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The Role of Women in Support Groups

By John Hoffman

When you talk to wives of prostate cancer patients, sooner or later you are bound to hear someone say, "This is a family disease." That's hardly surprising. Women have traditionally acted as "minister of health" in most families, so they expect to be active partners in their husbands' journey with prostate cancer.

But the involvement of spouses is by no means limited to caring for the prostate cancer patient. Women often act as information gatherers and, at times, seekers of support. In fact, about 80 percent of first-time callers to CPCN's toll-free number are women.



John Oliffe, assistant professor of nursing at the University of British Columbia recently did a study that focused on women's participation in support groups. He and his colleagues conducted in-depth interviews with 20 women who attended prostate cancer support group meetings in British Columbia. The researchers also attended and recorded their observations about women's participation at meetings of 13 BC support groups.

Overall, this research confirmed Oliffe's impression from previous research on prostate cancer groups: women play an important role in these groups that many people think of as male territory. He was surprised, however, at how many women were taking part. "We found that there were more women at meetings than we expected to see," says Oliffe.

Oliffe identified three general roles played by women in prostate cancer support groups: social facilitator, background supporter, and cancer co-survivor.

Social facilitators do various things to enhance the social connections that are so important to support groups, such as greeting people, welcoming new members, and looking after the refreshments. Background supporters tended to be less active. They would sit beside their husbands, often not saying much. Sometimes they took extensive notes, which the women said allowed their husbands to focus on the discussion.

"Cancer co-survivors participated more like active stakeholders," says Oliffe. "They took part in discussions much like men did, except that they were more likely to express emotion and ask directly for support from others." Many of these women attended with their partners, but some attended alone.

In fact, some of the women interviewed said their husbands might not have attended support group meetings on their own. "At one of the meetings, a woman told the group leader that her husband was reluctant to join the meeting and was actually outside in the car waiting to drive her home," Oliffe explains.

"Together, they went out to the car and convinced the man to come in and join the meeting."

In general, women said they were there to support their husbands, but it was also clear that they had needs of their own. As one spouse put it, "I went to support my husband because he was newly diagnosed, but I was also quite overwhelmed by the amount of information there was." Another said, "I had a need to talk. As much as your family and friends love you, they don't really have the knowledge. I believe that the groups can help enormously emotionally, and I think that emotion plays a huge role in the disease."

Linda Garshon, a long-time member of Toronto Side by Side, the women's group that operates in tandem with the support group Toronto Man to Man, agrees. "The whole family has to get involved," she says. "The wife needs to know what to expect. If a man's having surgery, the catheter comes home with you. That can be very intimidating at first. Women can help each other prepare for it. I sure wish someone had done that for me when my husband was diagnosed nine years ago."

Side by Side was launched in 1996. Women meet separately from men once a month (Man to Man meets bimonthly) for discussion and sharing. Every two months, Man to Man also hosts awareness nights, attended by both men and women. These are more informational in nature, featuring presentations by doctors and other health professionals.

ProstAid, in Calgary, is considering the idea of starting a women's group. Their first effort in that direction was to devote a regular meeting to women's issues. Andrea Beck, a PhD student in clinical psychology at the University of Calgary who facilitated the evening, explains how she prepared for the women-focused program. "I got together with six women, who volunteered to help me plan the evening, and we discussed the challenges and issues that affected them personally, things like what coping strategies worked and what didn't work and changes in the couple relationship." The group identified a number of key areas to address, and one or two women agreed to speak when each of the issues was raised.

One major issue was the difficulty women experienced getting help because they were not the patients. "Some felt that not a lot of support is offered to the partner," Beck says. Spouses also talked about the difficulty of dealing with their partner's erectile problems and fatigue and also the emotionality and decreased libido often experienced by men undergoing hormone treatment.

It's not hard to imagine that it might be difficult for both men and women to initiate discussion of some of these issues in a mixed-gender group with their partners present. "When we opened it up for discussion and questions, we asked people to write their questions down on cards," says Beck. "The anonymity made it a little easier."

This kind of structured focus on women's experience might be helpful, Oliffe says, because women often feel some anxiety about exactly how active a role to play. Women often said things such as "I wasn't sure how much the spouse was supposed to say because the group was already set up, and it's a men's group."

Obviously, the numbers of female participants noted by Oliffe's team suggests that many women manage to overcome that initial uncertainty and tension. That's good because it's quite clear to Oliffe that women play a very important role in support groups. "During the course of our study, two of the groups folded and both of those were men-only groups. I can't say for sure that's why they folded, but I'd suggest groups might want to think more about the role spouses can play in bringing more people out and sustaining an

active membership. In some groups women might be the glue that holds the group together."

But women who want to get involved should understand an important message. *Don't expect that men will operate and behave in a group in the same way that women would.* "Some women have said to me that men don't talk like they should, but I think men just talk the way they talk and it's different from what women would do, but it works. There's a lot of literature that says men don't look after their health, but the guys in prostate cancer support groups are definitely the exception to the rule. I think it's one of the great stories in men's health promotion."

Acknowledging the important role of women in supporting men with prostate cancer, the CPCN will devote a special session to the issue at its national conference, to be held in Calgary, Alberta from the evening of August 3 through to noon August 5, 2008.

New blood tests for prostate cancer

The PSA test, which assesses the amount of prostate-specific antigen in the blood, has been for many years the gold standard blood test for alerting men to the possibility that they might have prostate cancer. But the test does have some drawbacks. Other conditions, such as aging and benign prostatic hyperplasia (BPH), increase the levels of PSA in the blood and lead to "false positives" --- men thinking they might have prostate cancer when they don't. On the other hand, the PSA test sometimes misses cases of cancer, a worrying possibility called a "false negative." (See an archived article from April 2005 on the topic of false positives.)

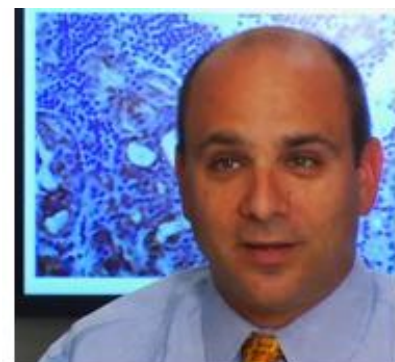


So researchers in Canada and around the world have been busy trying to come up with a better blood test for prostate cancer.

Early prostate cancer antigen-2 (EPCA-2)

One promising discovery, first reported about a year ago, is EPCA-2. Dr. Robert Getzenberg of the James Buchanan Brady Urological Institute at Johns Hopkins is the lead author of a small retrospective study on using this blood protein to test for prostate cancer.

The study, which appeared in the April 2007 issue of *Urology*, looked at the EPCA-2 levels in the blood of 330 Hopkins patients. The men studied had various medical histories: normal PSA levels and no evidence of the disease, high PSA levels and normal biopsies, a diagnosis of BPH, normal PSA levels yet a diagnosis of prostate cancer, prostate cancer confined to the prostate, prostate cancer that had spread outside the prostate at the time of surgery, and various other benign conditions.



[Watch a Johns Hopkins video press release on EPCA-2](#)

Getzenberg and his team found that the EPCA-2 test was negative in 97 percent of the men who did not

have prostate cancer. Besides this, men with no evidence of prostate cancer during digital rectal exams (regardless of their PSA levels), as well as men suffering from other types of cancer or from benign conditions, all had EPCA-2 levels below the one that researchers used as a cut-off --- 30 nanograms per millilitre. A press release from Johns Hopkins compares these findings with the results of a multi-institutional study published in 2003 in the *Journal of Urology*, which found that PSA levels between 4 and 10 nanograms per millilitre were accurate in identifying patients without prostate cancer only 19 percent of the time. (See this [press release](#).)

Research is ongoing and still promising. Getzenberg reported in May 2007 that expanded studies continue to demonstrate that early prostate cancer antigen-2 (EPCA-2) has high sensitivity and specificity. (In non-clinical language, a sensitive test detects almost all cases of prostate cancer --- few false negatives. And a specific test detects prostate cancer almost exclusively --- few false positives.) According to Dr. Getzenberg, "A blood test based on EPCA-2 may greatly improve our ability to accurately detect prostate cancer early and minimize the number of false positives, therefore lowering the number of unnecessary biopsies." The other possible use of EPCA-2 is in distinguishing between men whose prostate cancer is confined to the prostate and those whose cancer has spread. EPCA-2 levels, says Dr. Getzenberg, seem to be much better than PSA levels at separating these two groups of men.

Still, it is really too early to tell whether EPCA-2 testing will work better than the traditional methods of diagnosing prostate cancer. The initial Johns Hopkins study, while promising, was retrospective (meaning it tested men whose cancer status was already known), and it was small. In other words, it did not reproduce the conditions under which the PSA test is currently used, so accurate comparisons are difficult. It should also be noted that Dr. Getzenberg holds a patent on the test and has consulted for and received a grant from Onconome, a Seattle biotech company developing EPCA-2 as a commercial product. The prestigious National Cancer Institute also supports Dr. Getzenberg's EPCA-2 research, and larger clinical trials are underway. Preliminary results may be available as early as the end of 2008.

Gene-variant testing for prostate cancer risk

A second study, published in the February 28 issue of the *New England Journal of Medicine*, looked at the DNA of 2,893 Swedish men with prostate cancer and 1,781 healthy men of similar ages to determine whether men with single-nucleotide polymorphisms (SNPs) in five particular areas of their DNA had an increased risk of developing prostate cancer. A SNP (pronounced "snip") is a genetic variation --- a change in the DNA sequence --- that occurs when one single nucleotide (A, T, C, or G) is altered. Although many SNPs have no effect on cell function, researchers think that some of these genetic variations predispose people to diseases and influence responses to particular drugs.

In this case, researchers looked at 16 SNPs from 5 regions of the chromosomes in all of the men. They found that 5 of these SNPs were more common in the men who had prostate cancer. When they looked at these 5 specific SNPs individually, they found that each was associated with prostate cancer, but only moderately. But it was a different picture when men had more than one of these SNPs --- the more of these SNPs the higher the likelihood that the man had prostate cancer.

Men with a family history of the disease and the 5 SNPs accounted for about 46 percent of the cases of prostate cancer in the Swedish men that were studied. The researchers also calculated that men with five risk factors or more had an odds ratio for prostate cancer of 9.46. (A family history of the disease is equal to one risk factor as is each SNP.) Dr. David Penson warns in a *Medscape Urology* interview about these findings that an odds ratio is not the same as relative risk, so "you can't say [about men with 5 or more risk factors] that they're 9 times more likely to develop cancer than men who don't have the 5 ... but

they're clearly at much greater risk."

Three other studies published in the February 10 online edition of [Nature Genetics](#) consider prostate cancer risk and genetic variations. Research teams from the United Kingdom, the United States, and Iceland, working independently, uncovered at least 10 new genetic variations associated with an increased risk for prostate cancer. One of these studies, lead by Dr. Julius Gudmundsson of deCODE Genetics Corp. in Iceland, found that a particular genetic variation (2p15) is strongly associated with the risk of developing an aggressive form of prostate cancer. According to Dr. Durado Brooks, director of prostate and colorectal cancers at the American Cancer Society, "This is the sort of information that has the potential to be most useful in the clinical setting."

Although investigating the connection between genetic variations and the risk of developing prostate cancer does add to our knowledge of the disease, some worry that genetic testing of this sort may do as much harm as good. "Technology today enables us to find out a huge amount of information," says Dr. Gelmann of Columbia University's cancer centre. "But how does the public deal with this information? How does it help them make decisions? And, if they make a decision, does that lead to a day, a week, a month, of life saved?"

Still, the genetic genie is out of the bottle and unlikely to get stuffed back in. The researchers who published the January 2008 article have already founded the company Proactive Genomics, which is making its Focus5™ prostate cancer risk test available for about \$300. Not far behind were the researchers from deCODE, who now offer deCODE ProCa™ a \$500 test of eight known genetic variants associated with prostate cancer risk.

Physical activity and decreased prostate cancer risk

Men who engage in regular physical activity as part of their jobs seem to have a decreased risk of prostate cancer. Researchers reported this conclusion in the February 2008 issue of *Cancer Causes and Control* after studying prostate cancer incidence among male workers at a nuclear and rocket-engine testing facility in Southern California. ([Get more information](#) about this study.)

Other research has suggested that regular and fairly continuous exercise, but not intermittent exercise, can lower prostate cancer risk. Among 53,000 Norwegian men, for example, investigators found a lower incidence of prostate cancer for those who were active both recreationally and on the job. But just working as a manual labourer did not lower men's risk. Dr. Terryl Hartman, professor of nutritional studies at Pennsylvania State University agrees. His team found that men with high levels of long-term physical activity were less likely to develop prostate cancer, but those in heavy manual labour experienced fairly average risk for the disease.



The thinking is that, to lower your prostate cancer risk, you need regular and "dynamic" activity rather

than more "static" work, such as heavy lifting. So get out those running shoes and hiking boots!

The biology behind how physical activity affects prostate cancer risk is not known definitively. Researchers speculate, however, that regular physical activity alters hormone levels in men. Male athletes and others with high levels of sustained physical activity, for example, have lower levels of both total and free testosterone --- the main male hormone or androgen. And we do know that reducing androgen levels in men who have prostate cancer can slow the progress of the disease. This knowledge is at the basis of hormone therapy for prostate cancer.

Other factors related to regular, dynamic physical activity might help lower prostate cancer risk. Body fat levels and content, diet, insulin levels, and the amount of other non-androgenic hormones in the body can also be affected by exercise and may be involved in lowering prostate cancer risk. One difficulty in determining the exact effects of exercise on prostate cancer incidence is that it is very hard to design randomized clinical trails to test for these effects. Just imagine trying to get thousands of men to engage in and record a specified amount and sort of physical activity over, let's say, ten years, and you see the trouble. This is one reason that current studies often focus on men who have to be physically active as part of their jobs.

Still, even though it may be hard to prove, it makes sense that daily physical activity not only enhances a man's general health but, more than likely, helps protect him against prostate cancer.

CPCN National Conference 2008

The CPCN national conference will feature wonderful western-style hospitality, internationally renowned prostate cancer researchers, and a special session for spouses and sweethearts, who share the effects of this disease with their loved ones and give so much valuable support to men battling prostate cancer and survivors.

Delegates will gather at Calgary's Fairmont Paliser, an elegant and historic hotel that opened for business almost one hundred years ago on June 1, 1914. And CPCN President Bob Shiell promises some great leisure-time fun. "We always do something special in the way of entertainment," he says.



The conference, which runs from the evening of August 3 through to noon August 5, will undoubtedly give participants some time off to experience the sights and sounds of this vibrant, cosmopolitan city, which still retains a small-town feel. In the downtown core, you can visit the newly renovated Calgary Tower, stroll through the Devonian Gardens, or explore the heritage of the Canadian West by visiting the Glenbow Museum. And there are more attractions further afield.

As for the conference's attractions, there are plenty.

Dr. Stephen Strum, a medical oncologist well-known in the treatment of prostate cancer for over 25 years, will speak about the conference's theme --- "Stayin' Alive" and healthy through all stages of the prostate cancer journey, from early detection to survivorship. Dr. Strum has authored or co-authored more than 100 research papers, books, and articles on prostate cancer and related issues. An interesting aside is that Dr. Strum, an American, has a long association with Canadian researchers. He studied under Canadian-born Nobel Prize winner Dr. Charles Huggins, who, as early as 1940, demonstrated that the surgical removal of the testicles of men with metastatic prostate cancer dramatically improved their condition. And, in 1983, Dr. Strum formed a partnership with Dr. Fernand Labrie of the Université de Laval to explore the use of combination hormone therapy in treating prostate cancer. (For more information on this therapy, visit the Hormone Therapy page of CPCN's website.)

Continuing with the conference theme, Dr. Mark Moyad will speak on the dietary and nutritional aspects of prostate health. Dr. Moyad is the author or co-author of numerous books on prostate cancer, including *Complementary Medicine for Prostate Health*; *Promoting Wellness for Prostate Cancer Patients*; and *The ABC's of Nutrition and Supplements for Prostate Cancer*.

And, of course, we can't forget Canada's own Dr. John Trachtenberg, holder of the prestigious Fleck Tanenbaum Chair in Prostatic Diseases at the University of Toronto. Dr. Trachtenberg has a keen interest in refining treatments for men who have small, low-risk prostate cancer tumours. He wants to find treatments that are more forceful than active surveillance but have fewer side effects than aggressive conventional therapies. As he said at the World Congress on Controversies in Urology, held in Barcelona this February, "We need to find a way to treat this low-risk, low-volume prostate cancer that will have the best balance of cancer control and maintenance of quality of life."

