose cells appear closest to normal are considered grade 1 and generally are the least aggressive; those with highly irregular, disorganized features are classified as grade 5 and generally are the most aggressive.

The Gleason score is derived by determining the two most prevalent organizational patterns in the tumor, assigning each a grade, and then adding the two numbers together. For example, if the most common pattern is grade 3 and the next most common pattern is grade 4, the Gleason score would be $3 + 4 = 7$. Most pathologists do not recommend assigning Gleason scores below 5 based on needle biopsies because when the prostate is removed and the entire gland is evaluated, lower Gleason scores are almost always upgraded.

Most urologists would classify Gleason scores of 5 and 6 as low-grade tumors, a Gleason score of 7 as intermediate, and Gleason scores of 8, 9, and 10 as high grade, with the least favorable outlook.

The Gleason score was originally devised by Donald F. Gleason, M.D., a pathologist who created the unique and now ubiquitous scoring system in the 1960s based on his observations of prostate tissue taken from biopsy samples of more than 300 patients. The prostate tissue, when riddled with microscopic tumors, had a certain pattern when viewed under a microscope, and Dr. Gleason took note of that, assigning numbers to the various architectural patterns. He finally arrived at five representative pictures that were characteristic of all the patients. When reviewing background data on the patients, a strong correlation was found between their "Gleason score" and the patients' death rates.

By the late 1980s, Dr. Gleason's system was used in all medical publications on prostate cancer, and is still included today throughout the world. Your PSA test result, along with your Gleason score, predicts the likely outcome of prostate cancer and it's the gold standard test that will be used to diagnose more than 186,000 men this year with the disease.

www.johnshopkinshealthalerts.com/alerts/prostate_disorders/

Prostate size does not affect results of surgery

NEW YORK (Reuters Health) - Prostate size affects the technical difficulty of radical prostatectomy -- total surgical removal of the prostate gland as a treatment for prostate cancer -- but not the functional results, according to researchers at Memorial Sloan-Kettering Cancer Center in New York.

Dr. Joseph A. Pettus and colleagues analyzed outcomes in 3,067 men treated by 5 surgeons at their hospital. As they report in *The Journal of Urology*, each man had a radical prostatectomy without chemotherapy, hormone treatment or radiation therapy.

Reported prostate size was based on weight, which ranged from 15 to 389 grams. (For comparison purposes, 15 grams is the weight of 1/8 cup of flour, while a full cup weighs 110 grams.)

According to the paper, with increasing prostate size there were increases in estimated blood loss and time required for the surgery. The authors noticed that with increasing size, surgeons were more likely to remove every trace of the cancer.

But, the investigators found, there was no significant association between specimen weight and rate of side effects (including erectile function and urinary continence) or relapse 1 year later.

"Prostate size influences operative difficulty...but the increased difficulty does not seem to translate into worse functional results," Dr. Pettus and his associates conclude.

How Long Do Medications Last?

Readers want to know: Are medications that have passed their expiration dates good to use, or should they be discarded? Here's the answer from Johns Hopkins.

Think of expiration dates -- which the U.S. Food and Drug Administration (FDA) requires be placed on most prescription and over-the-counter medications -- as a very conservative guide to longevity. The expiration date is a guarantee from the manufacturer that a medication will remain chemically stable -- and thus maintain its full potency and safety -- prior to that date. Most medications, though, retain their potency well beyond the expiration date, and outdated medications, whether prescription or over-the-counter, are not usually harmful.

In a study conducted by the FDA on a large stockpile of medications purchased by the military, 90% of more than 100 medications were safe and effective to use years after the expiration date. The drugs in the FDA study, however, were stored under ideal conditions -- not in a bathroom medicine cabinet, where heat and humidity can cause drugs to degrade.

If your medications have been stored under good conditions, they should retain all or much of their potency for at least one to two years following their expiration date, even after the container is opened. But you should discard any pills that have become discolored, turned powdery, or smell strong; any liquids that appear cloudy or filmy; or any tubes of cream that are hardened or cracked.

To help maintain potency, store your medications in a closet or cabinet located in a cool, dry room. Also, don't mix medications in one container: chemicals from different medications can interact to interfere with potency or cause harmful side effects. If two or more medications have been mingled for any period of time, discard them.

A few medications, like insulin and some liquid antibiotics, do degrade quickly and should be used by the expiration date. Also, consider replacing any outdated medications that you're taking for a serious health problem, since its potency is more critical than that of an over-the-counter drug you take for a headache or hay fever. If in doubt, consult a pharmacist.

New this issue:

In this issue of the DE you will find a short survey and a business reply envelope. Please take a few minutes to complete this and send it off to us. We want to ensure that our database is up to date. We are also in the process of determining how many of our members would prefer to receive the DE by e-mail. As Prostaïd grows and evolves we are exploring more ways that we can connect with the people we serve. Do we have people who would be willing to meet with those recently diagnosed? Are there members who would like to spread our awareness message with public presentations? Should we be making hospital visits?

Prostaïd is at the forefront of Prostate Cancer support groups in Canada. Help us to determine where we can go next with your support!

Volunteers Needed!

We would like to start a peer support group for women (WAPC) and a group for men in the north.

Wellspring has offered us space to see if there is a demand for a second group for whom SCHC was too far. The inaugural meeting will be held on Tuesday October 20, 2009 @7:30PM. Would you be interested in helping to lead this group? Please contact Karen at 403-455-1916 to express your interest.



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Prostaid Calgary Warriors

The Prostaid Calgary Warriors are a caring and compassionate group, well organized and full of information for those men and their families dealing with advanced prostate cancer. The Warriors serve the very important needs of hormone refractory Prostaid Calgary members and all those who have an interest in management of advanced prostate cancer. The Prostaid Calgary Warriors meet on the second Tuesday of each month at 6:14 pm prior to the main Prostaid Calgary meeting. Warriors meet just outside the auditorium at Foothills Hospital in room #AGW2 . Signs will be posted. Men with advanced prostate cancer, their partners and family members are most welcome

Women and Prostate Cancer hold monthly meetings at 730 pm on the 4th Tuesday of every month at South Calgary Health Centre, 31 Sunpark Plaza South East. These informal meetings allow women to share their concerns and experiences in a friendly non-threatening environment.

At the same time, in a different room at SCHC a men's peer support meeting is also held. If you would like more information about either meeting please contact either Barb or Dave Todd at 403 271 6141.

Prostate Cancer and Sexuality Information sessions:

Location: Tom Baker Cancer Centre, Boardroom, Main Floor Rm CC105

Presenter: Dr. John Robinson, Department of Psychosocial Resources

403-355-3211

Dates: October 5, November 2 11:30-12:30PM

No registration required.

Many thanks to our many friends and supporters!

Prostaid has many generous individuals and companies who support our community work. On behalf of our 900+ members, thank you for your generosity. With your support we will continue our good work in 2009 and onward!

Newsletter * General Meetings * Hospital Visits * One-On-One visits * Speakers * Website

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