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Canadian Nurses' Perspectives on Prostate Cancer Support Groups

A Survey Study

KEY WORDS

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Background: Prostate cancer support groups (PCSGs) are community-based organizations that offer information and psychosocial support to men who experience prostate cancer and their families. Nurses are well positioned to refer men to a range of psychosocial resources to help them adjust to prostate cancer; however, little is known about nurses' perspectives on PCSGs. **Objective:** The aim of this study was to describe nurses' views about PCSGs as a means to making recommendations for advancing the effectiveness of PCSGs. **Methods:** A convenience sample of 101 Canadian nurses completed a 43-item Likert-scale questionnaire with the additional option of providing comments in response to an open-ended question. Univariate descriptive statistics and content analysis were used to analyze the quantitative and qualitative data, respectively. **Results:** Participants held positive views about the roles and potential impact of PCSGs. Participants strongly endorsed the benefits of support groups in disseminating information and providing support to help decrease patient anxiety. Online support groups were endorsed as a practical alternative for men who are reluctant to participate in face-to-face groups. **Conclusions:** Findings suggest that nurses support the value of Canadian face-to-face and online PCSGs. This is important, given that nurses can help connect individual patients to community-based sources providing psychosocial support. **Implications for Practice:** Many men benefit from participating in

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PCSGs. Aside from positively endorsing the work of PCSGs, nurses are important partners for raising awareness of these groups among potential attendees and can directly contribute to information sharing in face-to-face and online PCSGs.

Prostate cancer (PCa) is the most commonly diagnosed cancer among North American men.^{1,2} Moreover, increased life expectancy and improved screening are expected to contribute to increases in PCa diagnoses over the next decade.^{3,4} With 5-year survival rates nearing 100% in the United States⁵ and 95% in Canada,⁶ many men experience PCa as a chronic illness, and in line with this, the demand for psychosocial support programs is likely to rise. That said, studies suggest many men experiencing PCa have unmet psychosocial needs.⁷ To remedy, at least in part, the existing and emergent shortfalls, community-based prostate cancer support groups (PCSGs) run by volunteers offer free information and psychosocial care for PCa patients and their families.^{8,9} However, PCSG sustainability can be challenged by a number of factors, including the group's connections to healthcare providers and their ability to attract new members.¹⁰ The purpose of this article is to describe nurses' views about PCSGs as a means to making recommendations for advancing the effectiveness of PCSGs.

■ Prostate Cancer Support Groups

Evidence confirms that PCSGs can play a crucial role in alleviating anxiety and providing reassurance throughout the PCa illness trajectory.^{11,12} Information sharing is foundational to PCSGs, and 2 types of knowledge are typically disseminated. The first relates to biomedical aspects of PCa disease and its treatments, and this information is often delivered by expert guest speakers from a wide range of health-related fields.^{13,14} Such information can help men understand their biomarkers and treatment options for primary and recurrent PCa. The second type of information relates to men sharing their illness experiences of PCa. Key to this is men's explicit permission to discuss diverse PCa-related topics and provide mutual help to one another in a nonjudgmental environment.⁹ The blend of PCa disease and illness information shared at PCSGs has been shown to foster a sense of meaning and purpose for attendees, mitigate psychosocial aspects of cancer by empowering men with PCa and help men and their families cope with life after diagnosis and treatment(s).⁸ Despite the benefits that attending a PCSG may bring, many men are reticent to go to a "support" group. Barriers to attending a PCSG include men's denial about the need for additional support and belief that they are in control of the situation,¹⁵ clinicians' lack of endorsement, concerns about anonymity, and a fear of stigma and vulnerability through participation.¹⁶ The Internet has also emerged as a PCa resource, and many men seek online information and/or to connect with other men experiencing PCa.¹⁷ In this regard, online PCSGs can augment and/or bypass some of the barriers men cite to attending face-to-face PCSGs.¹⁸

Despite the availability of PCSGs, many men who experience PCa live with unmet psychosocial oncology needs.^{7,13} Nurses are often at the forefront of coordinating and directly providing clin-

ical and psychosocial care services to men with PCa. For example, nurses play key roles in PCa screening,¹⁹ men's treatment decision making,²⁰ and offering strategies for dealing with treatment adverse effects.²¹ Nurses can also influence men's uptake of community-based psychosocial oncology services. That said, little is known about nurses' perspectives on PCSGs.

■ Methods

Study Design

As part of a larger study of PCSGs, a Web-based survey (www.hostedinCanada.com) was used to collect responses from nurses between September 2012 and September 2013. Comprising conventional item responses and an open-ended question, the objective of this mixed-methods study design was to describe nurses' views about PCSGs as a means to making recommendations for advancing the effectiveness of PCSGs.

Study Instrument

The Web-based survey questionnaire used for the current study was adapted from Steginga and colleagues'¹⁶ 2007 study tool. Items for Steginga and colleagues'¹⁶ survey questionnaire were derived from findings drawn from qualitative interviews investigating healthcare providers' (27 urologists and 9 radiation oncologists) views of PCSGs. To confirm item relevance, a follow-up paper-based survey applying a 5-point Likert scale was completed by 30 clinicians, from which 5 key themes were identified.¹⁶ In terms of adjustments to the survey, we included 6 demographic questions and added 6 items to the original survey questionnaire to solicit nurses' views about Web-based PCSGs. In summary, 6 sets of attitudinal item groups comprising 43 items were rated on a 5-point Likert scale (where 1 = strongly disagree and 5 = strongly agree). Each attitudinal item group measured nurses' perspectives about the (1) ways that PCSGs positively influence men's adjustment to PCa, (2) ways that PCSGs negatively influence men's adjustment to PCa, (3) reasons why men choose to attend PCSGs, (4) reasons why men choose not to attend PCSGs, (5) factors influencing the effectiveness of PCSGs, and (6) features influencing the effectiveness of Web-based PCSGs. An open-ended question, "What other comments would you like to make about prostate cancer support groups and/or this survey?" was included at the end of the questionnaire to solicit remarks to help contextualize the quantitative findings. Reliabilities for the current study ranged from 0.72 to 0.95. The survey questionnaire is available from the corresponding author upon request.

Recruitment Procedures

Following university ethics approval, members of Nurse Practitioner Canada (N = approximately 2800) and the Canadian Association

of Nurses in Oncology (N = approximately 1000) were e-mailed by the respective organizations administrative directors and provided study details and instructions for potential participants. Registered nurses currently practicing in Canada and able to understand English were eligible to participate, and a URL in the body of the e-mail hyperlinked participants directly to the Web-based survey questionnaire. Although we were unable to track how many potential participants opened the e-mail and/or viewed the survey questionnaire, the estimated return rate was 2.7% based on the total number e-mails sent out. An incentive of a \$50 gift card was offered and mailed to respondents upon receipt of the completed survey.

Sample

A total of 101 registered nurses, comprising 94 females (93.1%), 23 PCa specialist nurses (22.8%), and 15 nurse practitioners (14.9%) completed the survey questionnaire. Respondents worked in a variety of healthcare settings including primary care, oncology (eg, brachytherapy, chemotherapy), and palliative care nursing (Table). Respondents ranged in age from 25 to 63 years (mean, 47 years) and had an average of 12 years' experience working with PCa patients. The majority of respondents (n = 79 [78.2%]) had previously referred patients to PCSGs.

Data Analysis

This study comprises 2 sets of data: quantitative survey questionnaire responses and qualitative responses to an open-ended question. Univariate descriptive statistics were used to analyze the ordinal Likert data. Of the 101 respondents, 35 (34.6%) provided comments in response to the open-ended question. These qualitative data were coded to match the survey's 6 sets of attitudinal items. The first 3 authors individually read the respondent's comments and allocated excerpts to specific codes. Formal content analysis of the coded qualitative data was used to confirm and contextualize the findings drawn from the survey questionnaire. Consensus about the fit of the qualitative data and the overall analyses and interpretation were reached through discussion among the authors, all of whom have extensive research experience.

Results

Ways That PCSGs May Positively Influence Men's Adjustment to PCa

Survey respondents evaluated 7 features of PCSGs that may positively influence men's adjustment to PCa (Figure 1). Ratings of these features were uniformly high. A majority of respondents either agreed or strongly agreed that the following factors positively influenced men's adjustment to PCa: providing information about PCa and the treatment experience and coping from a range of perspectives (n = 96 [95.0%]), providing access to information about community supports and resources (n = 96 [95.0%]), providing opportunities to share experiences (n = 95 [94.1%]), facilitating social identification (feeling not alone) (n = 93

 **Table • Participants' Demographics**

Age (y) mean, 47.0 (range, 25–63)	
20–30	9 (8.9%)
31–40	19 (18.8)
41–50	28 (27.7%)
51–60	40 (39.6%)
≥61	5 (5.0%)
Gender	
Female	94 (93.1%)
Male	7 (6.9%)
Practice location (province)	
Ontario	28 (27.7%)
Alberta	17 (16.8%)
British Columbia	16 (15.8%)
Nova Scotia	15 (14.8%)
Manitoba	13 (12.9%)
Quebec	5 (5.0%)
New Brunswick	3 (3.0%)
Newfoundland and Labrador	2 (2.0%)
Prince Edward Island	2 (2.0%)
Years working with prostate cancer patients	
0	4 (4.0%)
1–10	49 (48.5%)
11–20	32 (31.7%)
21–30	13 (12.8%)
≥31	3 (3.0%)
Linkages to PCSGs—some respondents had multiple linkages	
Presenter at group	26 (26.7%)
Refereed patients to group	79 (78.2%)
Group member	1 (1.0%)
Group leader	1 (1.0%)
No linkages	12 (11.9%)
Other (n = 13)	
Presented prostate cancer-related information in different capacities	13 (12.9%)
Types of practice—some respondents had multiple affiliations	
Hospital	34 (33.7%)
Cancer center	60 (59.4%)
Primary care	8 (7.9%)
Private	3 (3.0%)
Other(s)	
Community care setting	6 (5.9%)
Educational Institute	2 (2.0%)

Abbreviation: PCSG, prostate cancer support group.

[92.1%]), providing emotional support for patient or partner (n = 92 [91.1%]), providing social support (friendship to combat loneliness) (n = 91 [90.0%]), and providing reassurance to relieve anxiety (n = 82 [81.2%]). While reassurance was rated the lowest of the items, information and a sense of community were highlighted as the factors positively influencing men's adjustment to PCa. The high endorsement of information and sense of community support was also evident in analyses of the qualitative data, as illustrated by the following excerpt: "Prostate cancer support groups are an extremely effective way to promote the dissemination of correct and current information regarding this type of cancer and its treatments. They also provide an opportunity for people to sit with others who have the same diagnosis and to learn how others cope" (a 59-year-old female general

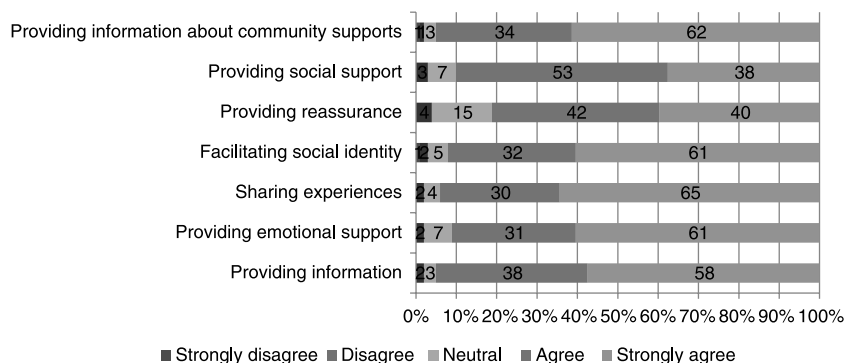


Figure 1 ■ Ways that prostate cancer support groups may positively influence men's adjustment to prostate cancer.

oncology nurse who has been working with PCa patients for 39 years).

Ways That PCSGs May Negatively Influence Men's Adjustment to PCa

Nurses rated 9 items on the potentially negative influences of PCSGs in men's adjustment to PCa including: meeting with dominant members who push their own views; hearing misleading, inaccurate, or irrelevant information; hearing highly negative stories with no balance; creating decisional conflict in relation to treatment; promoting 1 clinician; being too heterogeneous or confusing to meet some individuals' needs; having speaker topics not relevant to the man's individual situation; being confrontational; and promoting 1 treatment approach (Figure 2). Approximately half of the respondents agreed or strongly agreed that hearing misleading, inaccurate, or irrelevant information (n = 51 [50.5%]) was a significant concern. Creating decisional conflict in relation to treatment (n = 49 [48.5%]), hearing highly negative stories with no balance (n = 48 [47.5%]), and meeting with dominant members who push their own views (n = 44 [43.6%]) followed as the other most likely PCSG features to negatively influence men's adjustment to PCa. The median response for the other 5 items was neutral (3) with no specific factors being identified

as particularly influential. In addition, these negative influences in the scaled survey questions were also echoed in the responses to the open-ended question: "Many of my patients have attended the various support groups (...), and many have struggled with inaccurate information and been led to believe another treatment option is best based on hearsay" (a 52-year-old female nurse who has been working with PCa patients for 14 years).

Reasons Why Men May Choose to Attend PCSGs

The items most strongly endorsed as the reasons that men may choose to attend PCSGs by respondents were as follows: in search of information (n = 97 [96.0%]), to discuss cancer treatment and related concerns (n = 88 [87.1%]), and to seek reassurance and relieve anxiety about treatment choices (n = 88 [87.1%]). Social interaction (n = 60 [59.4%]) and to help others (n = 53 [52.5%]) were endorsed less, with 18.8% (n = 19) disagreeing or strongly disagreeing that men were motivated to attend PCSGs as a means to help others (Figure 3). Of course, the reasons for attending a PCSG in the longer term may change as suggested by a respondent who explained:

Knowledge, evidence, and information, and these factors actually motivate them. I think support groups that emphasize the knowledge piece draw men out, and social

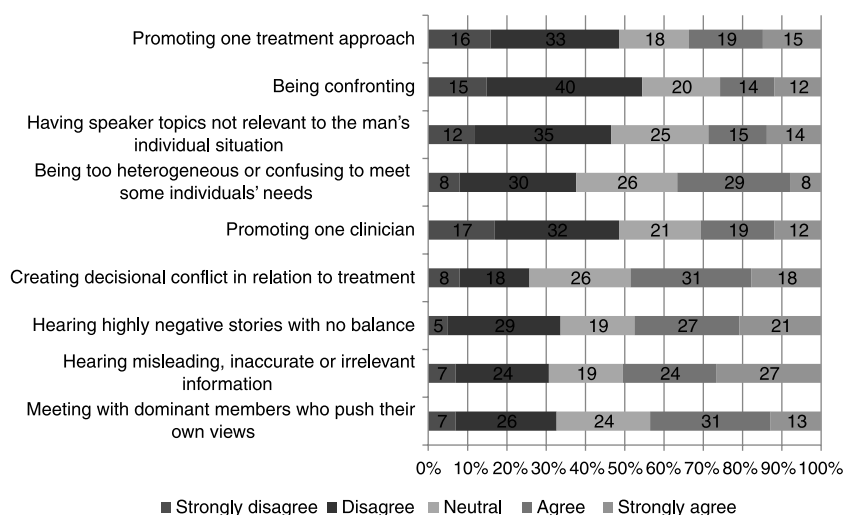


Figure 2 ■ Ways that prostate cancer support groups may negatively influence men's adjustment to prostate cancer.

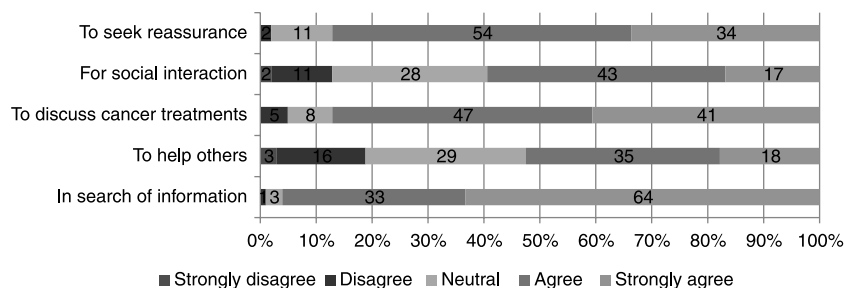


Figure 3 ■ Reasons why men may choose to attend prostate cancer support groups.

support/emotional support become a natural and desired outcome. (A 58-year-old female palliative care nurse who has been working with PCa patients for 25 years)

Reasons Why Men May Choose to Not Attend PCSGs

Nine items were used to examine respondents' perceptions about the reasons why men might not attend PCSGs. A majority of respondents agreed or strongly agreed that men not wanting to discuss their problems with others (n = 90 [89.1%]), a lack of knowledge about groups (n = 86 [85.1%]), perceived weakness in sharing emotions (n = 75 [74.3%]), wanting to move past their cancer experience (n = 75 [74.3%]), denial or avoidant coping (n = 75 [74.3%]), coping well and having no need (n = 65 [64.4%]), language difficulties (n = 59 [58.4%]), and having enough information to make a treatment decision (n = 57 [56.4%]; Figure 4) were reasons for men not to attend PCSGs. These results highlight nurses' perceptions that common male health-related characteristics including self-reliance and strength are deterrents to attending PCSGs, as reflected by the following response to the open-ended question:

We used to have a support group in our community, run by a cancer nurse. [It] was not really well attended, as far as I know. I suspect this was in large part because of the nature of men. (A 38-year-old female nurse practitioner who has been working with PCa patients for 5 years)

Features Influencing the Effectiveness of PCSGs

Overall, respondents agreed or strongly agreed that an effective face-to-face PCSG should avoid bias by not promoting 1 treatment viewpoint (n = 97 [96.6%]), have a leader trained in group

facilitation and management (n = 96 [95.0%]), cover diverse topics relevant to different disease stages and treatments (n = 95 [94.1%]), have regular input from and communication with a broad range of medical and allied health professionals (n = 94 [93.1%]), and be involved and supported by other related health organizations (n = 92 [91.1%]). Least endorsed was being patient driven (n = 88 [87.1%]) (Figure 5). Confirmed by written responses were suggestions that facilitation was key to group effectiveness:

Good group facilitation makes a lot of difference in the success of the group. Another key factor seems to be consistency and reliability in frequency of the meetings. The group also needs to be easily accessible. (A 47-year-old female oncology nurse who has been working with PCa patients for 15 years)

Ways That Web-Based PCSGs Should Be Developed to Enhance Their Effectiveness

Featuring evidence-based healthcare provider presentations in "real-time" audio/video conferences (n = 93 [92.1%]), providing brief summaries about PCa and health information (n = 92 [91.1%]), and facilitating discussion and promoting camaraderie (n = 92 [91.1%]) were agreed or strongly agreed by respondents as important characteristics of effective online PCSGs. In response to the question if PCSGs should provide separate areas for men and their partners, 73.3% (n = 74) agreed or strongly agreed. There was less endorsement of the items "does not require log in permissions to aid user anonymity" (n = 59 [58.4%]) and "is led and moderated by a prostate cancer survivor" (n = 40 [39.6%]; Figure 6). Respondents' comments were generally positive about online PCSGs, although some cautions were offered based on comparisons between online and face-to-face programs as illustrated by the following response:

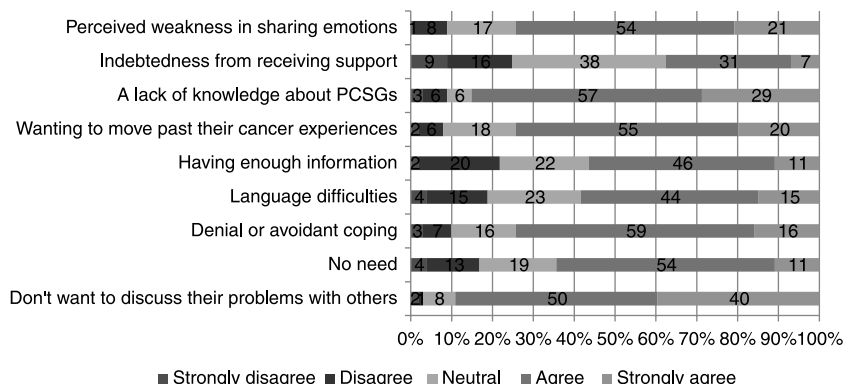


Figure 4 ■ Reasons why men may choose to not attend prostate cancer support groups.

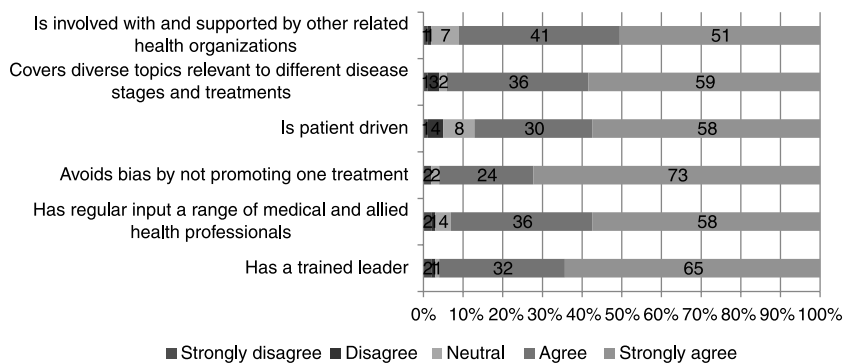


Figure 5 ■ How effective a prostate cancer support group may be in helping men with prostate cancer.

Not so sure you can successfully substitute a Web-based program for the intangible benefits of meeting in person and feeling the sense of mutual support. (a 58-year-old female oncology nurse practitioner who has been working with PCa patients for 15 years)

■ Discussion

The findings suggest Canadian nurses have positive views on the value of PCSGs. The responses also confirm longstanding empirical evidence about the important roles played by Canadian PCSGs in supporting men throughout their PCa experience.¹⁸ This is heartening because the nurses' linkages to, and endorsement of PCSGs may galvanize professional and lay service collaborations toward collectively advancing the health of men who experience PCa and their families. Given the influence nurses have in providing and coordinating care, as an enclave they are ideally positioned to signal PCSGs as a legitimate option for men. Previous work by Oliffe et al¹⁰ has highlighted that the sustainability of PCSGs is contingent on attracting new attendees, and in this regard, nurses might aid the viability of PCSGs by raising awareness of the groups among potential attendees and/or directly referring patients to a support group. The benefits from these actions could extend to professional services wherein the demand (and perhaps costs) for professional psychosocial oncology services might be reduced. Related to this, respondents could also begin to remedy men's ignorance about PCSGs: a factor they

perceived as a significant barrier to men's participation in support groups.

Contrasting respondents' favorable views were concerns about misinformation at PCSGs and the potential for that to negatively impact men's adjustment to PCa. Echoing previous findings by Steginga et al,²² the current study confirmed nurses' doubts about the ability of PCSGs to present impartial information and up-to-date evidence. While these concerns might ease the willingness of nurses to promote PCSGs, it is important to thoughtfully consider the genuine potential for misinformation both in the context of PCa and at PCSGs more specifically. For example, the science around PCa and its treatments is rapidly evolving, and in this regard, it can be reasonably argued that current interventions supported as evidence based or best practice will change over time. Reflecting this, PCa specialists often differ on specific treatments and regimens, with patients routinely encouraged to solicit "second" and "third" opinions to understand all their options and make informed choices.²³ In this context, it might be that PCSGs are best understood and promoted by nurses as offering diverse illness perspectives centered on the patients' experiences, rather than claiming particular biomedical PCa disease and/or treatment expertise.

Concerns about misinformation might also be quelled by extending formal linkages, wherein nurses and other healthcare providers present content at PCSG meetings to assist attendees to decipher and synthesize the ever-changing information available to them at groups and online. It is also important to note

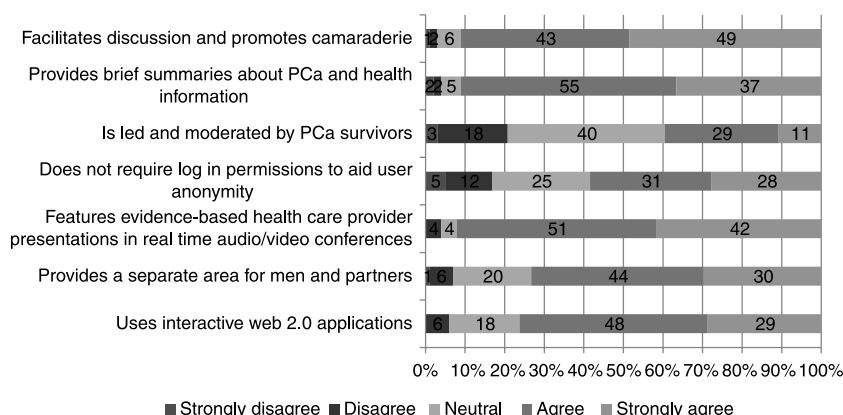


Figure 6 ■ Ways that Web-based prostate cancer support groups should be developed to enhance their effectiveness.

that while information was strongly endorsed by respondents as the reason men attended PCSGs, reassurance was viewed as a significant benefit to attendees, and this benefit likely outweighs concerns about the risk for harm being invoked by misinformation. Further to this, concerns about misinformation may reflect exposure to individuals who air their grievances at PCSGs rather than the overall work of the groups. As Oliffe et al¹⁰ suggested, PCSG leadership is critically important to governing outlier attendees exhibiting such behaviors: an observation reflected in the current study findings wherein respondents strongly endorsed a trained facilitator as the lynchpin to effectual PCSGs.

The benefits of online versus face-to-face PCSGs include an increased capacity for anonymity and greater access for rural and remote men and their families.²⁴ While there is evidence to suggest significant urinary and sexual health improvements for men accessing an online PCSG,²⁴ ensuring interactivity has been highlighted as an important inclusion toward fully engaging end users.^{25,26} In soliciting comments from the respondents, it was evident that, overall, online PCSGs were understood as value adding to face-to-face groups by reaching more men. The responses to the survey items confirmed that evidence-based interactive materials were an important design feature, whereas the suggestion that an online PCSG be facilitated by a survivor drew the least backing. Of course, while we can only speculate about these results, cautionary comments provided by respondents suggested that some older men might be challenged to engage with an online PCSG. Building on this, it may be that there are also concerns about PCa survivors having the expertise to maintain and/or facilitate a Web-based PCSG.

■ Implications for Practice

Nurses have much to offer PCSGs, and in turn, PCSGs can provide a unique platform for nurses to influence and advance the well-being of men who experience PCa and their families. The ever-expanding and diverse scope of nursing practice also bodes well for nurses to champion much needed sustainable ties between professional and community-based volunteer-run psychosocial oncology services. By referring patients, presenting content at face-to-face and online PCSGs nurses can quell the potential for misinformation amid better understanding effective clinical practice pedagogies and specific information needs of men who experience PCa.

■ Limitations

Limitations include the use of a Canadian convenience sample of nurses, 79 of whom reported referring patients to PCSGs. Given the nature of this sample, the findings may not be generalizable to other Canadian nurses, nor can the results be espoused as reflecting the views of nurses working outside Canada. However, these limitations provide direction for future research, which might include larger comparative studies within and between countries where PCSGs are widespread (eg, Australia, Canada, United Kingdom, United States), as well as targeted exploration about

how professional and community collaborations can be garnered to expand the capacity and reach of psychosocial PCa services.

■ Conclusion

Based on the nurses' views of PCSGs, the indications are that respondents endorsed PCSGs and were willing to promote these resources to meet the short- and longer-term needs of men who experience PCa. In addition, respondents viewed Web-based support groups as practical and viable alternatives for men who were reluctant to participate in face-to-face PCSGs. Given the expected increases in PCa, and the trend toward many men experiencing PCa as a chronic illness, attention to sustaining and growing a range of targeted psychosocial oncology services including PCSGs would seem warranted. Nurses as the largest healthcare provider group in Canada are highly influential in promoting and directly supporting such services. In this regard, it is clear that while conceding that PCSGs do not appeal to all men, there is strong potential for nurses to make visible all of the resources available to men who experience PCa and their families.

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