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How Prostate Cancer Support Groups Do and Do Not Survive: British Columbian Perspectives

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Many prostate cancer support groups (PCSGs) have formed in North America during the past decade, yet their operation or factors influencing sustainability are poorly understood. This article reports micro (intragroup), meso (intergroup), and macro (group/structure) analyses drawn from the fieldwork and participant observations conducted for an ethnographic study of PCSGs based in British Columbia, Canada. The findings indicate that effective group leadership is integral to group sustainability and the recruitment and retention of attendees. At the meso level, intergroup connections and communication were often informal; however, the primary purpose of all the PCSGs was to provide information and support to

men and their families. Many PCSGs were uncertain how formal associations with cancer fund-raising societies would influence group effectiveness. Macro issues such as prostate cancer activism resided with individual group "champions" through activities coordinated by provincial and national PCSG organizations. However, activism did not guarantee group sustainability. The study findings reveal why some groups flourish while others appear untenable, and form the basis for discussion about how PCSG sustainability might be best achieved.

Keywords: prostate cancer; support groups; group sustainability; cancer psychosocial support

Prostate cancer is the most common malignancy among men in Western society (Schiff & Mulhall, 2005) and results in diverse psychosocial and health issues for survivors and their families. There is evidence about the associated challenges and effects of prostate cancer and its treatments on quality of life (Kirschner-Hermanns & Jakse, 2002; Palmer, Fogarty, Somerfield, & Powel, 2003), gender and gender relations (Fergus, Gray, Fitch, Labrecque, & Phillips, 2002; Navon & Morag, 2003), and specific issues of potency and urinary continence (Chapple &

Ziebland, 2002; Fergus, Gray, & Fitch, 2002; Gray, Fitch, Fergus, Mykhalovskiy, & Church, 2002; Oliffe, 2005, 2006). Research to date has demonstrated that men have prostate-specific and general health needs across the entire illness trajectory, and a growing body of empirical evidence indicates that psychosocial support and health and illness information are integral to the well-being of men who have prostate cancer. Increasingly, community-based support services such as prostate cancer support groups (PCSGs) have emerged as resources for men and their families to deal with the challenges of living with prostate cancer.

PCSGs are relatively recent phenomena in several countries and are more common in North America than the rest of the world (Coreil & Behal, 1999; Visser, Riemens, Van der Jagt, Vingerhoets, & Voerman, 2001). Canadian-based PCSGs began in the early 1990s in urban centers, and two British Columbian (BC; Vancouver and Victoria) groups were among the first to operate. Since that time, the number of PCSGs has grown to 31 in BC and 118

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nationally (Canadian Prostate Cancer Network, 2003). Current understandings of the efficacy of support group interventions are strongly dominated by breast cancer experiences (Classen et al., 2001; Coreil, Wilke, & Pintado, 2004). However, an emergent literature discussing PCSGs has focused on the benefits of attendance, and content and format of meetings (Coreil & Behal, 1999; Eakin & Strycker, 2001; Krizek, Roberts, Ragan, Ferrara, & Lord, 1999; Smith, Crane, Byers, & Nelson-Marten, 2002; Visser et al., 2001).

Specifically, the format of PCSG meetings typically includes a combination of educational content and sharing of personal experiences (Coreil & Behal, 1999). There is some evidence that PCSGs are useful in mitigating the psychosocial aspects of cancer by conveying information, empowering patients, enhancing and facilitating social and psychosocial adjustment, and helping patients cope with life after a diagnosis and treatment of cancer (Evans & Connis, 1995; Fawzy et al., 1990; Gray, Fitch, Davis, & Phillips, 1996; Manne, 2002; Steginga, Occhipinti, Dunn, Gardiner, Heathcote, & Yaxley, 2001). Benefits for men who attended PCSGs include the expression of negative affect and an attitude of realistic optimism, enhanced adjustment, and reduced distress (Cordova et al., 2003). A survey of men who attended a professionally led PCSG reported that the sharing of prostate cancer experiences gave men reassurance, helped alleviate anxiety, and provided a more positive outlook and perception of being more involved in their treatment (Gregoire, Kalogeropoulos, & Corcos, 1997). Experiences with Canadian-based PCSGs indicated that men derived a sense of meaning and purpose through attending support group meetings (Gray, Fitch, Davis, & Phillips, 1997). There is also evidence for greater overall satisfaction with treatment; higher physical function, vitality, and sexual and mental health scores; and fewer complaints about urinary and bowel problems among men who attended PCSGs compared with men who did not attend (Katz et al., 2002).

The limitations of PCSGs have also been documented. For example, based on an interview study with 34 Canadian men and their partners, Gray, Fitch, Phillips, Labrecque, and Fergus (2000) suggested PCSGs are poorly attended because men typically avoided disclosure. Other reasons for poor attendance included low perceived need for support, fear of stigmatization, the need to minimize the threat of illness to aid coping, practical necessities in the workplace, and the desire to avoid burdening others (Gray et al., 2000). Men's misperception that the meetings were geared toward emotional support of the terminally ill (Krizek et al., 1999) and health

care professionals' lack of awareness of PCSGs (Smith et al., 2002) have also been identified as barriers to men attending support groups.

In summary, published studies have described discreet aspects of PCSGs, but little research attention has focused on the groups themselves. Our ethnographic study of PCSGs began with an interest in how groups functioned. However, early on in the study, it was noted that some groups struggled and some groups had stopped meeting, while others were enduring, met regularly, and attracted large numbers of attendees. The emergent issue of group sustainability was investigated, and the purpose of this article is to describe PCSG sustainability issues and thoughtfully suggest proactive ways forward to ensure the continuance of these important community-based services. The study is guided by the overarching research question: How do group composition, intergroup linkages, and associations with professional cancer services influence the sustainability of PCSGs?

Materials and Methods

A qualitative ethnographic design, including fieldwork and participant observation, provided an effective way to build contextual understandings about PCSGs. A micro-ethnographic approach was used in which the focus was on particular behaviors in particular settings, rather than attempting to portray a whole cultural system (Wolcott, 1990). The primary characteristic of the study was its commitment to cultural interpretations of social norms and practices in the specific context of PCSGs (Boyle, 1994; Muecke, 1994). This approach was effective for explicating the ways in which PCSGs operate and the multilevel factors that can influence group sustainability.

Procedure

Following approval from a university-based ethics review committee, the designated leaders from each PCSG were contacted by telephone to discuss the proposed research and request permission for two male researchers to conduct participant observations at a minimum of one group meeting for each group. The group leaders were supportive of the study and, with the permission of the group members, provided opportunities for the researchers to explain the participant observations and overall aims of the research and invite members to participate in the interview

Table 1. Fieldwork and Participant Observation Guide

Category	Specific Researcher Focus
Group demographics and general observations	How old is the group? How many people attend? How is the group managed and led? Describe the meeting venue, organization, and materials used.
Meeting format and group composition and interactions	How is the meeting started? What information is provided and how is it disseminated or discussed? What is the focus of the formal meeting? What topics do guest speakers present, and are presentations followed by a question and answer session? What type of language is used (e.g., biomedical or lay)? What are predominant member interactions before, during, and after the meeting? How are new members brought into the group? How are men who want specific prostate cancer advice identified and reacted to? How is treatment discussed? How are member testimonials solicited? What needs are predominant and what patterns of interaction exist in subgroups (leaders, new and long-term members)?
Philosophy and politics	How cohesive is the group? What are the sustainability issues raised by the members? What is the philosophy and purpose of the group? How does the group attract and retain members? What group (cultural) norms exist? What group commitment and connections to external organizations exist?
Advocacy	How is prostate cancer awareness raised? What activist activities are proposed and completed?

portion of the larger study. The two researchers observed the meetings from distinctly different vantage points, usually at the back of the meeting room, to maximize what was seen. A fieldwork and participant observation guide (Table 1) was used to direct observations, and shorthand notes were made by each of the researchers. Observations focused on group activities and member interactions along with general descriptions of the meeting room, setup, and number of attendees.

Immediately after each meeting, the two researchers discussed their notes and observations,

with the conversations (averaging 1 hr in duration) digitally recorded and transcribed verbatim. Informal discussions with individual group members occurred during the fieldwork, and direct participant quotes were recorded when possible. The transcribed record of the participant observations, along with the field notes, were discussed by the investigative team—including those researchers who attended the PCSG meeting—to develop understandings about each group. Field notes and participant observation data were generated during 2005 and 2006 at the meetings of 15 BC-based PCSGs. The groups were selected to ensure diversity, with rural and urban and small and large groups recruited from locations throughout BC. Composition and activities that characterized each PCSG are presented in Table 2. Each PCSG is referred to with a number (1-15) to ensure anonymity and confidentiality.

Participant observations were also conducted at fundraisers organized by the groups and provincial and national PCSG conferences. The data collection methods were identical to the aforementioned approaches used at the PCSG meetings. Finally, telephone interviews were completed with the executive director of the Canadian Prostate Cancer Network (CPCN) as well as ex-leaders from five disbanded PCSGs to discover their perspectives about the factors that contributed to their group's demise.

Data Analysis

The study method utilized the interpretive traditions of qualitative research in which an in-depth understanding of the groups was sought. As data collection progressed, the investigative team met to discuss interpretations and explore how best to fracture and manage the observation and field note data. Diverse elements—including individual group member interactions and organizational aspects—were analyzed and the micro, meso, and macro categories were defined and adapted to inductively code the raw data (Morse & Field, 1995). Although the analysis did not proceed in a linear fashion, the following steps outline the analytic procedures used. Through repeatedly reading the participant observation and field note data, ideas and interpretations about recurring, converging, and contradictory patterns were developed by the investigative team. Key concepts and preliminary themes were identified for each of the micro, meso, and macro categories, along with illustrative examples from the data (Spradley, 1980). Descriptive notes and data exemplars

Table 2. Prostate Cancer Support Group Characteristics

Group	Participants	Male	Female	Duration (minutes)	Speaker	Formal Sharing	Location	Year Established	New Members	Leaders	Self-reported Sustainability Issues
1	7	7	0	35	No	Yes	Hospital	1994	1 Male	2	Attracting new members
2	8	7	1	120	No	Yes	CCS** office	1996	1 Female	2	Leader fatigue
3	28	26	2	120	Oncologist	Yes	CCS office	1993	2 Male	1	Nil
4	100	82	18	120	Urologist	None	Hospital	1994	6 Male	Committee	Nil
5	4	4	0	120	No	Yes	CCS office	2001	0	1	Attracting new members
6	26	20	6	120	*Cancellation	Yes	Community center	1996	4 Male	Committee	Nil
7	32	26	6	120	Oncologist	No	CCS office	1996	1 Male	1	Leader fatigue
8	17	11	6	120	No	No	Church	1994	0	1	Attracting new members
9	13	10	3	80	Oncologist	No	Hospital	1999/2000	2 Male	1	Attracting new members
10	21	12	9	120	Dietician	Yes	Church	2000	1 Female	2	Leader fatigue
11	27	21	6	120	Support group leader	No	Church	1993	0	1	Attracting new members
12	11	9	2	90	No	Yes	Recreation center	1998	0	1	Attracting new members
13	52	47	5	120	No	Yes	Municipal health center	1992	1 Male	1	Nil
14	65	41	24	120	Oncologist	Yes	Hospital	1992	5 Male	Committee	Nil
15	12	9	3	120	No	Yes	CCS office	1994	0	1	Attracting new members
Total	423	333	90	Mean = 109.6	7	10	—	Mean = 10.5 years	32	—	—
		Mean = 28.2	Mean = 22.2	Mean = 6					Mean Male=1.6		Mean Female=.5

*Guest speaker was replaced by two videos on prostate cancer.

**Canadian Cancer Society.

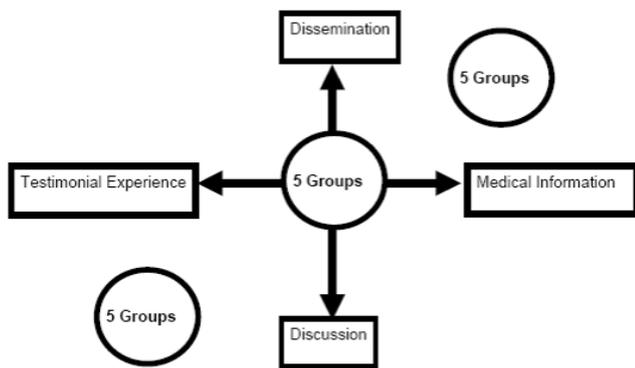


Figure 1. Prostate cancer support group meeting formats.

for each of the emergent themes were developed so that the relationships between them were illuminated. Themes defined as coherent patterns—both within and across the data—were identified and developed through these iterative processes (Stenner, 1993). Examples from coded themes were retrieved and compared across the groups. Any “outlier cases” that did not fit with conceptual understandings of the data were explored to develop explanations for the observed variability.

A critical issue in establishing valid, trustworthy data in qualitative inquiries is the extent to which a high level of self-reflexivity is built into the analysis (Dyck, Lynam, & Anderson, 1995). In this study, for example, it was critical to reflect on the extent to which the presence of the researchers in the field might have influenced the interactions observed (Anderson, 1991). It was also important that the researchers shared reflections on how their experiences influenced interpretations and approaches to the analysis. An audit trail was made so that all procedures used and decisions made were documented, including the origins and development of themes. Credibility of findings, or the participants’ recognition of analytical representations of experiences as their own, was established through sharing preliminary findings with members of PCSGs and inviting them to comment on the analysis, as well as soliciting formal reviews and feedback from five PCSG “champions” on an earlier draft of this article (Acker, Barry, & Esseveld, 1983; Ellis & Bochner, 1996).

Context of the Study

PCSG Meeting Formats

Although all the support groups in this study were focused on providing health and prostate cancer information, the meeting formats and strategies used to engage attendees were diverse. In terms of information sources, testimonial experiences and medical data were predominant, and two forms of exchange—discussion and dissemination—were used in varying proportions to share and convey information at the group meetings. For example, within group 2, the 8 participants, most of whom had been attending the group for more than a year, relied exclusively on discussions drawn from their prostate cancer experiences as a way of sharing information with each other. Conversely, group 4 (with more than 100 members) relied on experts to disseminate medical information and an entire 2-hr meeting focused on the role of vitamin D in the primary and secondary prevention of prostate cancer. A third format was to divide the meeting either side of a refreshment break, so that equal time was available for formal presentations and small subgroup discussions drawing on attendees’ testimonials. Typically, in this format, a guest speaker would present specific health and/or prostate cancer information during the first hour and, after a short refreshment break, small group facilitated discussions provided opportunities for participants to share their experiences in the second hour. The way in which PCSGs subdivided for the small group discussions varied. For example, after a formal presentation, group 14 had women meet separately and the men joined a treatment or trajectory-focused circle (i.e., prostatectomy, radiation therapy, newly diagnosed men, etc.) to discuss related issues. In Figure 1, the observed PCSG meeting formats are illustrated.

In general, testimonial experience was invited and discussed, and medical information was disseminated at group meetings. However, it is important to note that these activities were not mutually exclusive. For example, when presenters invited audience questions, discussion often ensued in which group members drew on their experiences to contextualize, and occasionally challenge, the information that had been presented.

PCSG Composition

Because the PCSGs were open groups, with new members joining at any time, composition varied at

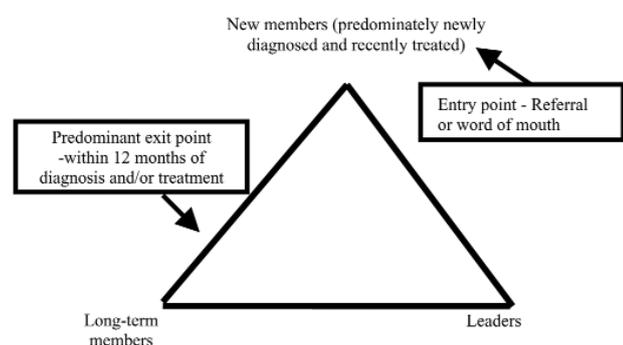


Figure 2. Individual patterns of association with prostate cancer support groups.

each meeting. For the purposes of this research, attendees were categorized as new members, long-term members, or leaders. New members were defined as those who had been attending the group for less than 12 months, and the men in this subcategory were often deciding on treatment[s] or experiencing acute treatment-induced side effects. Long-term members were defined as participants who had been attending PCSGs for more than 1 year but had not taken up group leadership roles. In addition to keeping up to date with the latest health and prostate cancer information, long-term members were interested in sharing their experiences to help others. The third subcategory was leaders, and these men organized and facilitated group meetings. Some groups had committees to share the responsibilities whereas others relied exclusively on one leader. For the most part, leaders matched group resources—both testimonials and medical—with the needs of attendees. The connections between the three aforementioned member subgroups are illustrated in Figure 2.¹

Findings

The findings are arranged into three key themes drawn from the data and reflect exploration of the micro, meso, and macro level influences on the sustainability

¹At the groups we attended, women filled the three aforementioned group associations. In terms of sustainability, it was difficult to draw conclusions about the influence of women. However, women were strongly invested in some prostate cancer support groups and made substantive contributions to the group meetings.

of PCSGs. Sustainability, for the purposes of this research, reflected accepted definitions—meeting present needs without preventing future generations from meeting their needs (Scottish Enterprise, 2006). The primary theme at the micro level was the importance of leadership in meeting diverse individual needs at group meetings. At the meso level, the tensions between group emancipation and formalizing affiliations were consistently represented and had implications for group sustainability. A seemingly discordant relationship existed between the national PCSG vision for activism and the capacity of many groups to engage with such activities; the potential consequences of this finding for group sustainability are presented in the macro level influences section.

Micro Level Influences: Leadership as the Lynchpin to Meeting Diverse Individual Needs

In comparing meeting formats and group composition, three factors—all of which were contingent on group leadership—were strongly linked to group sustainability. First, group leaders had to have the capacity to manage the organization and promotion of group meetings. For example, groups 4, 6, 13, and 14 had leadership committees that met regularly to plan group meetings, which they actively promoted by telephoning and e-mailing members. Leaders were also responsible for recruiting speakers. Because the leaders from groups 3 and 7 had strong linkages to doctors who specialized in prostate cancer, these groups benefited from having ready access to expert speakers. In addition, some newly diagnosed men were referred to the groups by physicians who regularly presented at PCSGs. Unfortunately, the leadership of some groups fell entirely to one or two people, often for long periods of time, and this became a burden, especially for elderly men experiencing declining health. In groups 5, 7, and 10, one leader was responsible for all aspects of the group, and although commended by group members, the leaders' repeated requests for others to take up leadership roles did not result in identification of successors. Sustainability was an issue in these groups, because no matter how strong in terms of the number of attendees, without leadership succession planning, the group was in jeopardy if the current leader stood down. This finding was supported in interviews with the ex-leaders from five disbanded groups; they confirmed that the workload responsibilities associated with sole leadership contributed to

their group's demise. The study findings indicated that cohesive, committee-based leadership that used a "divide and conquer" approach was most likely to result in effective and sustainable PCSGs. This was evidenced by the long-term success of groups 4 and 14 whose leadership committees had high-profile speakers present and regularly attracted relatively large numbers of attendees.

Second, the ability of the group leaders to engage new members and establish rapport and a prevailing sense of camaraderie was particularly important. The majority of first-time attendees were newly diagnosed men, and specific strategies were used by some groups to welcome new members. For example, at group 4, one leader welcomed and invited new members to raise their hands at the beginning of the meeting and another designated leader formally greeted the six first-time attendees, all of whom were newly diagnosed, to discuss various treatments for more than an hour after the official meeting. Similarly, the leader of group 13 talked with new members (in this particular case, men and their wives) during the refreshment break and at the conclusion of the formal meeting. Regardless of the specific strategy, it was crucial that new members were explicitly included, given permission and opportunity to talk, ask questions, and receive the information they required (where possible, both testimonial and medical). These strategies fostered inclusion and positively influenced new members to return to the group on a regular basis.

Third, in addition to meeting the information needs of newly diagnosed men, the group meetings needed to offer "new" information to maintain the interest of long-term members, because their commitment to the group was often premised on continuing to learn, as well as "giving back" to newly diagnosed men. This was achievable in mid- to large-sized groups with leaders who had ready access to health care professionals willing to formally present prostate cancer and health information. For example, oncologists explained brachytherapy and HiFu radiation at group meetings, and the presentations drew on current research and clinical practice. Although the content was not always personally relevant to long-term members, their knowledge base and capacity to help others was increased by engaging with such information. In some smaller groups, a "stalemate" existed in which all the men were long-term members who regularly recounted their cancer stories because little new information was available to stimulate other dialogue or advance individual and/or the collective expertise of the group. This was evident at groups 1,

5, and 8 where the members had met for many years and the discussions were more general and social. This is not to discount the value of such social connection, which was clearly evident at the groups. However, in terms of sustainability, very few "new" men had accessed these groups in the previous 2 years, and the capacity of these groups to meet the information needs of newly diagnosed men in particular was therefore limited.

Meso Level Influences: Emancipation or Affiliation

At this level, the analysis revealed some interesting tensions that appeared to contribute to group sustainability. Although philosophically all the groups were committed to sharing information in ways that would assist men and their families to better understand and meet the challenges of living with prostate cancer, each of the groups developed a distinctly different style in the way they achieved these goals. Many of the groups prided themselves on the way they functioned and recognized their contributions to local as well as global populations of prostate cancer survivors in many ways. Group 6 had a 10-point charter that listed the group's aims and perhaps best represented the shared philosophy of PCSGs. Points 1 through 8 described how the group helped individuals. For example, the first aim was "to provide an opportunity to meet with other prostate cancer patients/survivors and their supporters." Points 7, 8, and 9 addressed broader issues including a commitment to prostate cancer advocacy, research, and raising public awareness. Many men also wore pins and wrist bands to signify their prostate cancer survivor status. For example, reef knot pins (designed by the Vancouver Island Prostate Cancer Research Foundation in 2002), symbolizing strength, unity, and courage, became the national symbol of PCSGs, and blue prostate cancer wristbands with the same motto were commonplace at the meetings. Survivorship was a strongly represented ideal within and across the groups, and empowerment and emancipation were often implicit but nonetheless strong motivators for men who wanted to be self-directed in accessing and distributing prostate cancer-related information. The activities of some groups were particularly notable and often commented on by members of other groups. For example, group 4 was revered by the wider PCSG community for its ability to attract between 80 and 100 people to each meeting. Group 11 was particularly well known for its rich history that included "marching on the steps of

parliament" to bring prostate cancer to the attention of politicians at a time when it was receiving little attention.

Contrasting with this current of empowerment and building individual group identities was the lure of the potential benefits of collective power that could be obtained by linking PCSGs together. This tension was best reflected at a conference convened by a provincial PCSG organization that was established in 1998 to highlight the work of all the BC-based support groups. Specifically, support group members formed the British Columbia Foundation for Prostate Disease (BCFPD) to promote awareness, conduct fund-raising events, and contribute financial support to prostate cancer research. The 2005 inaugural BCFPD conference attracted 150 delegates, including health care providers and survivors from 19 BC-based PCSGs. Formal presentations showcasing current prostate cancer research and epidemiological trends were made, and community and professional collaboration was evident as researchers, health care providers, and prostate cancer survivors collectively engaged with cultural ideologies that support and celebrate cancer research.

Two parts of the conference related specifically to PCSG sustainability issues. First, a roundtable discussion explored strategies to more effectively communicate between groups and formalize an affiliation with the BCFPD to support and guide the activities for all BC-based PCSGs. Although attendees supported the ideas presented, no agreement or resolution was made. By choosing not to formally unite, many groups remained separate and independent, and this had implications for some groups' sustainability because, in essence, they had forgone the BCFPD's offer to provide free resources and support. In addition, the lack of solidarity reduced the collective power and capacity to negotiate rewarding affiliations with professional organizations.

Second, Canadian Cancer Society (CCS) representatives proposed formal linkages with all the PCSGs to ensure a consistent meeting format, direct content and topics, standardize group leader credentials, and take over the BCFPD fund-raising and distribution activities. This generated much discussion, and the consensus was that many PCSGs would prefer to retain their autonomy and not formally link with the CCS. The subsequent written correspondence from the CCS reiterating the conditions of their proposed association was interpreted by many group members as restrictive and perhaps naive in terms of what men and their families wanted from

PCSGs. It is important to note that the work of PCSGs is unpaid, and there was widespread reluctance to work *for* (or to be perceived as working for) rather than *with* professional organizations. In terms of group sustainability, it is unclear if linkages to professional associations—such as that achieved by affiliating with a national, well-known, and respected cancer society—would ultimately benefit PCSGs. Formal linkages to professional organizations can enhance public perception of group legitimacy and expertise. However, the CCS-affiliated PCSGs that participated in this study attracted relatively small numbers of attendees and, in some cases, were reliant on the work of volunteer leaders who were reluctant to continue, given their current workloads. The value of formalizing affiliations was, therefore, difficult to demonstrate to other groups.

Macro Level Influences: Insufficient Capacity for Activism

At the macro level, the primary influence on the sustainability of PCSGs lay in the groups' commitment to and capacity for activism. Although most groups and their members were, by definition, advocates at the local level, disjunctures between the national vision for activism and the capacity of many groups existed. This left some groups vulnerable to collapse if their limited resources were redeployed from local to more global activist activities. This experience was reflected in the CPCN conference. The CPCN is a nonprofit organization that advertises and links Canadian-based PCSGs "virtually" on the World Wide Web (WWW; <http://www.cpcn.org/>). The CPCN comprises one paid employee and board members from PCSG representing 7 of the 10 provinces, and receives financial support from pharmaceutical companies (40%), donations (10%), and private business (50%). The mandate of the CPCN is threefold: (a) to create and support PCSGs, (b) to increase public awareness of the disease, and (c) to advocate for better prostate cancer research funding and treatments. To meet these objectives, the CPCN provides materials to start a PCSG and seeks to raise public awareness through mainstream media. It also provides "lay" committee members to the Canadian Prostate Cancer Research Initiative grant review panels, whose funding monies are derived from public donations made to and allocated by the CCS.

The 2006 third annual CPCN conference was held in Calgary, and approximately 60 PCSGs (including 13 groups from BC) were represented. The

conference, titled "Winning the War on Prostate Cancer," had a strong military theme that permeated the meeting through the use of "battle" metaphors, along with various props (dog tags, World War II metal helmets, and disarmed grenades). Militarism was introduced early on in the conference when the host introduced himself as the general and made a call for "reinforcements in the battle against prostate cancer." Dog tags were then issued to the conference delegates to signify their soldier status and preempt deployment in locating the cause (enemy) and administering the cure (entering into combat to defeat the enemy), in the ultimate war against prostate cancer.

The conference focus was activism, and the keynote speakers explicitly linked their presentations to what survivors could do to advance prostate cancer awareness and research. Two presentations highlighted the importance of activism, and the first speaker, an American-based medical oncologist, began his presentation with a provocative call for a "new" prostate cancer motto of "no bullshit." He stressed the need for patients to lobby government, policy makers, and regulatory organizations to accelerate the Food and Drug Administration (FDA) approval of emergent pharmacologically based prostate cancer treatments. The second speaker, a urologist, suggested "nihilist doctors," who did not truly care about their patients, were unacceptable. A third speaker drew on her expertise in securing monies for charities to outline how PCSGs might successfully lobby media to increase government funding for prostate cancer research. These presentations were followed by small group work to facilitate delegates' brainstorming for ideas about how PCSGs might best move from advocacy to activism, and more visibly contribute to winning the war against prostate cancer.

Despite the clear intent to address macro prostate cancer disease and treatment issues, some uncertainty was evident about how and what survivors, and PCSGs in general, might best contribute. The commitment and capacity for activism varied among the conference delegates. For some men, the primary allegiance was to their PCSG and other "activist" activities were contingent on their energy and resources. For others, the focus had clearly shifted from meeting the needs of attendees at monthly PCSG meetings to more global issues that demanded activism. By definition, all the conference delegates were prostate cancer advocates; however, fewer men aligned with the CPCN activist mandate. The divide was likely influenced by divergent interpretations about the structure and role of the CPCN. The CPCN is a traditional

collective in that it appeals to the general public and corporate donors based on the deservedness of those for whom the group advocates. Yet, the CPCN also embodies some characteristics typical of radical organizations in its claims that it is the basic obligation of the state to provide for its prostate cancer citizens (Brainard & Siplon, 2000). This is not to suggest a dichotomy or that the CPCN must be either a traditional or radical organization. However, the CPCN identity is strongly reliant on the perceptions of its members, many of whom interpreted the annual gathering as a "common" interest group, rather than an opportunity to establish a social movement. Ultimately, it appeared that little filtered down from the CPCN conference to support the day-to-day operations and sustainability of individual PCSGs.

Discussion and Conclusions

As evidenced by this study and other research about community-based patient support groups, considerable time and effort goes into the operation and maintenance of PCSGs (Kaps, 1994; Mankowski & Silvergleid, 2000; Mason, 1993). Despite the benefits of PCSGs (Cordova et al., 2003; Evans & Connis, 1995; Gray et al., 1997; Gregoire et al., 1997; Katz et al., 2002; Manne, 2002; Sharp & Aviv, 1996), group sustainability is an important issue that has attracted little research attention. In the past 12 months while collecting data from 15 groups for this study, 9 BC-based PCSGs disbanded. In addition, many groups that participated in the study were challenged to attract and retain members, maintain cohesive leadership, and provide up-to-date information in a rapidly changing field. This is the first study to identify and describe factors related to the sustainability of PCSGs. Among the groups in this study, factors influencing sustainability existed at several levels and included strong effective leadership within PCSGs, resolving tensions between emancipation and affiliation, and building capacity for activism. Understanding these factors provides important directions for addressing long-term viability and ensuring that PCSGs, a key resource for men and their families who are living with prostate cancer, continue to be available.

First and foremost, as others have observed in professionally led cancer support groups (Lieberman & Golant, 2002), the success and longevity of PCSGs is reliant on effective leadership and management. PCSG leadership is challenging for lay volunteers because 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 the use of specific facilitator strategies at meetings appeared to be integral to satisfying attendees' needs and fostering their camaraderie and commitment to the group. Although group members were adamant that PCSGs needed to be survivor led and our observations suggested that leaders derived much satisfaction from their hard work, being a group leader required significant time, energy, and commitment that few men were able or willing to take on. Similar to problems described by both professional and nonprofessional leaders of cancer support groups (Kirsten, Butow, Price, Hobbs, & Sunquist, 2006), PCSG dependence on one or two leaders and lack of defined terms and tenure meant that leaders were at risk for "burnout." In these situations, the long-term viability of the PCSG was often at risk. Finding ways to support the leadership of PCSGs and the development of succession planning is likely to be critical to ensuring the sustainability of the groups.

Second, longevity of PCSGs, not unlike other support groups (Wituk, Shepherd, Warren, & Meiseen, 2002), is linked with maintaining an adequate number of members. Our findings suggest that the growth of PCSGs is reliant on visionary leaders who can respond to emergent trends both in terms of information content and potential member markets. Specifically, the current interest in active surveillance (previously referred to as watchful waiting), as distinct from "choosing" a prostate cancer treatment, needs to be thoughtfully addressed because the majority of group members observed in this study were strongly oriented to accessing and/or providing treatment information. Therefore, many PCSGs, as they currently operate, might have limited appeal to those men who choose active surveillance. If PCSGs can respond proactively, there might be considerable advantages in attracting men who take up active surveillance because they will likely have long-term needs and interests in accessing (and perhaps sharing) diet, exercise, and other health promotion information. This information would also be highly attractive to another emergent group, men experiencing prostate cancer recurrence following primary treatment(s).

In terms of audience, the WWW might offer important opportunities to maintaining, and perhaps expanding, membership within PCSGs. This Internet resource has offered an abundance of prostate cancer information and anonymous "support" that could compete with, and further reduce, the uptake of face-to-face PCSGs (Klemm, Hurst, Dearholt, & Trone,

1999; Pinnock, Jones, & Education Committee of the Australian Prostate Cancer Collaboration, 2003). However, rather than threatening PCSGs' current activities, the WWW can provide leaders with a powerful medium to advertise and offer group resources to both "virtual" and "in-person" members. The WWW can also facilitate the sharing of effective "in-person" PCSG meeting strategies and up-to-date information with some groups where this is more difficult to access. That said, the ultimate success of extending PCSGs to virtual environments will be contingent on having resources to design, deliver, and regularly update information in ways that men can easily access and understand and explain to others.

The third main issue related to sustainability is whether PCSGs should link with professional organizations. What appears to be lacking is "real" support for the groups, inclusive of financial and human resources, as well as some agreement about the specific roles that PCSGs can take up (and sustain) within the Canadian public health care system. One option for PCSGs in this study was to link with cancer fund-raising societies such as the CCS. The skepticism expressed by many PCSG participants, based on concerns that groups would end up working for organizations that dictate the terms and conditions under which they operate, suggests this kind of allegiance may not be useful. Most PCSGs will resist anything resembling a "takeover" or "branding" by organizations that do not have the capacity to provide resources and willingness to negotiate mutually acceptable terms of operation. From our perspective, the ideal form of collaboration would empower and promote PCSGs, and draw both public and health care professionals' attention to the valuable services provided to men and their families. Therefore, formal linkages with prostate cancer practitioners and their governing associations might best accomplish a reciprocity that explicitly directs men and their families to *all* the available resources.

If collaboration cannot be negotiated, one advantage of operating independently is that the groups can continue to tailor their activities to the needs of the group/community. Many PCSG leaders are experienced, successful men in their own right and have sufficient skills to ensure group success. This is evidenced by how well some groups operate, and the collective ability of the groups to independently raise and distribute significant funds to support prostate cancer research. Perhaps some of the money raised by the groups could be reinvested, and/or alternate forms of group sponsorship solicited,

to facilitate self-governance dedicated to ensuring the continuance and expansion of all the groups. Survivor-managed organizations (e.g., the BCFPD) need to clearly demonstrate the benefits of PCSGs linking with them. Only by first formalizing these types of relationships are PCSGs likely to have the collective power to negotiate satisfying affiliations with professional organizations.

Finally, building capacity for activism appears to play an important role in the viability of PCSGs. At the macro level, activism currently lays with a few prostate cancer "champions," and a disconnect exists between the global enterprise of such endeavors and the more acute "grassroots" PCSG sustainability issues. It is unclear how activist activities and outcomes will affect individual PCSGs. However, activism demands energy and resources that will likely reduce the capacity and potential of some groups, especially those groups from which activists originate. Although the brotherhood was clearly evident at the CPCN national conference, the plan for activism is in its beginning and perhaps most fragile stages. It is vital to recognize that the CPCN's vision for prostate cancer activism is ultimately contingent on PCSG resources. Therefore, from our perspective, although activism is important, it is also inextricably linked to the sustainability and growth of each PCSG. Expanding activities, rather than consolidating the foundations that focus on helping men and their families at group meetings, is likely to exhaust many group resources.

There are several caveats to the interpretations of this study. The study focused on PCSGs in one jurisdiction, and the findings are derived from researcher interpretations of the field work and participant observation data. Therefore, the perceptions of individuals who attend support groups may differ, and experiences of these groups may be unique because of the context in which they are functioning, and the level of support they receive from the medical community and other organizations. Research is warranted on PCSGs in other contexts to explore factors that influence their sustainability and effectiveness. In this study, field work included data collection from a variety of sources to provide insights to factors that influence PCSGs at multiple levels. It is possible, however, that recall biases may have influenced study findings. A longitudinal study of PCSGs may provide additional direction and advice to those establishing new groups, as well as those who are committed to maintaining effectively functioning groups.

In summary, the study findings provide important directions for addressing PCSG sustainability issues.

The extraordinary commitment of unpaid volunteers in leadership roles, who themselves are living with prostate cancer, was inspiring. Although members of PCSGs may be able to use the findings of this study to enhance group effectiveness, the wider community needs to be involved in identifying ways to ensure that this valuable resource continues to be available for prostate cancer survivors and their families.

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References

- Acker, J., Barry, K., & Esseveld, J. (1983). Objectivity and truth: Problems in doing feminist research. *Women's Studies International Forum*, 6(4), 423-435.
- Anderson, J. M. (1991). Reflexivity in field work: Toward a feminist epistemology. *Image: The Journal of Nursing Scholarship*, 23(2), 115-118.
- Boyle, J. (1994). Styles of ethnography. In J. Morse (Ed.), *Critical issues in qualitative research methods* (pp. 159-185). Thousand Oaks, CA: Sage.
- Brainard, L., & Siplon, P. D. (2000, August-September). *Cyberspace challenges to mainstream advocacy groups: The case of health care activism*. Paper presented at the American Political Science Association, Washington, DC.
- Canadian Prostate Cancer Network. (2003). Retrieved April 5, 2006, from: <http://www.cpcn.org/search.asp?field=PROVINCE&search=BC>
- Chapple, A., & Ziebland, S. (2002). Prostate cancer: Embodied experience and perceptions of masculinity. *Sociology of Health and Illness*, 24(6), 820-841.
- Classen, C., Butler, L. D., Koopman, C., Miller, E., DiMiceli, S., Giese-Davis, J., et al. (2001). Supportive-expressive group therapy and distress in patients with metastatic breast cancer: A randomized clinical intervention trial. *Archives of General Psychiatry*, 58(5), 494-501.
- Cordova, M. J., Giese-Davis, J., Golant, M., Kronnenwetter, C., Chang, V., McFarlin, S., et al. (2003). Mood disturbance in

- community cancer support groups: The role of emotional suppression and fighting spirit. *Journal of Psychosomatic Research*, 55(5), 461-467.
- Coreil, J., & Behal, R. (1999). Man to Man prostate cancer support groups. *Cancer Practice*, 7(3), 122-129.
- Coreil, J., Wilke, J., & Pintado, I. (2004). Cultural models of illness and recovery in breast cancer support groups. *Qualitative Health Research*, 14(7), 905-923.
- Dyck, I., Lynam, J., & Anderson, J. (1995). Women talking: Creating knowledge through difference in cross-cultural research. *Women's Studies International Forum*, 18(5), 611-626.
- Eakin, E. G., & Strycker, L. A. (2001). Awareness and barriers to use of cancer support and information resources by HMO patients with breast, prostate, or colon cancer: Patient and provider perspectives. *Psycho-Oncology*, 10(2), 103-113.
- Ellis, C., & Bochner, A. (Eds.). (1996). *Composing ethnography: Alternative forms of qualitative writing*. Walnut Creek, CA: AltaMira.
- Evans, R. L., & Connis, R. T. (1995). Comparison of brief group therapies for depressed cancer patients receiving radiation treatment. *Public Health Reports*, 110(3), 306-311.
- Fawzy, F. I., Cousins, N., Fawzy, N. W., Kemeny, M. E., Elashoff, R., & Morton, D. (1990). A structured psychiatric intervention for cancer patients. I. Changes over time in methods of coping and affective disturbance. *Archives of General Psychiatry*, 47(8), 720-725.
- Fergus, K. D., Gray, R. E., & Fitch, M. I. (2002). Sexual dysfunction and the preservation of manhood: Experiences of men with prostate cancer. *Journal of Health Psychology*, 7(3), 303-316.
- Fergus, K. D., Gray, R. E., Fitch, M. I., Labrecque, M., & Phillips, C. (2002). Active consideration: Conceptualizing patient-provided support for spouse caregivers in the context of prostate cancer. *Qualitative Health Research*, 12(4), 492-514.
- Gray, R., Fitch, M., Davis, C., & Phillips, C. (1996). Breast cancer and prostate cancer self-help groups: Reflections on differences. *Psycho-Oncology*, 5(2), 137-142.
- Gray, R. E., Fitch, M., Davis, C., & Phillips, C. (1997). Interviews with men with prostate cancer about their self-help group experience. *Journal of Palliative Care*, 13(1), 15-21.
- Gray, R. E., Fitch, M. I., Fergus, K. D., Mykhalovskiy, E., & Church, K. (2002). Hegemonic masculinity and the experience of prostate cancer: A narrative approach. *Journal of Aging and Identity*, 7(1), 43-62.
- Gray, R. E., Fitch, M., Phillips, C., Labrecque, M., & Fergus, K. (2000). To tell or not to tell: Patterns of disclosure among men with prostate cancer. *Psycho-Oncology*, 9(4), 273-282.
- Gregoire, I., Kalogeropoulos, D., & Corcos, J. (1997). The effectiveness of a professionally led support group for men with prostate cancer. *Urologic Nursing*, 17(2), 58-66.
- Kaps, E. C. (1994). The role of the support group, "Us Too." *Cancer*, 74(7 Suppl), 2188-2189.
- Katz, D., Koppie, T. M., Wu, D., Meng, M. V., Grossfeld, G. D., Sadesky, N., et al. (2002). Sociodemographic characteristics and health related quality of life in men attending prostate cancer support groups. *Journal of Urology*, 168(5), 2092-2096.
- Kirschner-Hermanns, R., & Jakse, G. (2002). Quality of life following radical prostatectomy. *Critical Reviews in Oncology/Hematology*, 43(2), 141-151.
- Kirsten, L., Butow, P., Price, M., Hobbs, K., & Sunquist, K. (2006). Who helps the leaders? Difficulties experienced by cancer support group leaders. *Support Cancer Care*, 14, 770-778.
- Klemm, P., Hurst, M., Dearholt, S. L., & Trone, S. R. (1999). Gender differences on Internet cancer support groups. *Computers in Nursing*, 17(2), 65-72.
- Krizek, C., Roberts, C., Ragan, R., Ferrara, J. J., & Lord, B. (1999). Gender and cancer support group participation. *Cancer Practice*, 7(2), 86-92.
- Lieberman, M. A., & Golant, M. (2002). Leader behaviours as perceived by cancer patients in professionally directed support groups and outcomes. *Group Dynamics*, 6(4), 267-276.
- Mankowski, E. S., & Silvergleid, C. S. (2000). A review of self-help and mutual support groups for men. *International Journal of Self Help & Care*, 1(3), 281-299.
- Manne, S. L. (2002). Prostate cancer support and advocacy groups: Their role for patients and family members. *Seminars in Urologic Oncology*, 20(1), 45-54.
- Mason, M. A. (1993). A prostate cancer support group: Does it work? *Urologic Nursing*, 13(3), 95-96.
- Morse, J. M., & Field, P. A. (1995). *Qualitative research methods for health professionals* (2nd ed.). Thousand Oaks, CA: Sage.
- Muecke, M. A. (1994). On the evaluation of ethnographies. In J. Morse (Ed.), *Critical issues in qualitative research methods* (pp. 187-209). Thousand Oaks, CA: Sage.
- Navon, L., & Morag, A. (2003). Advanced prostate cancer patients' relationships with their spouses following hormonal therapy. *European Journal of Oncology Nursing*, 7(2), 73-80; discussion 81-82.
- Oliffe, J. L. (2005). Prostatectomy induced impotence and masculinity. *Social Science & Medicine*, 60(10), 2249-2259.
- Oliffe, J. (2006). Embodied masculinity and androgen deprivation therapy. *Sociology of Health & Illness*, 28(4), 410-432.
- Palmer, M. H., Fogarty, L. A., Somerfield, M. R., & Powel, L. L. (2003). Incontinence after prostatectomy: Coping with incontinence after prostate cancer surgery. *Oncology Nursing Forum*, 30(2), 229-238.
- Pinnock, C. B., Jones, C., & Education Committee of the Australian Prostate Cancer Collaboration. (2003). Meeting the information needs of Australian men with prostate cancer by way of the internet. *Urology*, 61(6), 1198-1203.
- Schiff, J. D., & Mulhall, J. P. (2005). Neuroprotective strategies in radical prostatectomy. *BJU International*, 95(1), 11-14.
- Scottish Enterprise. (2006). *Glossary*. Retrieved November 11, 2006, from: http://www.scottish-enterprise.com/sedotcom_home/help/help-glossary.htm

- Sharp, J. W., & Aviv, L. (1996). Patient resources for prostate cancer. *Cancer Practice*, 4(4), 216-218.
- Smith, R. L., Crane, L. A., Byers, T., & Nelson-Marten, P. (2002). An evaluation of the Man to Man self-help group in Colorado and Utah. *Cancer Practice*, 10(5), 234-239.
- Spradley, J. P. (1980). *Participant observation*. New York: Holt, Rinehart and Winston.
- Steginga, S. K., Occhipinti, S., Dunn, J., Gardiner, R. A., Heathcote, P., & Yaxley, J. (2001). The supportive care needs of men with prostate cancer. *Psycho-Oncology*, 10(1), 66-75.
- Stenner, P. (1993). Discoursing jealousy. In E. Burman & I. Parker (Eds.), *Discourse analytic research: Repertoires and readings of texts in action*. London: Routledge.
- Visser, A., Riemens, E., Van der Jagt, T., Vingerhoets, S., & Voerman, B. (2001). Social support for prostate cancer patients. *Psycho-Oncology*, 10, S32-S33.
- Wituk, S. A., Shepherd, M. D., Warren, M., & Meiseen, G. (2002). Factors contributing to the survival of self-help groups. *American Journal of Community Psychology*, 30(3), 349-366.
- Wolcott, H. F. (1990). *Writing up qualitative research*. Newbury Park, CA: Sage.