

The Role of Prostate Cancer Support Groups in Health Promotion



Executive Summary: 2009

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The Role of Prostate Cancer Support Groups (PCSGs) in Health Promotion

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Introduction

In Canada, no cancer is more common to men than prostate cancer (PCa).¹ In 2007, 22,300 Canadian men were diagnosed with PCa, and an additional 4,300 died of the disease.² Old age is the strongest predictor of PCa development^{3,4} and it is estimated that the proportion of elderly Canadians (>65 years of age) will increase from 13.2% (4.2 million) of the total population (2005) to 24.5% (9.8 million) by 2036.⁵ Men are also living longer with PCa, and the death rate continues to be significantly lower than the incidence rate.⁶ 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.^{6,7} 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,⁸⁻¹⁷ and quality of life.¹⁸⁻²⁰ The roles of breadwinner, husband and father are often altered, and pursuits of work and leisure can be undermined.^{8-9,15-17} Furthermore, most PCa treatments affect potency and urinary continence, which directly affect men's sexuality and intimate relationships.^{12-13, 14-17, 21-24}

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. The three-year study was funded by the Canadian Institutes of Health Research (CIHR), Institute of Gender and Health and through their generous support we were able to explore:

- the feasibility of survivor-volunteer led PCSGs,
- men's and women's patterns of engagement with, and perspectives about PCSGs, and
- factors shaping men's health promotion practices at PCSGs.

The purpose of this report is to summarize the findings drawn from the study and make practice and research recommendations. The content shared in this report has been published in academic journals, the 'Our Voice' PCa survivor magazine and on the Canadian Prostate Cancer Network (CPCN) web site (<http://www.cpcn.org/>) and presented at conferences, workshops and PCa meetings in Canada, the USA, Australia and Europe.*

Prostate Cancer Support Groups in British Columbia

PCSGs are relatively recent phenomena, and the Vancouver group in British Columbia (BC), established June 1992, was among the first groups to operate in Canada. Previous studies of Canadian PCSGs, including an interview study of 12 men mostly in leadership roles in Winnipeg, Toronto and Ottawa-based groups, indicated that men derive a sense

* Please refer to Publications and Presentations (page 18 through 20) for specific details.

of meaning and purpose through attending support group meetings.²⁵ 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.²⁶ Both studies recommended further research to more fully understand how PCSGs operate in Canada, and in 2005 we were able to build upon these earlier studies.

Methods

Study design

A qualitative ethnographic design, including fieldwork, participant observations, and individual interviews provided an effective way to establish understandings about PCSGs.²⁷ The primary characteristic of the study was its commitment to cultural interpretations of the practices and social norms at the PCSGs.²⁸⁻²⁹

Sample

We attended and observed meetings at 16 groups in diverse rural and urban locations in BC, Canada. The PCSG meeting details based on fieldwork and participant observations are included in Table 1. Five groups focused their meetings on psycho-educational presentations, six groups were discussion-based, and five groups combined psycho-education with discussion. All the groups were led by PCa survivor volunteers and the number of attendees ranged from 4 to 100 people ($M = 27$). Potential interviewees volunteered from each PCSG and from that pool we interviewed 54 men with varying group associations. Specifically, 22 men held leadership roles (e.g., leader, facilitator, secretary), 16 were long-term members (attending for more than 12 months) and 16 were short-term members (attending for less than 12 months); all completed individual semi-structured interviews. In total, the 54 interviewees accounted for approximately 16% of all the men observed at the group meetings, and they ranged in age from 53 to 87 years ($M = 71.27$ years; $SD = 8.52$ years) and had attended PCSGs for an average of 5 years ($SD = 4$ years)[†]. The majority of the men were married ($n = 51$) and retired ($n = 44$). The interviewee's mean time since PCa diagnosis was 6 years ($SD = 5$ years)[†]. Three men had not been treated; of the 51 men who had been treated, 15 had a prostatectomy, 6 received androgen deprivation therapy, 4 brachytherapy, 4 radiation therapy, and 22 a combination thereof. We also expected to recruit one woman from each PCSG to participate in the interview component of the study. However, many women were eager to talk with us, and we interviewed 20 women from 11 of the 16 groups. On average, 5.6 (21%) of the attendees at each of the PCSG meetings that we observed were women. Women interviewees self-identified as Anglo-Canadian ($n = 14$) and Northern European ($n = 6$), ranged in age from 54 to 84 years ($M = 68.5$ years), and most were retired ($n = 15$). Most participants ($n = 16$) attended with their husbands and, at the time of the interview, had attended group meetings from 6 months to 13 years ($M = 6.5$ years). The women's demographic data reflected what was typically observed at the group meetings.

[†] Length of time attending the group varied widely, ranging from 1 month to 13 years as did time since diagnosis (1 month to 19 years).

Table 1. Prostate Cancer Support Group characteristics

Group	Number of Participants (all)	Number of Men	Number of Women	Meeting Duration (Minutes)	Speaker	Formal Sharing	Location	Urban/Rural	Years Established	New Members at Meeting	Leaders
1	7	7	0	35	No	Yes	Hospital	Urban	12	1 Man	2
2	8	7	1	120	No	Yes	*Office	Urban	10	1 Woman	2
3	28	26	2	120	Oncologist	Yes	*Office	Urban	13	2 Men	1
4	100	82	18	120	Urologist	No	Hospital	Urban	12	6 Men	Committee
5	4	4	0	120	No	Yes	*Office	Rural	5	0	1
6	26	20	6	120	No	Yes	Community Centre	Urban	10	4 Men 1 Woman	Committee
7	32	26	6	120	Oncologist	No	*Office	Urban	10	1 Man 1 Woman	1
8	17	11	6	120	No	No	Church	Urban	12	0	1
9	13	10	3	80	Oncologist	No	Hospital	Urban	7	2 Men 1 Woman	1
10	21	12	9	120	Dietician	Yes	Church	Rural	6	1 Man	2
11	27	22	6	120	Survivor	No	Church	Rural	13	0	1
12	11	9	2	90	No	Yes	Recreation Centre	Rural	8	0	1
13	52	47	5	120	No	Yes	Municipal Health Centre	Urban	14	1 Man	1
14	65	41	24	120	Oncologist	Yes	Hospital	Urban	14	5 Men 5 Women	Committee
15	12	9	3	120	No	Yes	*Office	Rural	12	0	1
16	5	5	0	90	No	Yes	*Office	Rural	1	0	2
Total	428 (100%)	338 (79%)	90 (21%)		7/16 speakers	11/16 sharing	6/16 *Office	10/16 Urban	159	32 (Men 72%) (Women 28%)	9/16 – one leader
Range	4 – 100								1 – 14		
Mean	26.8								9.9		
SD	25.0								3.5		

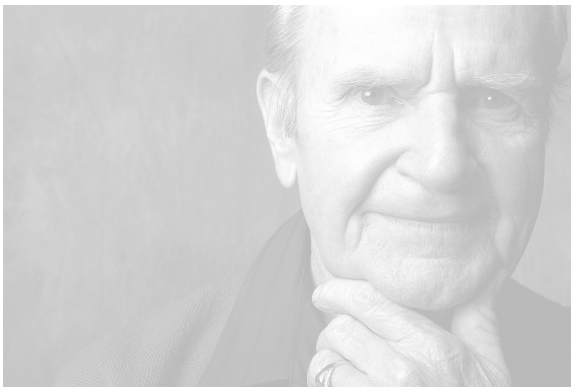
* Office provided by Canadian Cancer Society

Key Findings

The key study findings related to (1) group sustainability, (2) health promotion strategies, (3) the use of humour and (4) the roles of women in PCSGs. We also assessed the PCa information shared by Canadian newspapers to better understand how that medium messages the public about PCa.

1. Prostate cancer support group sustainability

Early on in the study we noted that the groups often struggled and some groups had stopped meeting; while others were enduring, meeting regularly, and attracting large numbers of attendees. While collecting data from the 16 groups in this study, we became aware of 9 BC-based PCSGs that had recently disbanded, and many of the groups that we attended were challenged to attract and retain members, maintain cohesive leadership, and provide up-to-date information in a rapidly changing field. Group sustainability was formally investigated to better understand these issues.



While collecting data from the 16 groups for this study, we became aware of 9 BC-based PCSGs that had recently disbanded, and many of the groups that we attended were challenged to attract and retain members.

Leadership and management

As others have observed in professionally-led cancer support groups,³⁰ the success and longevity of PCSGs is reliant on effective leadership and management. PCSG leadership can be challenging for lay volunteers. The groups attract men and women with a wide diversity of needs that fluctuate considerably from one meeting to the next. Cohesive leadership, shared management, and specific group facilitation strategies were integral to meeting the needs of attendees and fostering their camaraderie and commitment to the group. Group members were adamant that PCSGs needed to be survivor-led, yet being a group leader required significant time, energy, and commitment that only a few men were able or willing to provide. Similar to problems described by both professional and nonprofessional leaders of cancer support groups,³¹ PCSGs' dependence on one or two leaders and lack of defined terms and tenure, meant that group leaders were at risk for burnout. In these situations, the long-term viability of the group was uncertain. Finding ways to support the leadership of PCSGs and the development of succession planning was critical to ensuring group sustainability.

Collaboration or emancipation

PCSG sustainability was also influenced by linkages with professional organizations. One option for the PCSGs in this study was to affiliate with cancer fundraising agencies. However, concerns were expressed by some PCSG attendees that the groups would end up working for organizations that dictated the terms and conditions under which they operated. Many PCSGs were resistant to anything resembling a “takeover” or “branding” by organizations that did not have the capacity to provide resources to the groups and willingness to negotiate mutually acceptable terms of operation.



The study findings about PCSG sustainability are available in more detail at:



Oliffe, J.L., Halpin, M., Bottorff, J.L., Hislop, T.G., McKenzie, M. & Mroz, L. (2008). **How prostate cancer support groups do and do not survive: A British Columbian perspective.** *American Journal of Men's Health*, 2(2), 143–155.

2. 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.³² 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. At the same time, through group discussions, the men shared their health promotion practices. Three PCSG strategies are outlined to detail the specificities of how PCSGs achieved this activity.

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. For example, an 81-year-old participant connected with another man at the monthly PCSG meetings who had the same treatment and similar PCa biomarkers. When the man missed a few meetings the participant telephoned him at home to make sure he was doing well:

An environment conducive to men’s talk was established to normalize PCa, and to promote the individual and collective health of group members.



I phoned him and talked to his wife. And I said ‘Is [support group member] sick?’ And she said, ‘No he’s cross-country skiing’...and I said, ‘Well, if he can do it, I can do it too’...This is extremely important to me that you find a guy that has a Gleason of 9, that’s gone through the same treatment I’m going through now a couple years later because his was 3 years ago. He’s doing really good. He’s cross-country skiing.

Mixing health and illness information

The ability of PCSGs to mix PCa and health information afforded the “light and shade” to maintain the men’s interest without overwhelming them. Rather than an exclusive focus on PCa, 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. Complementary and alternative medicines were also discussed as a means to maintaining and improving health. A 74-year-old man who had been attending group meetings for less than 12 months talked about the impact of group conversations, specifically citing meditation as key to reducing his PCa induced anxiety:

A lot of the apprehension, the trauma that is associated with first hearing about cancer, a couple of fellows there talked about meditation and I was never big on that, but I do that now.

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 sub-groups (i.e., prostatectomy, radiation therapy, brachytherapy, etc.) which newly diagnosed men could access to discuss specific information. A 72-year-old participant who had recently undergone brachytherapy explained that he was able to provide more information than otherwise would have been available to a man wanting to make a treatment decision:

It set his mind at ease because he was finally able to talk to somebody who has been through the brachytherapy process. Prior to that, the information he had, had come from the urologist and his family doctor who have never gone through the whole process.



The study findings about health promotion and illness demotion are available in detail at:



Oliffe, J.L., Gerbrandt, J., Bottorff, J.L., & Hislop, T.G. (In Press). **Health promotion and illness demotion at prostate cancer support groups.** *Health Promotion Practice.*

3. 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.

Disarming stoicism

By opening with a joke or inserting a humorous remark, regardless of whether it brought shrieks of laughter or a few sniggers, the men were able to manufacture something that others could actively engage with and react to. Humour often subtly disarmed stoicism in ways that did not necessarily demand talk from each and every man who attended the group. Instead, a shared joke or laughter constituted a group activity, and there was often a central character(s) in each who enjoyed sharing 'their' humour as a remedy. A 74-year-old man explained that understanding and empathy existed within the group and humour was used to signal that, and to reassure newcomers that their cancer and group-related anxiety would dissipate over time:

There are a couple of fellows there that didn't say a word all night. I could tell by their posture that they have just been diagnosed and they were obviously terrified as I was when I was first diagnosed. There's a lot of anxiety there and those fellows were not prepared to open up. Others were there who have been through this, sort of around the road on this thing. Some of them were quite humorous about this and that was a nice balance between these guys.

A shared joke or laughter constituted a group activity, and there was often a central character(s) in each who enjoyed sharing 'their' humour as a remedy.



Marking the boundaries

Men also used humour to introduce potentially sensitive PCa issues such as urinary incontinence, sexual dysfunction, and death. A quip or joke was often put forward to gauge the group's interest, and to assess whether the discussion of ordinarily taboo topics was permissible. A long group discussion about treating erectile dysfunction (ED) took place after a 66-year-old participant who had been attending PCSG meetings for three years signalled his intact male libido but acknowledged the challenges of successfully treating ED:

I was talking about using Viagra to see whether it will help, well it gave me a headache—maybe that’s a good thing!? There was humour about that, that went into the room. It’s kind of light-hearted and people are trying to make the best of it, of a bad joke.

Although the humour was well-intended, many group leaders were aware of the need to strategize the use of humour to ensure the comfort of all attendees. A 65-year-old group leader of 10 years explained:

You’ve got to be very careful. The humour is clean, non-judgmental and you’ve got to be very, very careful on how you deliver the humour...You’ve got to know your group and what people are in the group. The people that I was giving a bad time to, [they] enjoyed the bantering back and forth...They would egg me on and I would egg them on and it was fun and they loved it. Other individuals, you can’t do that.

Our analyses revealed how humour can be integral to legitimizing men’s support group involvement and engagement with self-health. A sense of humour can give a group member a tool for expressing complicated emotional states, while the wit itself may buoy self-esteem and silence self-criticism. In the PCSG settings, humour can regulate the emotional atmosphere by enlivening social interactions. Thus, the sharing of laughter is an indication of a degree of shared safety and establishes an intimacy in interpersonal relations and facilitates communication by, for example, promoting cohesion among group members. Additionally, humour itself can be therapeutic because of the way it gives pleasure.

The study findings about the use of humour at PCSGs are available in more detail at:



Oliffe, J.L., Ogradniczuk, J., Bottorff, J.L., Hislop, T.G., & Halpin, M. (In Press) **Connecting humor, health and masculinities at prostate cancer support groups**. *Psycho-Oncology*.

4. 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”³⁷⁻³⁹ in which the disease, as well as its treatments, affect gender identities and

relations across the entire illness trajectory.^{10,12-14,17} 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. A 64-year-old woman who had been attending group meetings for one year explained:

I went to support my husband because he was newly diagnosed but I also was quite overwhelmed by the amount of information there was....So I found that maybe the support group there would be an opportunity to begin to make more sense of ...the medical aspect of it but also maybe the psychological, also to hear people’s stories and then for myself to be able to not only discuss things with my husband but hopefully to discuss things with 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. A 75-year-old woman who had been attending group meetings for 10 years explained:

I only go with him....Every once in a while he would say, “I do not know why I am going anymore.” I always come back with, “Well it is for the other fellows that are there, the new people, because you are a survivor.” I think it is important for them to hear the survivors....I sometimes wonder why we go too, but it is for the others.

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 life. A 60-year-old woman, who had attended group meetings with her husband for ten years, explained her role:

I'm the refreshment lady...The tea, coffee, actually I used to make everything at one time...they had a meeting, I wasn't there, [laughs] and they voted me to do it [laughter]...Because there's a lot of people that didn't want to do it, it doesn't have to be the woman, it could be the guys but they didn't want to do the coffee, 'How much coffee do I put in, how much water do I put in?' you know, and they'd really stress themselves out about it.



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. A 65-year-old woman who had been attending group meetings for one year explained that during group discussions and the associated question period, she remained quiet because her husband was the one who needed to talk:

I don't get involved with the questioning because it's [husband] that has it, and he's the one that knows how he feels so if he has a question he'll ask but I don't really say anything.

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, as suggested by a 59-year-old woman who had been attending group meetings for 12 years:

I had a need to talk desperately, I had my friends who had empathy and caring but they had no idea what I was going through and if any of them were losing their husbands, they were losing them through divorce not this. As much as your family and friends love you and care about you, often they don't really have the knowledge, this group can give you that knowledge. I believe that the groups can help enormously, emotionally, and I think that emotion plays a huge role in the disease. I think people underestimate the importance of it.

The study findings about women and PCSGs are available in more detail at:



Bottorff, J.L., Oliffe, J.L., Halpin, M., Phillips, M. McLean, G., & Mroz, L. (2008). **Women and prostate cancer support groups: The gender connect?** *Social Science and Medicine*, 66, 1217–1227.

5. Canadian newspapers' portrayals of PCa

Providing information to men and their families is the primary role of PCSGs. However, there is implicit and sometimes explicit concern that “lay” perspectives might be inaccurate or biased. In thinking about where else men and their partners might access PCa information we decided to systematically analyze how two national Canadian newspapers, *The Globe and Mail* and the *National Post*, portray PCa. Articles published between 2001 and 2006 that contained the term “prostate cancer” in the title or text were collected and a total of 417 PCa articles were analyzed to reveal the following three themes.

Treatment imperative

PCa screening and treatment technologies were detailed in 178 (42%) articles. Seventy-two articles mentioned the prostate specific antigen (PSA); however, uncertainty about the efficacy of the PSA test was discussed in approximately half of the articles ($n = 35$). In terms of PCa treatment modalities, articles focused on hormone treatments ($n = 64$), surgery ($n = 29$), radiation therapy ($n = 29$) and brachytherapy ($n = 10$). The vast majority of these articles appeared in the business section, and hormone treatments (as the most expensive PCa therapy heavily subsidized by the federal government) were often linked to pharmaceutical companies' stock market prices. When PCa treatment side effects, including erectile dysfunction (ED) were discussed, typically it was combined with the marketing of pharmaceutical remedies. For example, the unveiling of Viagra's™ competitor, Cialis™ detailed the testimonial of a 54-year-old man who had developed ED following PCa surgery. The advantages of Cialis'™ longer half-life were highlighted in the man's testimonial, “because it lasts for 36 hours, [sex] doesn't have to be a planned event, which is very attractive. It leads you back to a much more normal life”.⁴⁰

The good fight

Ideologies emphasizing courage in men's PCa battles predominated in 117 articles (28%), and the commentaries routinely featured men in sports, politics, and the entertainment industry to detail the specificities of the good fight. Typically, men's achievements were detailed and PCa was background but linked to men's willingness to fight the cancer across the illness trajectory.

Self-health and public awareness

Sixty-three articles (15%) detailed dietary intervention and supplementation strategies including the integration of foods containing lycopene and other nutrients proposed to be implicated in delaying cancers – including PCa development. The articles lacked detail but pointed to specific foods as health- enhancing and cancer- preventing. Some articles indicated that men should take responsibility for their health; however, it was women who were most often portrayed as the lynchpin in surveying and informing men's health practices. An example of this included an article describing how Theresa Heinz-Kerry's medical knowledge – and knowledge of her husband's health – may have saved her husband's life:

Ms Kerry knew enough to have her husband's blood retested for C-reactive protein, a little-known indicator of potentially cancerous inflammation. Two days before Christmas, his doctor told Mr. [John] Kerry his wife's fears were well placed; he was in the very early stages of PCa.⁴¹

Overall, our analyses indicated that PCa is depicted most often in commerce based articles and stories about men's courage. In addition, there is little consistency in the PCa screening and treatment information presented, nor are there directions or strategies provided to guide men about how best to engage in self-health.

The study findings about PCa and Canadian newspapers are available in more detail at:



Halpin, M., Phillips, M., & Oliffe, J.L. (In Press) **Prostate cancer in Canadian newspaper media: Representations of illness, disease and masculinities.** *Sociology of Health and Illness*.

Recommendations

Implications for practice

The findings detailed in this report enabled us to thoughtfully consider how to maximize the impact of PCSGs. As such, the following recommendations are offered as strategies to ensure the continuation and growth of PCSGs:

- Although PCSGs will not appeal to all men, using the word “support” is associated with indebtedness or weakness and may discourage men from attending. We recommend a **name change** to **mutual help** or **men’s health** to more accurately reflect the core business of **education** and **information** and attract more men to group meetings.
- The **World Wide Web** offers an important medium to extend and promote the work of PCSGs. That said, the ultimate success of **virtual PCSGs** is contingent upon having sufficient resources to design, deliver, and regularly evaluate and update information in ways that men can easily access and understand, and explain to others.
- The permission of others at PCSGs to talk about health and illness afforded men the freedom to actively engage in self-health. Therefore, men’s health promoters need to tailor content and **encourage** and **expect men to talk**, rather than disseminating generic information or telling men how to look after their health and respond to illness.
- **Humour** played a central role in how men interacted at the groups and this might also be useful in the delivery of other **men’s health promotion programs**.
- **Balancing PCa information with discussions about healthful practices** maintained the attendee’s interest, but avoided overloading men with information. This was important because rather than an exclusive focus on PCa, many opportunities existed for men to link health and illness and promote their health for reasons other than heeding expert advice or seeking a PCa remedy.
- **The needs of female partners** are underserved by professional health care services and, as such, women’s PCSGs might be an important additional resource to meet the needs of a greater number of women.

Future Research

We recommend that the following research questions be addressed to extend and promote the work of PCSGs in Canada:

- What are health care professionals’ connections to, expectations of, and recommendations for PCSGs?

- How can on-line PCSGs inform and influence PCa consumers and service providers?
- How might professionally facilitated psychosocial PCa interventions be administered on-line and at face-to-face PCSGs?
- What community-based PCa supports will best meet the needs of women?

Publications

Oliffe, J.L., Halpin, M., Bottorff, J.L., Hislop, T.G., McKenzie, M., & Mroz, L. (2008). How prostate cancer support groups do and do not survive: A British Columbian perspective. *American Journal of Men's Health*, 2(2), 143–155.

Oliffe, J.L., Gerbrandt, J., Bottorff, J.L., & Hislop, T.G. (In Press). Health promotion and illness demotion at prostate cancer support groups. *Health Promotion Practice*.

Oliffe, J.L., Ogrodniczuk, J., Bottorff, J.L., Hislop, T.G., & Halpin, M. (In Press) Connecting humor, health and masculinities at prostate cancer support groups. *Psycho-Oncology*.

Bottorff, J.L., Oliffe, J.L., Halpin, M., Phillips, M., McLean, G., & Mroz, L. (2008). Women and prostate cancer support groups: The gender connect? *Social Science and Medicine*, 66, 1217–1227.

Halpin, M., Phillips, M., & Oliffe, J.L. (In Press) Prostate cancer in Canadian newspaper media: Representations of illness, disease and masculinities. *Sociology of Health and Illness*.

Work in progress:

Oliffe, J.L., Bottorff, J.L., McKenzie, M., Hislop, T.G., Gerbrandt, J., & Oglov, V. Prostate cancer support groups, health literacy and consumerism: Are community-based volunteers redefining older men's health?

Oliffe, J.L., Bottorff, J.L., Austin, D., Hislop, T.G., & McKenzie, M. Taking care of business: Prostate cancer support group leaders.

Oliffe, J.L., Haines, R., Bottorff, J.L., & Phillips, M. Women's commentaries about prostate cancer survivors' health and illness practices.

Oliffe, J.L., & Bottorff, J.L. Couples at Prostate cancer support groups: A gender relations analysis.

Presentations:

Oliffe, J.L. (May, 2009). Findings from our PCSG study. Presentation at the Victoria Prostate Cancer Support Group, Victoria, British Columbia, Canada.

Oliffe, J.L. (March, 2009). Findings from our PCSG study. Presentation at the Surrey Prostate Cancer Support Group, Surrey, British Columbia, Canada.

Oliffe, J.L. (December, 2008). Your PCSG and Active Surveillance. Presentation to the Calgary PCSG. Calgary, Canada.

Oliffe, J.L. (December, 2008). PSCGs – What next? Presentation to the PCSGs Alberta Board of Directors. Calgary, Canada.

Oliffe, J.L. (October, 2008). Gendering prostate cancer in the context of support groups. Panel Keynote presented at the Spanish Ministry of Health, Women's Health Observatory Workshop, Madrid, Spain.

Oliffe, J.L. (August, 2008). The role of humour at PCSGs. Presentation at the Vancouver Prostate Cancer Support Group, Vancouver, British Columbia, Canada.

Oliffe, J.L. (June, 2008). Qualitative research methods for clinicians. Invited workshop at Vancouver Coastal Health, Vancouver, British Columbia, Canada.

Oliffe, J.L., Ogrodniczuk, J., Bottorff, J.L., Hislop, T. G., & Halpin, M. (May, 2008). Connecting humor, health and masculinities at prostate cancer support groups. Paper presented at the Canadian Association of Psychosocial Oncology, Halifax, Nova Scotia, Canada.

Bottorff, J.L., Oliffe, J.L., Halpin, M., Mroz, L., McLean, G., & Phillips, M. (May, 2008). Women attending prostate cancer support groups: The gender connect? Paper presented at the Canadian Association of Psychosocial Oncology, Halifax, Nova Scotia, Canada.

Oliffe, J.L. (October, 2007). International perspectives in men's health research. Panel Member, Australian National Men's Health Conference. Adelaide, South Australia.

Oliffe, J.L. (October, 2007). Empirical, methodological and theoretical: The men's health trifactor. Invited Workshop, Australian National Men's Health Conference. Adelaide, South Australia.

Oliffe, J.L. (October, 2007). Prostate cancer support groups: Canadian group sustainability. Keynote presentation at Prostate Cancer Foundation of Australia, Public Lecture. Adelaide, South Australia.

Oliffe, J.L. (September, 2007). Prostate cancer support groups – How are we doing? Keynote presentation at the Canadian Prostate Cancer Network (CPCN) and Canadian Prostate Cancer Research Initiative (CPCRI) Conference. Toronto, Ontario, Canada.

Oliffe, J.L. (July, 2007). Sustainability and PCSGs. Presentation at the Victoria Prostate Cancer Support Group, Victoria, British Columbia, Canada.

Oliffe, J.L. (June, 2007). Qualitative research methods for clinicians. Invited workshop at Vancouver Coastal Health, June, Vancouver, British Columbia, Canada.

Oliffe, J.L., Halpin, M., Bottorff, J.L., Mroz, L., Hislop, G., & McKenzie, M. (June, 2007). The sustainability of prostate cancer support groups: Are the grassroots burning? Paper presented at the 19th IUHPE World Conference on Health Promotion and Health Education. Vancouver, British Columbia, Canada.

Oliffe, J.L., Bottorff, J.L., Halpin, M., Phillips, M., McLean, G., & Mroz, L. (June, 2007). He said, she said: Women's commentary about men who attend prostate cancer support groups (PCSGs). Paper presented at the 19th IUHPE World Conference on Health Promotion and Health Education. Vancouver, British Columbia, Canada.

Bottorff, J.L., Oliffe, J.L., Halpin, M., Mroz, L., McLean, G., & Phillips, M. (March, 2007). The benefits, roles and reasons for women attending prostate cancer support groups. Paper presented at the Canadian Conference on Men's Health, Victoria, British Columbia, Canada.

Halpin, M., Phillips, M., & Oliffe, J.L. (March, 2007). Prostate cancer in the Canadian news media: A case of inconsistent messaging? Paper presented at the Canadian Conference on Men's Health, Victoria, British Columbia, Canada.

Oliffe, J.L. (March, 2007). Prostate cancer support groups in British Columbia. Keynote presentation at the Annual General Meeting and Banquet, British Columbia Foundation for Prostate Disease. Vancouver, British Columbia, Canada.

Oliffe, J.L. (October, 2006). Study outline – the role of PCSGs in health promotion. Presentation at the Surrey Prostate Cancer Support Group, Surrey, British Columbia, Canada.

Oliffe, J.L. (April, 2006). Preliminary findings – PCSG sustainability. Presentation at the Vancouver Prostate Cancer Support Group, Vancouver, British Columbia, Canada.

Oliffe, J.L. (September, 2005). The role of PCSGs in health promotion – an overview and invitation to participate in a new study. Presentation at the first BC Foundation for Prostate Disease Workshop, Vancouver General Hospital, Vancouver, British Columbia, Canada.

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Research Staff

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Administrative Staff



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Michael McKenzie, MD, FRCPC. Co-investigator, radiation oncologist and member of The Genitourinary Tumour Site Group at the British Columbia Cancer Agency (BCCA).

Appendix 1 - British Columbian Prostate Cancer Support Groups

ProCan Support Web site & Publication

(A Virtual BC Prostate Cancer Support Group)
Contact: George Main 604-574-5554
Email: gcmain@bcprostatecancer.org
Where: www.procansupport.com

Abbotsford PSA (Prostate Cancer Support & Awareness) Group

Contact: Val Strijack 604-856-5863 or Bill Lantz 604-858-1826
Email: Val_strijack@telus.net or billevelyn@shaw.ca
When: The 3rd Thursday of each month (no meetings July/August and December)
Time: 7:30 to 9:30 p.m.
Where: Peace Lutheran Church, at Ware and Marshall Rd. Abbotsford, B.C.

Ashcroft “Men’s Health Matters” Group

Contact: David Durksen 250-453-9864 – cell 250-457-3226
Email: ddurksen@coppervalley.bc.ca
When: The 2nd Tuesday of each month
Time: 7:00 p.m.
Where: Ashcroft Health Centre (Hospital)

Burnaby/New Westminster Prostate Cancer Support & Awareness Group

(East Vancouver, Burnaby, New Westminster)
Contact: Ian Baxter 604-421-8813
Email: ibaxter@telus.net
When: The 1st Saturday of each month
Time: 10:00 to 12:00 Noon
Where: 2nd floor Education Room ‘A’. Burnaby General Hospital - 3935 Kincaid Ave. Burnaby, B.C.

Campbell River/West Coast Prostate Awareness Group

Contact: Frank Greens 250-923-1357 or 250-286-9696, Merv Rotzien 250-926-0076 or Al Hodgkinson 250-923-1357
Email: hudsey@telus.net (Merv)
When: The 3rd Tuesday of each month
Time: 7:00 p.m. – 9:30 p.m.
Where: Altrusa House, # 12 142 Larwood Road, Campbell River

Comox Valley Prostate Cancer Support & Awareness Group

Contact: Brian Lunn 250-338-8235
Email: kenya-cottage@shaw.ca or prostatecancer@shaw.ca
Web site is www.members.shaw.ca/prostatecancer/
When: The 2nd Monday of each month (except July & August) October this year is the 20th, the 3rd Monday, to avoid Thanksgiving Day
Time: 7:30 to 9:00 p.m.
Where: Community Health Centre, 961a England Ave., Courtenay, B. C.

Coquitlam Prostate Cancer Support & Awareness Group

Contact: Norm Sherling 604-936-8703
Email: nsherling@shaw.ca
When: The 1st Tuesday of each month
Time: 7:00 to 9:00 p.m.
Where: Pinetree Community Centre, 1260 Pinetree Way. Coquitlam, B.C.

Cowichan Valley Prostate Cancer Support & Awareness Group

Contact: Gordon Thomas 250-743-6960
Email: gandmthomas@shaw.ca
When: The last Thursday of each month
Time: 7:00 to 9:00 p.m.
Where: Lecture Room, Cowichan Dist. Hospital, Duncan

East Kootenay Pc Support Group

Contact: Peter Wightman 250-427-4822 or Kevin Higgins 250-427-3322
Email: rosehawk@shaw.ca OR kevbeviggins@cyberlink.bc.ca
When: The 3rd Wednesday of each month
Time: 7:00 to 8:30 p.m.
Where: College of the Rockies, Cranbrook Campus

Kamloops Prostate Cancer Support & Awareness Group

Contact: Larry Reynolds 250-376-4011
Email: larube_kam@shaw.ca
When: Once a month (Please call 250-374-9188 for more info.)
Time: 10 a.m.
Where: Interior Health meeting room at 450 Lansdowne St

Kelowna Prostate Cancer Support & Awareness Group

Contact: Bren Witt 250-764-1031
Email: sbren@bcprostatecancer.org
When: The 2nd Saturday of each month
Time: 9:00 a.m. to 11:00 noon
Where: Kelowna Health Centre, 1340 Ellis Street.

Nanaimo Prostate Cancer Support Group

Contact: Malcolm W. Reville 250-756-3116
Email: mmmjo@shaw.ca
When: The 2nd Tuesday of each month
Time: 7:00 p.m.
Where: Nanaimo Cancer Society

North Shore Prostate Cancer Support & Awareness Group

Contact: Tom Sayle 604-929-3125
Email: teeandjay@shaw.ca
When: The 4th Tuesday of each month January to November (November – social night) no meeting in December
Time: 7:00 to 9:00 p.m.
Where: Lions Gate Hospital, Basement Auditorium

Parksville (DISTRICT 69) Prostate Cancer Support & Awareness Group

Contact: Doug Bamford 250-954-0887
Email: dbamford@shaw.ca
When: The 1st Wednesday of each month
Time: 7:00 p.m.
Where: 361 Willow Street, Parksville, B.C.

Pender Island Prostate Cancer Support & Awareness Group

Contact: Jim Dunn 250-629-3273
Email: jsdunn@shaw.ca
When: No Longer meets but Jim is willing to take calls.

Prince Rupert Prostate Cancer Support & Awareness Group

Contact: Judy Rea 250-622-6533
Email: None
When: The 1st Wednesday of each month
Time: 7:30 p.m.
Where: Health Unit

Qualicum Beach Prostate Cancer Support & Awareness Group

Contact: Jack Rossiter 250-951-2083
Email: None
When: The 1st Tuesday of each month
Time: 7:00 to 9:00 p.m.
Where: St Stephen Church

Quesnel Prostate Cancer Support & Awareness Group

Contact: Ron Campbell 250-992-2726
Email: ronbetcampbell@shaw.ca
When: meet on an as needs basis
Where: 332 Front St., Quesnel

Revelstoke Prostate Cancer Support Group

Contact: Darrell Goodman 250-837-3663
Email: mercury54@telus.net
When: under development (some fellows meet casually at a coffee shop)
Time: Being arranged – call Darrell

Salts Spring Island Prostate Cancer Support & Awareness Group

Contact: Chris Rieder 250-537-2720
Email: bigcedar@shaw.ca
When: The 3rd Tuesday of each month
Time: 1:30 to 3:30 p.m.
Where: Farmers' Institute

Sunshine Coast Pc Support Awareness Group

Contact: John Keates, Chair 604-885-4181
Email: kkeates@dccnet.com
When: The 1st Tuesday
Time: 7 p.m.
Where: St. John's United Church, Davis Bay, Sechelt

Surrey Prostate Cancer Support & Awareness Group

Contact: Leno Zecchel 604-596-2640 or George Main 604-574-5554
Email: lzecchel@uniserve.com or gmain@bcprostatecancer.org
When: The last Saturday of each month (not December)
Time: 10:00 am to 12:00 noon
Where: Cafeteria, Surrey Memorial Hospital 13750 96 Ave. Surrey, BC

Vancouver PSA (Prostate Cancer Support & Awareness) Group

Contact: Len Gross 604- 434-2100 or Gordon Dunn 604-739-5900
Email: lengross@shaw.ca or gordond2@smartt.com
When: The 1st Thursday of each month
Time: 11:00 a.m. to 1:00 p.m.
Where: Canadian Cancer Society Board Room. 565 West 10th Ave. Vancouver.

Vernon PSA (Prostate Cancer Support & Awareness) Group

Contact: Ed Eyford 250-545-6220 or Lloyd Mitchell 250-549-2362

Email: eaeeyford@telus.net or lloyd-marion@shaw.ca

When: The 4th Monday of Jan., Feb., Mar., Apr., May, Sept., Oct., & Nov.

Time: 7:30 to 9:30 p.m.

Where: The People Place 104-3402 27th Avenue

Victoria PSA (Prostate Cancer Support Association)

Contact: David Durksen or Andrew Godon 250-382-6531

Email: ddurksen@coppervalley.bc.ca or andrew.godon@gmail.com

When: The 2nd Tuesday of each month

Time: 7:00 to 9:00 p.m.

Where: Begbie Hall Royal Jubilee Hospital grounds, 2101 Richmond Ave. Victoria

White Rock/South Surrey Prostate Cancer Support & Awareness Group

Contact: John Morton 604-538-0011

Email: johnmorton@shaw.ca

When: No Longer meeting but John is willing to take calls.

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