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Exploring the Efficacy of Support Groups for *Men with Prostate Cancer*

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Abstract

For the 180,000 men who will be diagnosed with prostate cancer this year, improvements in the disease's medical management have prolonged life expectancy. Long-standing treatment side effects include bowel and urinary incontinence and erectile dys-function, which frequently are embarrassing and contribute to poor emotional well-being. Despite the popularity of support groups in alleviating emotional symptoms related to cancer and its treatment, few men participate in such groups. This article focuses on the reasons why men do not find support groups appealing and presents alternatives that may be more acceptable. Suggestions are made for clinical and research implications.

Prostate cancer is the most common form of cancer for American men and ranks second for cancer-related mortality.¹ One in five American men are affected, and the American Cancer Society estimates that more than 180,000 new cases and 37,000 deaths this year will be directly related to prostate cancer.¹ Outcomes from prostate cancer vary and largely depend on the disease stage at detection and method of treatment. Often embarrassing consequences of treatment are urinary and bowel incontinence and sexual dysfunction—common and frequently long-standing sequelae that affect emotional well-being even after successful treatment.

The popularity of health-related support groups has risen sharply to address the various educational and emotional needs of individuals.^{2–4} Support groups have been used to overcome addictive behaviors, offer prenatal guidance, deal with social problems, and cope with illness and bereavement. Support groups bring together people with similar experiences to share their frustrations, concerns, and fears and minimize feelings of isolation. These groups are a low- or no-cost opportunity to meet others in similar circumstances to share common concerns and offer mutual support.⁴

Support groups have a history in Protestant populist culture in which people help one another.^{3–5} Today, 40% of all Americans older than 18 have been involved in regularly scheduled support groups that provide care and support for participants.^{3,4} Approximately 8

to 10 million adults attend at least one of the half-million U.S. support groups. Both formal and self-help support groups can facilitate strategies for coping with life problems and illness for a variety of people with diverse needs.

Men with prostate cancer would benefit from support groups, yet they seldom attend them. Indeed, women outnumber men by three to one in cancer support groups.^{6,7} Such health-related organizations, including prostate cancer support groups, are sponsored by churches, hospitals, professional organizations, and community agencies in response to the unique challenges men face in developing coping strategies associated with their illness experience.^{4,8-12} The purpose of this article is to explore the efficacy of support groups for men with prostate cancer.

EMBARRASSMENT ASSOCIATED WITH PROSTATE CANCER AND SUPPORT GROUPS

Men learn patterns of behavior early in life that define what it is to be a man, and these patterns are reinforced throughout adulthood.^{13,14} Overall, the masculine role is one of power, control, strength, stamina, and toughness. Men do not wish to appear emotionally vulnerable; hence fragility is a weakness, and physical abnormalities often are ignored because the consequence of needing to be cared for is a certain sign of weakness. Men are expected to be logical and analytical in their thinking, and decisions typically are based on careful analysis.

Because men often make decisions based on solid analytical evidence, much of the primary support they seek is informational. Men may seek to clarify their experiences with others who share similar circumstances. They may turn to a family member, coworker, neighbor, or community leader who also has been diagnosed with prostate cancer. However, as men age, their social networks shrink as a result of retirement, relocation, and the death of friends and loved ones. This shift leads to a decrease in social contact. Support is frequently not available when needed, and men are not often active in seeking out new relationships.

Because the diagnosis and treatment for prostate cancer may cause incontinence and sexual dysfunction, men often feel embarrassment and shame. Therefore, despite the unique concerns a man with prostate cancer has, he typically does not attend support groups.^{6,7}

Indeed, some men with prostate cancer who are taking part in the first author's dissertation research have provided anecdotal information that emphasizes their apprehension: "I consider these things [urinary and erectile dysfunction] to be very personal, and I would be uncomfortable talking about them in a group, even if it were just a group of men."

HOW SUPPORT GROUPS WORK

Social comparison theory¹⁵ suggests that people want to talk to others with similar experiences except when the topic leads to embarrassment. Social exchange theory¹⁶ proposes that men evaluate their repertoire of support experiences to determine if someone in their support network can meet their ongoing needs. In addition, numerous programs of support are based on health promotion and maintenance needs.¹⁷

Accurate and current information on disease and treatment is made available to group members, enabling them to collaborate and develop problem-solving skills and insight from each other to deal with disease and treatment.¹⁸ Participants often make new friends, learn more about different types of illnesses, and meet others who are faced with similar life circumstances.¹⁹⁻²¹ Group dynamics provide members the opportunity to interact with each other to counter the avoidance that may be present between patient and well-meaning family members who often have misinformation and fears. Through interpersonal exchange in support groups, members gain coping skills and information to deal with their emotions and understand their illness.

AWARENESS AND ATTENDANCE OF PROSTATE CANCER SUPPORT GROUPS

Alerting men to the presence of prostate cancer support groups should be incorporated into a comprehensive plan of care. The first opportunity to discuss informational and emotional needs takes place at the time of diagnosis, but the stress associated with learning one has cancer interferes with cognitive processing and awareness of suggestions.²²⁻²⁴

Crawford and coworkers²⁵ interviewed 1000 prostate cancer support group participants and 200 urologists to find out more about the educational and emotional needs of men with prostate cancer. Ninety percent of the physicians and support group participants agreed that an important source of information regarding the emotional and educational needs of men with prostate cancer is the primary care physician. However, both patients and physicians agreed that the latter are not likely candidates to offer emotional support to their patients (68% and 65%, respectively). Moreover, when physicians and patients were asked if the physician did provide information about cancer support groups where emotional and educational needs could be met, only 71% of the physicians and 56% of the patients recalled such information, despite both physician and patient concurring that groups were a good source of emotional and educational support.

Prostate cancer negatively affects a man's sexuality and typically evokes intense emotions of isolation, fear, uncertainty, and depression.^{23,24} Men who are fortunate enough to discover prostate cancer early, when it is confined to the prostatic capsule, are candidates for curative treatment. However, the tradeoffs for cure are common and long-standing treatment side effects that include uri-nary, bowel, and sexual dysfunction, all of which affect a man's sense of self-worth and masculinity and contribute to depressive symptoms.²⁶ Indeed, curative therapy, such as radical prostatectomy, results in incontinence in as many as 59% of men²⁷⁻²⁹ and erectile dysfunction in as many as 60%^{24,30} of men treated. Even with a long-standing support system (eg, wife, lifelong partner, sibling), they typically experience depressive symptoms.³¹

CURRENT GROUPS FOR MEN WITH PROSTATE CANCER

Prostate cancer support groups operate in acute care settings and as part of patient treatment programs. These programs often are sponsored by one of the two major U.S. prostate cancer programs: the American Cancer Society's "Man-to-Man" prostate cancer program and the

American Foundation for Urologic Disease's "Us Too." Both programs came about as a result of a need identified by a urologist and a patient seeking to deal with the emotional havoc created by the prostate cancer diagnosis and treatment.^{16,32} The men involved felt isolated and were in search of current information about the disease and its treatment.

The mission of the group was to bring participants together to share their frustrations and become less isolated by learning to share their concerns and fears with others. Accurate and current information on prostate cancer and treatment is made available to members to enable survivors to collaborate, develop problem-solving skills, and take insight from each other on how to deal with the dilemmas of their disease and "move forward in their lives." Since its inception, Us Too has grown into the nation's largest prostate cancer support group, with hundreds of programs replicating the original group organization. Little is yet known about the efficacy of these support groups or member satisfaction with group participation.

CLINICAL RECOMMENDATIONS

To develop a comprehensive plan of care for men with prostate cancer, health care providers should determine if adequate supports are available in a man's support network to meet the common informational and emotional needs encountered. Strategies should be based on theory, practice, and empirical evidence that address the unique, gender-specific needs of men as they survive prostate cancer. Included in these strategies is a careful assessment of existing support systems, followed by the identification of others who have faced similar experiences. These men initially may feel more comfortable discussing the common long-standing problems of urinary, bowel, and sexual dysfunction with another person in a one-to-one relationship.

In the absence of adequate personal support networks, a program of one-to-one support can be established with volunteers who are prostate cancer survivors and know firsthand what it is like to cope with issues commonly regarded as embarrassing and threatening to masculinity. Knowing that others face similar circumstances may allay some of the fears and isolation that often accompany prostate cancer.

RECOMMENDATIONS FOR RESEARCH

Research is needed to identify the efficacy of alternative and complimentary means of support for men with prostate cancer. The developmental and psychologic orientation of "what it means to be a man" needs to be considered. Indeed, a one-to-one support program is consistent with many theories and may be a more acceptable means of support for men when compared with current support groups.

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