POSITIVE COPING IN INDIVIDUALS WITH PROSTATE CANCER: THE EFFECTS OF PROSTATE SUPPORT GROUPS, SOCIAL COMPARISON AND RELIGIOUS RESOURCES

by

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In the Faculty of Education

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ABSTRACT

This project investigates positive coping in individuals with prostate cancer. Both quantitative and qualitative analyses were carried out. For the quantitative data, individuals from five different provinces in Canada participated in this study. All of the psychological scales were designed to tap into their quality of life and their coping with prostate cancer. The psychological scales used in this study were: CES-D (depression scale); Duke University Religion Index (DUREL); Sense of Coherence (SOC); Life Orientation Test (LOT-R); The Brief COPE; Mental Adjustment to Cancer Scale (MAC); The Functional Assessment of Cancer Therapy-General (FACT-G), and Posttraumatic Growth inventory (PTGI).

The results indicate that depression is lower in this population than previously found in other studies, which may be because these individuals were attending a support group. Aspects that helped these individuals in coping with their prostate cancer were their religious/spiritual beliefs, support groups, family/friends, downward social comparisons, and their positive attitude. Multiple Regressions indicated that PTGI was positively associated with factors such as social/family well-being, religion, anxious preoccupation, self-distraction, and fighting spirit. The quality of life was positively associated with a fighting spirit, use of instrumental support, and negatively with anxious preoccupation, helpless/hopeless and self-distraction. However, linear regression indicated that depression was negatively associated with the quality of life when taken together in the model with fighting spirit and sense of coherence.
Altogether, the findings of this study outline the importance of religion, downward social comparison, a fighting spirit, social / family well-being and support groups for coping with prostate cancer.
DEDICATION

This thesis is dedicated to all of my family and friends, but especially to: my wife Meena – for all her love and support; my sister Manjit- for all her caring; my brother Jasbir- for always being there for the family; professor Darrin Lehman- for his kindness and encouragement; professor Meguido Zola for being so helpful; professor Cathy McFarland for being so caring and for providing me with constructive feedback, and my daughter Jasmyn- for being so nice and special in every way!
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DEFINITIONS

**advanced cancer:** Cancer that has spread to the bones, lymph nodes or other organs of the body (Lange & Adamec, 2003).

**benign prostatic hyperplasia (BPH):** An enlargement of the prostate caused by noncancerous cells (Lange & Adamec, 2003).

**brachytherapy:** Prostate cancer treatment in which radioactive seeds are implanted in the prostate gland to destroy the cancer cells (Lange & Adamec, 2003).

**catheter:** A tube that is inserted into the bladder to remove urine when it is difficult for a man to urinate (Lange & Adamec, 2003).

**culture:** “The norms, values, attitudes, and behaviors that are typical of an ethnic group and that stem from a common culture of origin transmitted through generations.” (Phinney, 1996, p. 920).

**ethnicity:** Phinney (1996) suggested that ethnicity is composed of three components: culture, ethnic identity, and minority status.

**external beam radiotherapy (EBRT):** Radiation therapy that is provided by machines that aim radiation beams at the prostate to destroy cancer cells. Patients usually receive treatments five days a week for at least four weeks (Lange & Adamec, 2003).

**gleason score:** A measurement that evaluates the appearance of prostate cancer cells in terms of how aggressive they are. The further from normal cells they look, the more advanced the score (Lange & Adamec, 2003).

**hope:** A multidimensional, dynamic life force that focuses on positive expectations of the future and is influenced by other people (Ersek, 1992).

**hormone therapy:** The use of drugs or surgery to block natural male hormones for the purpose of halting or delaying the spread of cancer (Lange & Adamec, 2003).

**localized prostate cancer:** Cancer that is confined to the prostate itself and has not spread (Lange & Adamec, 2003).

**metastasis:** Metastasis means that the cancer has spread from prostate to the bones, the lymph nodes or other parts of the body (Lange & Adamec, 2003).

**positive coping:** Dealing with prostate cancer in a positive way.
**prostate:** Prostate is a gland that is the size of a walnut and its located below the bladder at the base of the penis. The main function of this gland is to produce the fluid portion of the semen (Canadian Cancer Society information pamphlet on Prostate cancer).

**prostate specific antigen (PSA):** This is a test that measures PSA in the blood. High or rising levels of PSA may indicate prostate cancer. PSA test is used to diagnosed prostate cancer and to check to see if the treatment is working (Lange & Adamec, 2003).

**radical prostatectomy:** This is when there is surgical removal of the prostate and the seminal vesicles through an incision between the scrotum and anus (perineal), an incision in the lower abdomen (retropubic) or several small incisions in the abdomen using special instruments (laparoscopy) (Lange & Adamec, 2003).

**watchful waiting:** (expectant management) Physician monitors the cancer by checking PSA levels and looking for signs and symptoms of prostate growth. If the PSA levels start to go up, treatment may be started (Lange & Adamec, 2003).
CHAPTER 1
INTRODUCTION

This study examines the factors that influence positive coping in individuals diagnosed with prostate cancer. This research is significant because of the following reasons. First, prostate cancer is at epidemic proportions and the number of prostate cancer survivors is rapidly increasing. Second, there is a paucity of research examining the psychosocial adjustment amongst individuals with prostate cancer especially within the Canadian context.

Prostate cancer is the most common cancer found in Canadian men, and it has the second highest death rate after lung cancer (BC Cancer Agency Update, 2003). In 2002, there were 2,700 men that developed prostate cancer in British Columbia, and there were 18,200 new cases nationwide. According to the BC Cancer Agency, in 2002, 4,300 men died with prostate cancer in Canada. Further, 88% of the new cases are diagnosed in men over the age of 60, and 91% of the patients survive at least five years following their initial diagnosis. Moreover in Canada, 1 in 8 men will be diagnosed with prostate cancer in their life times. Given that prostate cancer is occurring at epidemic proportions, we have an opportunity and responsibility to study the personal experiences of surviving this cancer.

Even though research on the physical sequelae of cancer is well documented, research on the psychosocial sequelae of cancer has lagged behind. Studies suggest that the majority of cancer survivors do not report symptoms consistent with psychiatric diagnosis (Fritz et al, 1988; Koocher & O’Malley, 1981; Mulhern et al., 1989; Spirito et
A few studies have reported problems that appear to be associated with disease-related variables (Kazak et al., 1994). Even ten years after treatment, events such as driving to the hospital, or smells associated with treatments may be stressful for these individuals (Hobbie, 2000).

Moreover, concerns have been raised about whether the absence of identified adjustment difficulties in cancer indicate a lack of disturbance per se, or the development of coping mechanisms that serve to mask these adjustment difficulties. Some studies have indicated "repressive adaptation" or higher levels of defensiveness, which may lead to lower levels of self-reported adjustment problems (Frank et al., 1997; Phipps et al., 1995). This "repressive adaptation" has led to the hypothesis that some cancer patients may use denial when confronted with direct questions concerning their psychosocial aspects (Worchel et al., 1992).

Another explanation for good psychosocial adjustment in some survivors of cancer may be that the trauma of cancer has actually enhanced their psychosocial functioning. Several studies have reported very low levels of depressive symptomatology amongst individuals with cancer (Greenberg, Kazak, & Meadows, 1989; Varni et al., 1996). This evidence of resilience during cancer may indicate that the trauma of cancer may actually enhance psychological functioning for some individuals; however, no study as examined the factors that may enhance psychological functioning in individuals with osteate cancer.
Inasmuch as patient well being is an area of growing importance in medicine, one must attempt to understand the experiences of surviving cancer. Many different variables may interact to determine the psychosocial impact of cancer. The literature suggests some survivors exhibit exemplary resilience whereas others exhibit long-term maladjustment (e.g., Fritz et al, 1988; Koocher & O’Malley, 1981). However, we know very little about the factors that mark increased risk of psychosocial maladjustment or those factors that provide buffering effects. Since one in eight men will develop prostate cancer in their life time, it is important to learn more about the predictors of adjustment and psychological well being in this group. For example, some studies highlight optimism as an important factor in achieving both goal attainment and social success for those coping with illness (e.g., Carver et al., 1993). But research is needed to determine the factors associated with poor and good psychosocial adjustment to prostate cancer based on the voice of the survivors themselves.

The construct of adjustment must also be expanded to go beyond objective physical functioning to include self-perceptions by survivors. Surviving cancer involves emotional, psychological, social sequelae (consequences), including living with a heightened chance of the recurrence of cancer. Often individuals diagnosed with prostate cancer live with pain, urinary incontinence, and impotence (Litwin, 1995). These symptoms are the results of common forms of treatments that are available for prostate cancer. Insight into those survivors’ ability in living through cancer risk will prove useful for those who have cancer. And interventions that improve coping, psychosocial support, and quality of life for individuals with cancer have lasting effects not only on
individuals and their families but also on society because of enhanced productivity and psychosocial gains throughout the life of these individuals.

Even though prostate cancer is rare amongst individuals from Asian backgrounds, another significant contribution of my research will be its focus on culture and how it influences the experiences of surviving cancer in men with prostate cancer. As noted earlier, in order to improve individuals' experiences of surviving cancer, psychological constructs that may influence psychosocial adjustment need to be studied. Special emphasis also needs to be given to the cultural factors that may influence the appraisal, coping, and adjustment processes related to surviving cancer. Research on the psychosocial aspects of cancer has all but ignored the impact of various cultures. Presently, within the Canadian context, there are no studies that have focused on the cultural dimension of individuals with prostate cancer. This study will examine the cultural background and family values that may have important ties to the psychosocial aspects of surviving cancer. In general terms, different cultures may hold different values and therefore define "success" or maturity differently. Cultural attitudes may also affect the survivor's and family's ways of appraising and coping with cancer. Therefore, interventions that are designed to enhance psychosocial adjustment among cancer survivors must consider cultural factors.

Although no specific research has addressed cultural factors inherent in surviving prostate cancer, there is a small emerging literature indicating that culture may influence the appraisal of stressful life events, the kinds of coping strategies individuals bring to bear, and how others react to the person experiencing the disease (Aldwin, 1994). Schweder (1993) defines cultural psychology as the study of culturally influenced
"experience-near" concepts and beliefs. Geertz (1973) defines "experience-near" to mean that the beliefs are used so unconsciously by people that they rarely acknowledge the belief's presence. These beliefs are implicit in people's self-functioning and guide their interpretation and representation. However, these beliefs may be unknown to the person. For example, the sense of the self as independent (i.e., autonomous, individualistic) is an experience-near concept for many Euro-North Americans (Markus & Kitayama, 1991), whereas the sense of the self as interdependent (i.e., connected, group-oriented) is characteristic of some East Asians.

Because prostate cancer is at epidemic proportions, it is imperative that we study the psychosocial meaning of survivorship. It is hoped that the findings of this study will improve the life situations of individuals with prostate cancer. The following section summarizes the research questions that are part of this study.
Research Questions

1. What factors enhance positive coping in individuals with prostate cancer?
   a. What role do the prostate support groups play towards positive coping in individuals with prostate cancer?
   b. What is the role of religion in coping with prostate cancer?
   c. What factors hinder positive coping with prostate cancer?

2. What kind of psychological growth, if any, did individuals with prostate cancer experience?

3. What kind of social comparisons, if any, do individuals with prostate cancer make?

4. In order to encourage positive coping in other individuals who may be diagnosed with prostate cancer, what advice do these survivors provide from their own personal experiences with surviving cancer?

5. Based on this study, what are some of the recommendations for youth in society, for health professionals working with prostate cancer individuals, and for prostate support groups?

6. How does culture influence the experience of cancer survivors?
CHAPTER 2
REVIEW OF LITERATURE

Variables related to psychosocial adjustment

Many variables have been shown to be related to coping with a chronic illness. These variables include socioeconomic status, satisfaction with the medical care, time since initial diagnosis (Obetz et al., 1980), type of cancer, lack of relapses, duration of treatment, self-esteem (Slavin et al., 1982) and quality of family relationships (Kupst & Schulman, 1988). Social circumstances of the patient and the family can also make a difference in adjustment to surviving cancer. Several resistance or buffering factors have also been identified in the literature. For example, Wallander et al. (1989) have identified resistance factors in psychosocial adjustment as intrapersonal factors (e.g., temperament), social-ecological factors (e.g., family environment, social support), and stress processing factors (e.g., coping strategies and cognitive appraisal). An information-seeking coping style has been associated with better adjustment to illness. However, coping has been shown to change over the time of an illness.

In addition to coping strategies, expectations of control over one’s environment (locus of control) seem to be a predictor in adaptation. Research indicates that persons with an internal locus of control are better adjusted than an external locus of control (Bensen & Deeter, 1992). An internal locus of control is a predictor for illness-related adjustment (Miles, Sawyer, & Kennedy, 1995).
Even though there are various psychosocial constructs that are related to cancer survivors’ psychosocial coping, the following constructs will form the focus of this study: religion/spirituality; support groups; depression; social comparison processes; family/friends and support processes; interdependent and independent self-construal; and the quality of life.
Religion/ Spirituality

Coping with any crisis involves factors such as one’s personality, past life experiences, family values, and religious preferences. Ebaugh et al. (1984) studied coping activities in response to crisis and found that Catholics used the church group for emotional support, Bahais focused on sacred writings, and Christian Scientists on positive thinking. However, within any one religion there are many different ways of describing the same doctrines. Within one group of Protestants three different coping styles were found, each of them based on a different assumption about God (Pargament et al., 1988). Even though there is great variability in religious doctrines, religions are thought to provide a set of parallel resources for individual coping. These parallel resources are: an interpretive schema, that enables people to discern spiritual meaning in experience; a supportive community where individuals have access to contextualized relationships; and rituals that help individuals to respond to crises of life such as cancer (Numbers and Amundsen, 1986).

Individuals faced with serious illness such as cancer focus religious responses around three existential axes: power/powerless, connection/disconnection, and meaning/meaningless (Burton, 1998). In the power/powerless axis, the individual is concerned about who is in charge of his/her life and how much control remains with him/her. In the connection/disconnection axis, the patient expresses concerns about relationships with friends, family and God. In the meaning/meaningless axis, the patient tries to make sense of his or her life. Each religion addresses these axes with its own teachings. Even though the exact process that individuals use to develop religious coping
is not well understood, religious coping responses are believed to involve a movement from the symbolic to the concrete and personal dimension of faith (Pargament et. al., 1992). As an aid to coping, religious beliefs interact with the life-changing events brought on by presence of a serious illness such as cancer, and beliefs themselves may undergo change. During this coping experience, some individuals may become more (or less) religious and others may experience a shift in the meaningfulness of their religious experience (Pargament et al., 1995).

Further, there is little agreement among researchers on how to measure religion, with measures including rates of church attendance, religious denomination, and single-item scales indicating the importance of religion in the individual’s life (Kendrick & Koenig, 2000). Therefore, it’s not surprising that research presents mixed findings, with many studies finding positive correlations, other studies finding none and some studies even finding negative effects of religion on the patient’s coping during serious illness (Jenkins & Pargament, 1995). For those studies that find a positive correlation, indicators of effective coping include less social isolation, less hostility and greater levels of transcendent meaning (Acklin et al., 1983). Other researchers have found higher levels of self-esteem (Jenkins & Pargament, 1988); less anxiety (Kaczorowski, 1989); greater hope (Mickley & Soeken, 1993), and psychological well being (Ell et al., 1989).

There is a strong correlation between religion, spirituality and good health. Prayer, meditation and church attendance have been correlated positively with good health (Koenig, 1999). Religious people have healthier lifestyles, stronger
marriages, recover more quickly from depression, and live longer, happier lives (Koenig, 1999). Koenig identified three components of religious activities that help individuals in coping with their illness. These components are organized, non-organized, and intrinsic endeavors. The organized religious dimension refers to attending church or other religious meetings. The non-organized dimension refers to religious activities that are performed privately such as Bible study or meditation. The third dimension is called intrinsic religiosity; this refers to the extent that individuals live in accordance with spiritual beliefs and values.

Indeed, a strong relationship exists between spirituality and physical health, as (Oxman et al. (1995) have found. Oxman et al. studied social participation in religious activities in cardiac surgery patients. The study found that only 5% of patients who received comfort from religion died six months after surgery, compared to the 20% of patients who had indicated that they did not receive comfort from religion. Other studies have found lower blood pressure in elderly individuals that reported attending church regularly (Koenig et al., 1998).

Koenig (1998) studied medically ill elderly patients' religious attitudes. He found that over 40% of the patients reported spiritual beliefs as their main coping source. Prayer also has been found to be an important coping resource in individuals with cancer (Dunkel-Schetter et al. (1992). Individuals high in intrinsic religiosity have also been found to have decreased medical symptoms and increased satisfaction in life. Therefore, spiritual resources seem to play an important part in the coping of individuals with medical illnesses and especially cancer.
For breast cancer patients, religion has been one of the most prevalent coping strategies used (Carver et al., 1993). Ginsburg et al. (1995) found that 44% of lung cancer patients identified religion as a major source of support. In Switzerland, studies conducted with cancer patients reveal that faith and God were important for 36% of the patients (Kesselring et al., 1986). However, mixed results with respect to religion are not surprising considering the variability in the religious measures used, ranging from frequency of worship attendance to indexes of beliefs (Dein & Stygall, 1997).

These mixed findings might also be the result of the function of an individual’s or family’s beliefs about illness. The beliefs about illness could be either constraining or facilitative (Wright et al., 1996). Thus, religious beliefs themselves could also function in either direction. Some cultural and religious beliefs could lead to diminished coping as well. In a study of women with breast cancer in Israel, those individuals who identified with an Oriental perspective (non-rational), as opposed to Western perspective (scientific and rational), attributed their cause of the disease to God or fate and were more likely to feel helpless and submissive (Baider & Sarell, 1983). Thus, many moderating variables may interact with each other to produce an active or hindering coping response. Moreover, religion can provide a way to create meaning in the world. Two different commitment orientations to religion, intrinsic and extrinsic, have been described in the literature (Mickley & Soeken, 1993). An intrinsic orientation refers to actively trying to live out the tenets of one’s faith. On the other hand, extrinsically oriented individuals practice religion to achieve certain goals (e.g., social status, emotional security) and religion is seen as something to be used. In a study of religious values and coping with
cancer, those with greater intrinsic religiousness reported less anger-hostility (Acklin et al., 1983).

These previous studies indicate mixed results in regard to religion and coping amongst mainly breast cancer patients; however, studies with individuals with prostate cancer are currently lacking in the cancer psychosocial literature. Presently, in the psychosocial literature related to individuals with prostate cancer, answers to the following questions are lacking: Do individuals with prostate cancer become more or less religious after they are diagnosed? What role does religion play in coping with prostate cancer?

Hypothesis and Rationale

Hypothesis 1: Among individuals with prostate cancer, there will be some shift in the meaningfulness of their religious experiences. Some survivors will become more or less religious than before. As an aid to coping, religious beliefs interact with the life-changing events brought on by presence of a serious illness such as cancer, and beliefs themselves may undergo change.

Rationale: During their coping experience, some individuals may become more or less religious and others may experience a shift in the meaningfulness of their experience (Pargament et al., 1995).
Support groups

Social support is believed to be one of the primary buffers or moderator between stress and health breakdown. It generally involves meaningful contact with other individuals and can be a source of affection, information, affirmation or tangible support. Social support may not be beneficial especially when it disrupts the family schedule or stresses the budget (Danielson, Hamel-Bissell, & Winstead-Fry, 1993). However, research has demonstrated that social support is generally beneficial for those facing a crisis. Social support received by one member of the family usually benefits the whole family because it enhances the problem-solving skills of the family (Stevens, 1988). A positive relationship has also been found between social support and desirable pregnancy outcomes such as fewer maternal and infant complications (Norbeck & Tilden, 1983). Others have demonstrated a relationship between social support and decreased mortality in heart disease (Berkman, 1986).

McCubbin and McCubbin (1989) outline five dimensions of social support: emotional (love and care exists); esteem (one is valued); network support (an understanding communication network exists); appraisal support (feedback about how well tasks are being managed), and altruistic support (receiving good will from others for having given something of one’s self). Social support may be beneficial because it may initiate changes in behavior that may reduce stress or facilitate recovery from stressful events (Ganster & Victor, 1988). Thus, individuals who attend social support groups may get advice from others about health promotion related to their illness or advice about how to contact a health professional. However, in order to assess the beneficial aspects of
social networks, it is also important to assess individuals’ perceptions of the support they are receiving (Wills, 1985). Social support may help foster a positive emotional state (Locke & Colligan, 1986), enhance self-esteem and sense of self-control (Wills, 1985), and provide opportunities for emotional intimacy (Rook, 1984).

For individuals diagnosed with cancer, one of the best ways to obtain social support is through mutual support groups of individuals with the same kind of illness. These groups provide members an opportunity to share their personal experiences about their problems and help validate the normalcy of certain feelings. These network supportive groups help their members through kinship, validation, role models, family support, knowledge, and the opportunity to help others. Thus, supportive groups pass along a reservoir of skills about how to manage a particular problem.

However, there are several obstacles to the maintaining of a mutual support group. These obstacles are: use of a deficit approach, ownership issues, and issues related to entry or exit from a social network group (Nichols & Jenkinson, 1991; Silverman, 1980). A deficit approach occurs when the group member is made to feel inferior because a professional may be preaching or using a jargon language. Respect for group members decreases this inferior feeling. The second problem about ownership exists when a professional is in control of a group and finds it difficult to let go of this control. When a professional does not allow a group to become autonomous, the professional may feel that he/she is not being paid for his/her professional services. Also, the group members may feel that their views are not welcome. Issues related to entry and exit from a group may involve questions such as who is a member of the support group and who is not.
To sum up, social support provides a positive buffer for individual members and their families for coping with an illness. Presently, within Canada there are over 100 prostate support groups; however, to present date, no study has looked at what role these support groups serve.

Hypothesis 2:

Individuals with prostate cancer should be able to describe benefits of their support group in terms of the five dimensions of social support outlined by McCubbin and McCubbin (1989).
Mood Disturbance and Cancer

A diagnosis of cancer is often a major life crisis causing the patient concerns for the well-being of family members, one's mortality, life-role changes, treatment side effects and financial concerns. Often a few cancer patients reach clinical levels of anxiety and depression (Spiegel, 1994) and Post Traumatic Stress Disorder (Dow, 1991).

Presently studies related to depression and coping methods for individuals with prostate cancer are almost non-existent. Medline data bases indicate that with respect to coping, depression and psychological growth in prostate cancer patients, no studies have been carried out in the Province of British Columbia. The majority of the research on prostate cancer patients has concentrated on the health-related quality of life issues. Often these patients live with pain, urinary difficulties (incontinence) and sexual dysfunction or impotence (Litwin, 1995). These symptoms are the result of common forms of treatments that are available for prostate cancer. These treatments are: Radical prostatectomy, surgery to remove the prostate gland; radiation, either external or seed implantation in the prostate gland; watchful waiting, where the prostate specific antigens are monitored over time; and hormonal therapy, a chemical form of castration.

The quality of life literature for individuals with prostate cancer indicates that depression is prevalent amongst this population immediately following treatment (Lubeck et al., 1999). Cancer patients who incur physical symptoms often experience mood disturbance (Given et al., 1993), and there appears to be a negative correlation between time since diagnosis and mood disturbance (Ma, 1996). In one study with prostate cancer
patients, 76% of patients who received radical prostatectomy reported being moderately to extremely upset because of the incontinence they experienced (Herr et al., 1993). Godding et al. (1995) also examined depression in men with different kinds of cancer, about 45% of these patients experienced moderate to high depression levels. However, depression for prostate cancer patients was not reported in this study. On the other hand, Heim and Oei (1993) have found moderate to severe depression only in about 15% of the prostate cancer patients, which was consistent with the depression level that is generally found in the elderly. Presently, the existing research presents mixed results in regard to depression and individuals with prostate cancer. Also, the relationship between time since diagnosis and mood disturbance is not clear. Litwin et al. (1995) indicate that as time since initial diagnosis elapses, mood disturbance decreases (Litwin et al., 1995); however, other authors indicate that mood disturbance increases from the time of diagnosis because of the increasing side effects of treatment (Herr, 1994). Also, the relationship between symptom distress (treatment side effects) and mood disturbance is presently unclear for prostate cancer individuals, with some studies suggesting there may be a correlation (Lubeck et al., 1999).

Herr (1994) investigated quality of life for those who had radical prostatectomy (n=50) and found that one to three years after surgery, 83% believed that surgery was a good choice, compared to only 47% after 5 years of surgery. Therefore, annoyance caused by incontinence may grow as the length of time increases after treatment. As far as inconvenience caused by impotence is concerned, other authors have found that for radical prostatectomy patients, age was not a factor (Brasalis, Santa-Cruz, Brickman, and Soloway, 1995). Generally education, support groups, and relaxation techniques alleviate
mood disturbance for patients, which leads to improved psychological well-being and increased length of life (Spiegel et al., 1989).

To conclude, even though mood disturbance has been studied in individuals with prostate cancer in previous studies, the following information is presently lacking in the literature: (a) From the patients’ perspective, what were some of the stressful aspects in coping with prostate cancer? (b) Amongst those who attend support groups, what percent of these patients have moderate to severe depression?

Hypotheses:

**Hypothesis 3:** Depression level found in these individuals will be lower than those found in previous studies because 95.5% of these men have attended support groups. This support group help may alleviate some of their symptoms of depression.

**Hypothesis 4:** When asked about stressful aspects, most individuals may talk about their treatment side effects related to incontinence and impotence. Individuals with prostate cancer may talk about incontinence and impotence since these are symptoms resulting from common forms of available treatment.
Social Comparison Processes

One way in which individuals may cope with their cancer is by social comparison. Individuals can gain feedback about themselves either by comparing with those who are better-off (upward social comparison) or by comparing with those who are worse-off (downward social comparison). Both the upward or the downward social comparison can lead either to positive or to negative effects depending on the individual and his/her situation (Taylor & Lobel, 1989). Aspects such as perceived control (Buunk et al., 1990), and anxiety (Mollerman, Pruyn, & Van Kippenberg, 1986) moderate the affective consequences and the type of comparison individuals may make.

An individual with cancer who engages in downward social comparison may find out that he is much better-off than others, or that he/she might get worse. On the other hand, an individual who makes an upward social comparison may find out that he/she is doing worse than others but that he/she may improve over time. Generally, cancer patients make downward social comparison to build self-esteem. However, this may only be true for those who have a high self-esteem (Buunk et al., 1990; Buunk, 1997).

Social comparison, however, may not be experienced in the same way in the elderly. Elderly persons tend to make more temporal comparisons and fewer social comparisons because they may have fewer social contacts and declining perspective-taking abilities (Suls et al., 1991). Therefore, it would be interesting to investigate the kind of social comparison these individuals make, and why they make these comparisons.
Currently, no studies have been done in the area of social comparison for individuals with prostate cancer.

Hypothesis 5: Because elderly individuals with prostate cancer may have declining perspective-taking abilities compared with younger individuals (Suls et al., 1991), social comparison would be rare in this older group.
Coping

Coping is defined as, “cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person” (Folkman & Lazarus 1988, p. 310). Coping processes are directed at either changing the situation (problem-focused coping) and/or regulating distress (emotion-focused coping). These processes incorporate two forms of appraisal: primary and secondary. In the primary appraisal, a person is concerned about what is at stake in the encounter; for example, self-esteem. In the secondary appraisal, the person is concerned about what he/she can do or what his or her options are for coping.

According to Folkman and Lazarus, the kinds of coping strategies one uses depend on whether or not the outcome is appraised to be amenable to change or not. Problem-focused coping is more likely if one perceives the outcome to be changeable, whereas emotion-focused forms of coping are more likely when the outcome is perceived to be unchangeable. Folkman and Lazarus further state that appraisals of person-environment are also influenced by the individual’s personal characteristics, such as pattern of motivation (e.g. commitment, values, and goals), beliefs about oneself and the world, personal resources available for coping, and social problem solving skills. Individual and cultural differences in these variables help to explain why some illnesses such as cancer are perceived to be a “threat” by one person and a “challenge” by another.

Furthermore, individual differences in coping are also present because coping in itself is a multidimensional process. For example, Folkman and Lazarus have identified two forms of problem-focused coping and six forms of emotion-focused coping. “Of the
two problem-focused forms, one is confrontive and interpersonal and the second emphasizes planful problem-solving. The emotion-focused forms include distancing, escape-avoidance, accepting responsibility or blame, exercising self-control over the expression of feelings, seeking social support, and positive reappraisal" (p. 311). Factor analyses have revealed other common coping factors. Ayers, Sandler, West, & Roosa (1996) factor analyzed ten coping scales and found four common factors: active coping (direct problem-solving, cognitive restructuring, and seeking understanding); social-support (problem-focused and emotion-focused support); distraction (physical release or energy and distracting action); avoidance (cognitive avoidance). On the one hand, individuals with active coping show better psychosocial adjustment to illness (Grey, Cameron, & Thurber, 1991). On the other hand, avoidance coping led to adjustment difficulties, such as depression and anxiety in individuals with cancer (Frank, Blount & Brown, 1997).

Lazarus and Folkman’s model indicates that appraisals are considered to influence coping responses, which in turn influence one’s psychosocial adjustment. However, appraisal and coping are not sufficient predictors of psychosocial adjustment. Chang (1998a) found that even after accounting for the variation associated with appraisal and coping, hope accounted for significant differences in life satisfaction. Synder’s hope theory (Synder, 1994) states that people are guided by efforts to reach and obtain their goals. Individuals who are high in hope have a preference for positive goal-directed thinking. According to Synder’s hope theory, hope is related to appraisals because hopeful individuals perceive stressful situations as a challenge. In regard to coping, the
hope theory predicts that individuals high in hope will address stressful situations with more engaged coping strategies compared with low hope individuals.

Individuals high in hope have been found to use adequate coping efforts (Chang, 1998b). Optimists maintain higher levels of subjective well-being during times of stress than do people who are less optimistic. Optimists cope in more adaptive ways than those who are less optimistic (Scheier & Carver, 1993). They are also likely to take direct action to solve their problems, and are likely to plan how to deal with adverse situations and are more focused in their coping efforts.

Similar to the construct of hope, sense of coherence (Antonovsky, 1987) is a “global orientation or view that things will work out as well as can be expected. Rather than being interpreted as a coping style, a sense of coherence is understood to be a construct that underlies the development of coping strategies” (Bowman, 1997, p.139). Sense of coherence is also dependent on one’s culture. Antonovsky described sense of coherence as having three components: comprehensibility that life makes sense; manageability that problems will be bearable; and meaningfulness, that life is challenging. Further, Antonovsky suggested that people might develop this worldview through life-experiences that are culture specific. Bowman found support for Antonovsky’s suggestion of sense of coherence being culturally sensitive. She found that Native American families emphasize religion and moral values while Anglo-American families appear to emphasize independence and achievement.

In contrast to sense of coherence, social responses may hinder one’s psychosocial adaptation. Ingram, Betz, Mindes, Schmitt, & Smith (2001) found that The Unsupportive
Social Interactions Inventory (USII) demonstrated four types of unsupportive or upsetting responses amongst college students concerning a stressful event in their lives. These responses were: distancing ("other person didn’t want to hear about it"); bumbling ("other person was uncomfortable talking about it"); minimizing ("felt I shouldn’t worry about it"); and blaming ("I told you so"). One’s network members may also respond in unsupportive ways. Wortman and Lehman (1985) identified three reasons why social network members may respond in unsupportive ways: network members may feel helpless; they may feel uncertain about what to say; or they may hold misconceptions about the adjustment process.

To sum up, according to the Lazarus and Folkman (1984) theory of stress and coping, psychosocial outcome is a result of the interaction between the stressful situation, an individual’s appraisal of that event, his/her resources, and the coping strategies used to manage that situation. Further, coping processes are hypothesized to be responsive to changes in one’s social context and to long-term changes in individuals as a result of one’s social, cognitive and biological development. Both situational factors and developmental changes contribute to changes in one’s coping responses. However, no Canadian study has yet given voice to individuals with prostate cancer to find out what aspects helped them in coping with their experiences.

**Hypothesis 6**: Because information regarding the coping strategies that survivors of prostate cancer use is currently lacking, the results of this study should describe the kinds of coping strategies that facilitate positive coping.
**Psychological Growth**

Individuals with a severe medical illness try to give meaning to their illness. An individual with an illness usually asks him or herself, “Why did this happen to me?” Different people may give different personal meaning to their illness. For example, some may see it as a punishment whereas others may see it as having some positive personal value. Lipowski (1970) stated that the subjective meaning given to an illness plays an important role in how individuals are able to deal with their illness. According to Lipowski, the meaning ascribed to an illness reflects knowledge, past experiences, beliefs about sick people and cultural background. He stated that giving meaning to a particular disease acts as a “cognitive nucleus” that influences motivational and emotional responses to disease, and thus coping strategies. Lipowski summarized these “personal meanings” into eight categories: challenge, enemy, punishment, weakness, relief, strategy, irreparable loss, and value. In the category “challenge,” illness is seen like any other challenging life situation which imposes demands and tasks to be mastered. For the given meaning “enemy,” disease is seen as a hostile force, and thus there is a need to fight this “enemy.” In the “punishment” category, disease may be perceived as just or unjust. “Weakness” implies that the disease is seen as a sign of loss of control. If one perceives an illness as a weakness, he/she may have a feeling of shame. The meaning of “relief” indicates respite from demands and responsibilities of being well. In the “strategy” category, disease is seen as a way to secure attention or support from others. “Irreparable loss” indicates that the disease is an overwhelming loss that nothing can replace. Finally, in the “value” category, an individual tries to give some intrinsic value to one’s illness. An individual may see illness as helping the person to grow in some way.
Even though some survivors of cancer do ascribe “value” as a meaning to their illness, very little is known about what this growing experience might be for individuals with prostate cancer. Barkwell (1991) studied meaning given to one’s experience with cancer, and collected data from one-hundred patients who were suffering from cancer related pain in Winnipeg, Manitoba. The average age of the participants in this study was 61.3 years, with the youngest participant being twenty-six years old. The data about the meaning patients attributed to their cancer-related pain was as follows: challenge (n=36), enemy (n=20), punishment (n=23), weakness (n=7), relief (n=1), strategy (n=3), irreparable loss (n=8), and value (n=2). Barkwell then described in details three main categories of meaning: challenge, punishment and enemy. The meaning of cancer related pain attributed as “value” by two individuals in this study, was not described in details as this was not a major category. However, it would be valuable to know what these “posttraumatic growth” experiences are.

In addition to meaning ascribed to one’s illness, the process of maintaining “hope” has also been studied in the literature. Ersek (1992) applied grounded theory methodology to elicit the experience of hope in twenty individuals, ages 20-58, who had undergone bone marrow transplantation (BMT) for leukemia. Based on the data, Ersek developed two categories to elaborate on the process of maintaining hope: “Dealing with it,” and “keeping it in its place.” “Dealing with it is defined as the process of confronting the negative possibilities inherent in the illness experience and allowing the full range of thoughts, behaviors, and emotions resulting from the recognition” (p.884). Dealing with it involves four components: appraising the illness experience as a threat; allowing the emotional response; working through it, and moving on. “Keeping it in its place is
defined as the process of managing the impact of the disease and its treatment by controlling one’s response to the disease and therapy” (p. 885). Keeping it in its place involves eight components: appraising the illness in a non-threatening manner; managing the cognitions related to the illness experience; managing the emotional response to the illness experience; managing the sense of control; taking a stance towards illness and treatment; managing uncertainty; managing the focus on the future, and managing the view of the self in relation to the illness. Ersek further states that categories of Dealing with it and Keeping it in its place may be conflicting and pose a challenge to integrate them into a coherent theory. “The overarching concept that eventually was developed to integrate these two categories is The Dialectic of Maintaining Hope [emphasis was in the original quote], which is defined as the process of reconciling, but not eliminating, the tension between Keeping It in Its Place and Dealing with It in a way that fosters and sustains hope” (p. 885). Thus, “The Dialectic of Maintaining Hope” allows the person to deal with a threat by limiting it, and thus maintaining hope. It is important to keep in mind that the above findings should be used with caution as the above study had only a small and homogeneous sample.

Recently studies have begun to focus on the positive outcomes associated with experiencing cancer. Posttraumatic growth is the perception of positive self-change that is reported by individuals after a traumatic life event. Many studies have reported psychological growth in individuals that have experienced various kinds of trauma (Affleck & Tennen, 1996; Lehman et al., 1993; McMillen, Smith, & Fischer, 1997). Perceived growth is believed to occur in three domains: changes in the perception of the self, changes in relationship with others, and changes in one’s philosophy of life with new
life directions and priorities (Tedeschi & Calhoun, 1996). In terms of self-perceptions, an individual may perceive him or herself to be coping with difficult challenges. For self-perceptions of change in relationship with others, an individual may experience an increase in interpersonal and emotional closeness with others, and understand the suffering of others (Calhoun & Tedeschi, 1990). Changes in life may involve changes in life priorities, and greater interest in religious or spiritual matters (Park, Cohen, & Murch, 1996).

Not only the individuals but also their families may experience growth as a result of a traumatic experience. For example, Lehman, Lang, Wortman and Sorenson (1989) found that 29% of the parents of children who were killed in a motor vehicle accident in their study reported that their marriage had become somewhat or much better. About one-third of the parents also indicated that their relationships with surviving children had improved.

However, presently the extent to which perceived psychological growth leads to psychological adjustment is not clear (Park, 1998). Some authors have reported moderate relationship between perceived psychological growth and psychological adjustment to breast cancer (Taylor, Lichtman, & Wood, 1984), and adjustment by mothers to infants hospitalized with serious health problems (Affleck & Tennen, 1991). However, Lehman et al. were unable to find a link between psychological adjustment and perceived psychological growth in their study. Presently, there is no clear explanation for these discrepancies in the findings (Calhoun & Tedeschi, 1998).
The exact mechanism of this perceived posttraumatic growth is also not very clear. Some researchers have even questioned the accuracy of this temporal change regarding perceptions of personal growth (Taylor & Armor, 1996). Taylor and Armor claim that in order to deal with the negative emotions associated with the traumatic event, some individuals may engage in cognitive distortions or illusions and thus may see their experiences in a positive way. However, other researchers see psychological growth in terms of shattering or reevaluation of previously held fundamental assumptions and rebuilding or new assumptions (Janoff-Bulman, 1992). "The demolition of old cognitive structures that provided a map for life and the struggle to rebuild are experienced, not merely observed" (Calhoun & Tedeschi, 1998). Individuals may also experience this personal change by changing schemas, personal narratives, or developing greater wisdom (Calhoun & Tedeschi, 1998). Further, these reevaluations of previously held assumptions may cause both distress and personal growth to coexist in individuals after a traumatic event (Calhoun & Tedeschi, 1998). Moreover, this personal change is considered to be multidimensional where it may occur in one domain but not in others.

A positive personal change as a result of adversity has been linked to use of more coping and active coping strategies (Collins, Taylor, Skokan, 1990). Psychological growth has also been linked with physical health in patients with cardiac health difficulties. Those male heart attack patients that reported more positive posttraumatic changes were less likely to have experienced a heart attack eight years later (Affleck, Tennen, Croog, & Levine, 1987). However, studies have found that reported negative changes are more predictive of psychological well-being than the reported psychological growth aspects (Curbow, Somerfield, Baker, Wingard, & Legro, 1993). Because these
positive perceptions are dependent on culturally-based implicit theories, it is possible that one’s culture may also have an influence in determining the kind of positive change that occurs (Ross, 1989).

Presently, there are no studies that have examined perceptions of personal growth in individuals with prostate cancer. Currently the answers to the following questions are lacking in the literature: What kind of perceptions of personal growth do individuals with prostate cancer describe as a result of experiencing their cancer? Is this perception of personal growth linked with their quality of life? This study may provide answers to some of these questions.

**Hypothesis and Rationale:**

**Hypothesis 7:** Even though some survivors of cancer experience psychological growth, not much is known about the details of this psychological growth. This study presumes that psychological growth from the experiences of survivors of prostate cancer. This study predicts that survivors of prostate cancer should experience psychological growth. This study also suggests that posttraumatic growth might be related to one’s coping processes, depression and quality of life.

**Rationale:** Lipowski’s (1970) personal meaning of illness as “value” supports the notion that some survivors of disease do experience a personal growth. Because some individuals with cancer eventually come to value their illness, they will be able to describe what this psychological growth is.
CHAPTER 3
LITERATURE REVIEW RELATED TO CULTURE AND POSITIVE COPING

Family/Friends and Support Processes

The emotional support received from family members or significant others is considered to be most helpful by patients (Helgeson & Cohen, 1996). Empirical evidence indicates the family’s effectiveness in helping people cope with cancer. Godding et al.’s (1995) study demonstrates the importance of social support for individuals newly diagnosed with prostate, lung and neck cancer. Godding et al. were interested in the predictors of depression in sixty-nine newly diagnosed males with different kinds of cancer. Their study found moderate depression levels at a 40% rate of participants; however, regression analysis indicated that 31.5% of the depression variance could be explained by the scores that patients received on their social support and quality of life measures. In a literature review done by Helgeson and Cohen (1996), it was found that cancer patients desired emotional support from the family, and when this support was absent, it was related to their poor psychological adjustment in coping with their cancer. In another study done with prostate cancer patients treated with radiation therapy, patient family communication was correlated positively with adjustment to cancer. Also, higher emotional support scores were related to lower depression and anxiety (Gotcher, 1993).

However, different cultures perceive the concept of family in different ways. Die-Trill and Holland (1993, p. 22) state that, “The American definition is the intact nuclear family. For Mediterranean cultures, a family is the extended network of aunts, uncles,
cousins, and grandparents, all of whom are highly involved in the patient’s care.” Within cultures such as Latinos, a cure is seen as requiring full family participation (Erzinger, 1991). Family-based oriented interventions may also be more effective for patients with a high belief in “familism” (Cousins et al., 1992). However, the sense of the extended family being higher in some ethnic groups does not guarantee that it will be mobilized during cancer diagnosis and treatment (Meyerowitz et al., 1998). Presently, how culture influences a family’s integration or how familism plays a part in individual’s adjustment to cancer is not well understood.

Culture may also influence the degree of communication within families. It is important to consider the meaning of “communication” and “support” when assessing the degree of communication and support between individuals of Eastern and Western cultures and their families. Communication in Western culture is associated with what is being spoken and “support” includes speaking out emotions and feelings. Whereas in Eastern culture, verbal communication may not be as important, support is based on unspoken actions or mutual understanding. From a Western perspective, silence may be a form of non-communication. However, Asian-Canadians may suppress negative emotions because of fear that such emotions may upset the family members and cause additional distress. In addition, there may be unwillingness among Asian-Canadians to disclose emotions because of the Eastern culture’s importance attached to self-control.
Hypothesis and Rationale:

Hypothesis 8: Individuals with prostate cancer from Eastern cultures may not have more extended family involvement than those survivors from the Western cultures.

Rationale: The sense of the extended family being higher in some ethnic groups does not guarantee that it will be mobilized during cancer diagnosis and treatment (Meyerowitz et al., 1998). Presently, how the sense of the extended family plays a part in individual’s adjustment to prostate cancer is not well understood.
The mediating variable for the influence of culture on behavior is the concept of self (Triandis, 1989). Triandis conceptualized each person's self as having three aspects: (a) the private self - cognitions, traits or behaviors of the person; (b) the public self - generalized others' view of the self; and (c) collective self - cognitions related to the beliefs about the self. When an individual is confronted with a social situation, he/she draws or samples from these three aspects of the self. The number of cognitions that constitute that dimension of self and the type of social situation determine which aspect of the self will be referenced.

Triandis proposed that one's culture affects the relative development of these selves. For example, on the one hand, collectivist cultures encourage the development of cognitions that refer to a group, thus increasing the probability that these cognitions will be sampled frequently by the individual. On the other hand, individualist cultures encourage the growth of cognitions that refer to an individual's cognitions. Empirical support for the development of two well-established self-concepts is well established (Singelis, 1994; Trafimow et al., 1991). To what extent collectivist cultures emphasize interdependence over independence in their coping will be investigated.
Hypothesis and Rationale:

Hypothesis 9: Prostate cancer survivors of cancer from Eastern cultures will emphasize more interdependence in their coping than independence. Interdependence coping implies greater emphasis on the social and cooperative aspects of coping than does independence. 

Rationale: According to Triandis (1989), collectivist cultures encourage the development of cognitions that refer to a group thus increasing the probability that these cognitions will be sampled frequently by the individual.
Summary of Hypotheses

**Hypothesis 1:** Among individuals with prostate cancer, there will be some shift in the meaningfulness of their religious experiences. Some survivors will become more or less religious than before. As an aid to coping, religious beliefs interact with the life-changing events brought on by presence of a serious illness such as cancer, and beliefs themselves may undergo change.

**Hypothesis 2:** Individuals with prostate cancer should be able to describe benefits of their support group in terms of the five dimensions of social support outlined by McCubbin and McCubbin (1989).

**Hypothesis 3:** Depression level found in these individuals will be lower than those found in previous studies because 95.5% of these men have attended support groups. This support group help may alleviate some of their symptoms of depression.

**Hypothesis 4:** When asked about stressful aspects, most individuals may talk about their treatment side effects related to incontinence and impotence. Individuals with prostate cancer may talk about incontinence and impotence since these are symptoms resulting from common forms of available treatment.
Hypothesis 5: Because elderly individuals with prostate cancer may have declining perspective-taking abilities compared with younger individuals (Suls et al., 1991), social comparison would be rare in this older group.

Hypothesis 6: Because information regarding the coping strategies that survivors of prostate cancer use is currently lacking, the results of this study should describe the kinds of coping strategies that facilitate positive coping.

Hypothesis 7: Even though some survivors of cancer experience psychological growth, not much is known about the details of this psychological growth. This study presumes that psychological growth from the experiences of survivors of prostate cancer. This study predicts that survivors of prostate cancer should experience psychological growth. This study also suggests that posttraumatic growth might be related to one's coping processes, depression and quality of life.

Hypothesis 8: Individuals with prostate cancer from Eastern cultures may not have more extended family involvement than those survivors from the Western cultures.

Hypothesis 9: Prostate cancer survivors of cancer from Eastern cultures will emphasize more interdependence in their coping than independence. Interdependence coping implies greater emphasis on the social and cooperative aspects of coping than does independence.
CHAPTER 4

METHODOLOGY

Even though the focus of this study is on the qualitative data, quantitative data was also collected to provide triangulation and to further understand the findings obtained through the qualitative data. Therefore, this study used both qualitative and quantitative methods to give voice to men with prostate cancer. For the qualitative part, a one-to-one semi-structured interview format based on the psychosocial constructs was used (see appendix B: qualitative interview). This qualitative interview focused on: treatment information and prior history; aspects that have helped or hindered with coping; role played by religion, and support groups in the lives of these individuals; any social comparisons that were made, and suggestions offered by the individuals to improve, if improvements can be made, to the current medical system of treating individuals with prostate cancer. Some qualitative information was also obtained from individuals (see appendix O) by asking them the following questions: 1) If having cancer has changed your view of the world, priorities in life, or life in general (either in a positive or negative way), please describe how your view of the world, priorities in life, or life in general has changed... 2) If you were to give advice to another person who was diagnosed with prostate cancer, please describe what advice you would give... 3) Please provide any other comments that you feel are important from your own experiences with prostate cancer. The intention was to supplement the qualitative interview data with some quantitative data as well.
Further, in order to achieve some of this supplementary information, the effects of various personality variables on psychosocial coping were investigated by standardized quantitative scales: Optimism/ Pessimism- Lot Life Orientation Revised Scale (Schier & Carver, 1985), The Brief Cope (Carver, 1997), Depression Scale- CES-D (Radloff, 1977), Mental Adjustment to Cancer Scale- MAC (Watson, Greer & Bliss, 1989), Duke University Religion Index- DUREL (Koenig et al., 1997), Sense of Coherence Scale- SOC (Antonovsky, 1987), The Functional Assessment of Cancer Therapy-General FACT-G scale (Cella et al., 1993), and the Posttraumatic Growth Inventory- PTGI (Tedeschi & Calhoun, 1996). All of these scales are elaborated in the instrumentation section. Only the data that was pertinent to the questions that were asked in this study was used from these quantitative scales.

Because existing research on psychosocial aspects of cancer has been primarily quantitative in nature (Compas et al., in press), perhaps not nearly enough attention has been paid to the personally important issues and psychosocial constructs such as emotional costs of treatment, life meanings, supports, and posttraumatic growth. Qualitative studies are much more likely to yield important factors to survivors’ construct of successful adjustment than closed-ended measures. In-depth interviews can provide more compelling understanding of the positive and negative experiences associated with surviving cancer. In-depth interviews provide much more latitude to the survivors to allow them to introduce topics of personal significance in explaining adjustment to cancer. This way they get an opportunity to express their thoughts and feelings, and lead to more accurate portraits of coping than generic coping checklists (Coyne & Gottlieb, 1996).
In-depth interviews may provide windows into survivors' emotional and cognitive worlds that self-reports fail to do. For example, Petrie and Pennebaker (2000) assessed negative affect (NA) amongst women with breast cancer using both a standardized self-report scale and with linguistic coding of negative affect words in an open-ended narrative written by the subjects. These women were followed over 4 years, and eleven from thirty five had died. Petrie and Pennebaker found that self-reported negative affect on the closed-ended scale was uncorrelated with the frequency of negative affect words in the open-ended context. Also, women with higher negative affect scores on the closed-ended self-report scales were less likely to die, whereas women who used more negative affect words in their narratives were more likely to have died or died more quickly.  

Pennebaker and King (1999) noted that the way people respond to self-reports are virtually uncorrelated with the words they use to describe themselves. Words people use to describe themselves correlate more highly with their behaviors than do self-reports. There is evidence to suggest that mental health can be predicted from the words that people use to describe themselves (e.g., Stiles, 1992). This investigation gave voice to the prostate cancer survivors. This study used a mix of quantitative and qualitative data.
Participants and sites

Twenty-seven men and one spouse were interviewed for this study and most of the data for this study was collected during July and August, 2003. From these twenty-eight individuals, twenty-four of them were interviewed one on one. Another two subjects were interviewed together. One subject was interviewed along with his wife. In order to preserve the identity of the individuals, a number from 1 to 28 was assigned to each individual. Twenty-five of the subjects had prostate cancer with the exception of subject numbers 23, and 24 who had surgery for probably benign prostatic hyperplasia (BPH); however, I am not sure because these men could not tell me. Subject numbers 1, 2, 7, 17, 18, 19, 21, 25, and 26 (total of 9 subjects) were interviewed at the support groups after the support group meeting had ended. Subject numbers 3, 4a, 4b, 6, 8, 9, 11, 12, 14, 15, 16, 20, 22, 23, 24, and 28 (total of 16 subjects) were interviewed at their homes. Subject number 20 was interviewed along with his wife. Subject 4a and 4b were interviewed together at the same time. Subject number 22 was recruited while sitting at an urologist’s office. Subject number 5 was interviewed at a Canadian Cancer Society Centre. Subject number 10 was interviewed at a restaurant. Subject number 13 was interviewed in a private office at his workplace. Almost all of these interviews were between half an hour to an hour long. By the location of their residence, a total of eight different municipalities from the province of British Columbia, Canada were represented by these men. These men were recruited by making visits to six support groups in different municipalities, by leaving study questionnaires at two urologists offices in two different municipalities, and by attending a provincially organized “Do it for Dad run” at a park in Burnaby, British Columbia. From all the individuals that wanted to be interviewed, these individuals were
randomly selected for interviews (with the exception of making active efforts to recruit men from the South Asian and Chinese background in this study). With participant’s consent, the interviews were audio-taped and transcribed. From these twenty-eight individuals, three of them declined to be audio-taped but agreed to have notes being taken during the interview. Most of these individuals also completed a questionnaire either prior to or after being interviewed. A summary about the background of those individuals that was sent in a questionnaire to me is also included in the results section. None of these individuals expected to be paid anything because they were told that the participation was totally voluntary and without any remunerations; however, in appreciation of their time, most men were given a small gift of a bouquet of flowers (up to a maximum of $10 worth) after the interview. All of the individuals were very welcoming especially when I interviewed them at their home, and at five of these individuals’ homes, I had either tea or soft-drink after the interview. Therefore, the comfort level of the individuals was very high as almost all of them had met with me previously either at the support group, urologist’s office or at the “Do it for Dad” run.
Participants that completed the psychological scales (quantitative part)

A total of ninety-two subjects participated in the quantitative part of this study. Because there was partially missing data for about four individuals, the following results are based on eighty-eight individuals only. Those who identified themselves as Caucasian / White, were 95.7 % of these participants. Further, 75% of these individuals were born in Canada, and the other 25% were born in eight different countries. The present residence of these individuals was from five different provinces in Canada (Alberta, B.C., Manitoba, Ontario, and P.E.I.) and at least eighteen different municipalities were represented.

Fourteen different heritage cultures were represented in this data, and 75.9 % of these men indicated that their heritage culture was North American. The variation in age was from forty-eight to eighty-nine years old, with a mean age of 68.06 (SD=7.940). The number of participants that did not participate in any religious activities was 30.7 %. Moreover, 48.9% of the participants had some university education, and there was quite a range in socioeconomic status. Further, 94.3 percent of the participants lived with a spouse or a partner. The divorce rate in this population was 6.8 percent. Majority of the individuals had two to four children, and 74% had retired. There was also quite a range in diagnosis time, ranging from less than six months to since ten years. Seventy-four percent of these individuals had localized cancer.

In these individuals, 81.8% of them had someone from their family or ancestry diagnosed with some kind of cancer. Over sixty percent of the individuals also had other medical conditions along with their prostate cancer. Most individuals, 95.5% of them,
attended a support group. Diet, environment, stress and genetics were cited as the causes of prostate cancer by these men.
Also, a total of 223 surveys were distributed. This thesis was based on the first ninety-two participants that had completed their surveys. Surveys were distributed in three urologists' offices in different communities in B.C., and they were also hand delivered to prostate cancer patients in the Province of British Columbia localities of Mission, Abbotsford, Vancouver, North Vancouver, Surrey, and Coquitlam. Moreover, surveys were mailed to one group leader in Calgary, Alberta; one group leader in Winnipeg, Manitoba; one group leader in Prince Edward Island; and one group leader in Toronto, Ontario. Individuals came from municipalities throughout British Columbia to attend the “Do it for Dad” run. Questionnaires on a volunteer basis were also handed out at a provincial “Do it for Dad” run in Burnaby, British Columbia. Considering that the study was done during the months of July and August, many support groups did not meet during these months and the ones that met had a dwindling membership. This dwindling population allowed me to pass along my questionnaires to various localities throughout Canada, thus making this study national to a large extent. In the urologists' offices, all the patients had access to the questionnaire if they wished. However, in the support groups, the questionnaires were only given to those who asked for them. I took about ten minutes from each support group’s time to introduce myself and my study, so that the men would feel comfortable about completing these questionnaires. Postage-paid envelopes were provided in which the individuals could mail the completed questionnaires at my home address.

Each questionnaire included instrumentation (psychological scales) and demographic information. Individuals could also check a box on the questionnaire if they also wished to do an interview with me. Demographic and background information that
was provided by the participants was: nationality; birth country; present city of residence; heritage culture; language spoken at home; age; religious preference; extent of participation in religious activities; marital status; whom the individual lived with; number of children; whether the individual was working or not; diagnosis date; stage of cancer; PSA level; Gleason score; metastasis disease; treatment for the first time or for a recurrence; kind of treatment and when it was received; kinds of medical conditions; any family member or ancestor diagnosed with cancer; attendance at a support group; kind of benefit perceived from a support group; smoking and drinking habits; use of alternative treatments; use of internet for finding out more about prostate cancer, and what these men considered to be the cause of their cancer. Socioeconomic status was assessed by using total family income and by an individual’s education.

This study utilized the mixed method design involving the long interview method (McCracken, 1988) and standardized psychological instruments. While it is important to study men with prostate cancer on normative measures it is also important to describe from the perspective of their experiences and the complexities of their coping with cancer. Combining quantitative and qualitative measures can enrich research, particularly in this context in which meaning and symbolic content are likely to be at the heart of the psychosocial sequelae. Use of both quantitative and qualitative measures also allowed for data “triangulation,” which improves credibility of qualitative data.

The surveys were hand scored, and the data was entered on SPSS 9.0. After the initial data was entered, it was rechecked by another Graduate student for its accuracy.
Along with descriptive statistics, correlation and linear regression analyses were carried out to evaluate the hypothesized relationships.
Analyses of the data

Creswell (1997, p.54) states that Phenomenological research involves long interviews and data is collected with informants ranging in number from five to twenty-five. The completion of categories and generation of themes can be reached with ten to fifteen participants (McCracken, 1988); however, the emphasis in this study was to recruit as many participants as possible, yet I was limited by my finances. First data extraction in this study was descriptive about the various themes that emerged related to the research questions asked. Taped interviews from the subjects were transcribed and then rechecked by another Graduate student for accuracy. Significant statements related to the research questions were extracted from these transcripts. Meanings were formulated from these significant statements. These significant statements were arrived at by carefully reading and reflecting about the statements that prostate cancer survivors made in the original context. The aggregate of formulated meanings were further organized into clusters of themes, and presented as a summary statement. These themes were then referred back to the original transcripts to see if there was any description in the original that was not accounted for in these cluster of themes. For each research question, an exhaustive description of the phenomenon (experiences of surviving cancer) was produced with all the examples from the narratives provided by the subjects. This summary of the phenomenon focused particularly on the commonalities present in the themes. All of the statements made by the individuals were kept intact so that these individuals’ comments would not be taken out of context. Keeping the statements of participants intact has the benefit of allowing other researchers to either verify the findings of this study or reach
their conclusions based on their own world-views, thus minimizing any bias in interpretation of the results.

Interrater reliabilities were also carried on the categories and items for each interview question by another graduate student. This graduate student was provided with all the statements and categories including items (categories with less than 3 responses) and asked to place the statements under the category or item that fit that statement the best. If a statement could not fit a category, the graduate student was asked to put that statement on the side for discussion. Interrater reliability was calculated by dividing the statements that we both agreed upon should go under a category by the total number of quotes in that category for each question. The interrater reliabilities are summarized below:
### Interrater Reliabilities

<table>
<thead>
<tr>
<th>Interview question or statement provided by the respondents</th>
<th>Percentage Agreement</th>
</tr>
</thead>
<tbody>
<tr>
<td>In coping with your prostate cancer what would you say has been the most difficult or stressful part for you?</td>
<td>91.7</td>
</tr>
<tr>
<td>Coping with one’s cancer can refer to the mental, physical, emotional or spiritual part of a person; please tell what helped you in dealing with your cancer?</td>
<td>92.3</td>
</tr>
<tr>
<td>With respect to surviving your cancer, have you ever compared yourself to others who might be better off or worse off than you?</td>
<td>84.6</td>
</tr>
<tr>
<td>Please describe for me what your prostate support group has meant for you?</td>
<td>86.5</td>
</tr>
<tr>
<td>What improvements, if any, do you think need to be made to the medical services and/or other support services that are provided for individuals with prostate cancer in your community?</td>
<td>93.3</td>
</tr>
<tr>
<td>What do you see as some of the challenges in running a support group?</td>
<td>100</td>
</tr>
<tr>
<td>Positive aspects of the current medical and support system for treatment of prostate cancer mentioned by individuals in this study.</td>
<td>93.1</td>
</tr>
<tr>
<td>Advice provided by the survivors for other individuals with prostate cancer.</td>
<td>100</td>
</tr>
<tr>
<td>How priorities in life have changed for these men.</td>
<td>84.6</td>
</tr>
<tr>
<td>If having cancer has changed your relationship with family members, how has your relationship with family members changed?</td>
<td>100</td>
</tr>
<tr>
<td>Categories and items under the title of “Two Punjabi individuals who did not have prostate cancer but had prostate difficulties.”</td>
<td>100</td>
</tr>
<tr>
<td>Suggestions for improving the system</td>
<td>100</td>
</tr>
</tbody>
</table>
Flanagan (1954) indicated that the categories should attain a score exceeding 75% agreement. All of the above mentioned categories surpass Flanagan’s criteria.

Furthermore, I wanted to calculate what percent of the group had used each category. However, this percentage would not have been meaningful because a few individuals had made statements that were put into more than one category under each question. Therefore, I was only able to state the ratio related to the number of individuals that had used a category over the total number of individuals that responded to the question from which that category was derived from. A ratio for each category is presented in brackets after that category.

In addition to the above analyses, zero order correlations were carried out between variables such as coping, religion, social support and posttraumatic growth. Also, multiple regression stepwise were carried out to find out which models best account for posttraumatic growth and the quality of life of these individuals with prostate cancer.
Psychological scales used in this study

CES-D (Centre for Epidemiologic Studies Depression Scale)

The CES-D scale (Radloff, 1977) was developed to measure depression, and is considered as a good depression and generalized disorder measure (Roberts, Vernon, & Rhoades, 1989). This scale is widely used in health care and medical research (Servellen et al., 1996). This scale consists of 20 items, and measures distress over the past week on a 4 point Likert scale. The Likert scale scores ranges from 0 (rarely or less than 1 day) to 3 (most or all of the time, 5 to 7 days). This scale has an internal consistency from .85 to .90, and a test-retest correlation between .45 to .70 (Radloff, 1977). CES-D’s concurrent validity is moderate with other depression measures ranging from .44 to .54 (Radloff, 1977). This scale’s scores have accurately distinguished between psychiatric hospital patients and patients’ in the general population. Structural equation modeling has revealed four factors in the CES-D: depressed affect, positive affect, somatic/vegetative symptoms, and interpersonal. CES-D also had utility in measuring depressive symptoms in a multicultural sample (Roberts et al., 1989). The above findings indicate that CES-D is a reliable and valid scale for measuring depression.

Duke University Religion Index (DUREL)

DUREL was developed by Koenig et. al. (1997). It measures three areas of religiosity: organized activities (synagogue or church attendance); unorganized activities (meditation, prayer or bible study); and intrinsic values (life directing values). DUREL was created to measure adults’ religious and spiritual activity, and has been used with medically ill and
psychologically distressed individuals in the Southeastern U.S. (Koenig et. al., 1998). DUREL has five items with the first two questions measuring the extent to which an individual participates in organized and unorganized religious activities. The last three items measure intrinsic values. The first two items are answered on a 6 point Likert scale: 1= more than once a week, and 6=never. The first two items of this scale were administered to seven thousand people in North Carolina between the ages of 19 to 90. These items are considered to be good indicators for organized and non-organized activities (Koenig et al., 1997). The intrinsic items are answered on a 5 point Likert scale where 1=definitely true of me, and 5= definitely not true. These last three items were chosen from the Hoge (1972) intrinsic religiosity scale based on the factor analysis. The 10 items of the Hoge scale were administered to 455 medically ill older patients in a southeastern United States hospital, and the three items with the highest loadings were selected for the DUREL scale. The 3 intrinsic value scale items are highly related to the Hoge scale with r=.85, and have a Cronbach’s alpha of .75 thus indicating good internal reliability (Koenig et al., 1997). When the scores are reversed on this scale, the higher score of 27 indicates higher religious resources.

Sense of Coherence Scale (SOC)

The SOC was created to measure the degree to which people believe their life is manageable, comprehensible and meaningful (Antonovsky, 1987). The original scale had 29 items; however, the scale was later shortened to 13 items. The 13 item scale was used in this study. The sense of coherence scale has been used throughout the world including cancer patients, Israeli soldiers and undergraduate students. The internal consistency reflected by the Cronbach’s alpha ranges from .84 to .93 (Antonovsky, 1987). The
Criterion validity of this scale was established on 122 psychiatric outpatients and 334 community residents (Sammallahi, Holi, Komulainen, & Aalberg, 1996). The sense of coherence had a negative correlation with depression (r=-.78). The sense of coherence has been administered to Native Americans and Anglo-American students in North Dakota, United States, and therefore has been applied to culturally diverse populations (Bowman, 1996). Its internal consistency was found to be between .79 and .90 with test-retest correlations ranging from .81 to .90 (Languis et al., 1992). Siegel (1990) recommend the 13 item scale for adults with cancer, and it has been used with cancer patients (Forsberg et al., 1996). The test-retest of the SOC was based on community residents who were 75 years and older, and found to be r=.87 (Steiner et al., 1996). Thus, it can be used with older individuals. Coward (1996) studied the concurrent validity of this scale using a sample of 152 adults. The sense of coherence scale was highly correlated with Cumbaugh and Maholick’s (1964) Purpose in Life Inventory (r = .73), and negatively correlated with emotional well-being (r = -.65). The internal consistency of this scale based on the Cronbach’s alpha ranges from .76 to .81 (Klang et al., 1996). The scale consists of 5 comprehensibility items, 4 meaningful items and 4 manageability items. The score on this scale can range from 13 to 91, with a higher score indicating higher sense of coherence.

Life Orientation Test (LOT-R)

Life orientation test is used to assess optimism versus pessimism, and is a ten item scale (Scheier & Carver, 1985). An example item is, “I hardly ever expect things to go my way.” The response choices for the scale range from (A) “I agree a lot” to (E) I disagree a lot. LOT-R has an internal consistency with Cronbach’s alpha of .78(Scheier & Carver,
Coping

The Brief COPE (Carver, 1997) is an abbreviated inventory of coping, and has been used extensively in research examining coping with stress. This scale has two items per each coping factor (e.g., active coping, use of emotional support) and was reduced from its previous version because the previous version was not very useful in health situations. Brief COPE has been used in research in individuals with breast cancer, and a community sample recovering from Hurricane Andrew (Carver, 1997). The Brief COPE has the following factors: self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioral disengagement, venting positive reframing, planning, humor, acceptance, religion, and self-blame.

Mental Adjustment to Cancer Scale (MAC)

Mental Adjustment to Cancer (Watson, Greer, & Bliss, 1989) provides information about factors related to adjustment to cancer. The dimensions measured by this scale are: fighting spirit, anxious preoccupation, helpless/hopeless, fatalism and avoidance. Ratings on the MAC scale are made on a 4 point scale ranging from “Definitely does not apply to me” (1) to “Definitely applies to me” (4). The MAC scale was normed on a sample of 400 patients from the Royal Marsden Hospital in the UK. The validity of the MAC scale was established by comparing the scores of patients with their spouses. Significant correlations were found between the patients and their spouses’ scores. The validity of the MAC scale was further tested by comparing the scores from the scale with clinical
ratings, and a high agreement (Kappa=.72) was found. Test development sample consisted of various types of cancer ranging from breast to male G.U. Mean age of the test development sample was 56 years.

The Functional Assessment of Cancer Therapy-General (FACT-G)

Cella et al. (1993) developed the Functional Assessment of Cancer Therapy scale. This scale is a 34 item Likert-type generic Quality of Life (QOL) measure. It mentions four dimensions of QOL: physical well-being, social/family well-being, emotional well-being and functional well-being. The functional well-being included statements as: I am able to work, I am sleeping well, and I am enjoying the things I usually do for fun. A 12 item prostate-specific (FACT-P) subscale was also included to have specific questions related to men with prostate cancer. Both the FACT-G and FACT-P have well-established reliability and validity (Cella et. al., 1993; Esper et al., 1997). The Cronbach alpha for all of the subscales is .89. The content validity of this scale was established by checking with the patients and oncologist specialists. The construct validity of this instrument was checked by Pearson correlations with several other scales (FLIC: functional living among cancer patients, r = .79; and Mood Distress r = -.68). The readability of the scale is at a grade 6 level, and it has been translated in 8 different languages. This scale yields a total quality of life score, that includes FACT-P score. One could also have a total score for each of its subscales. The current version (4.0) was used in this study.

The Posttraumatic Growth Inventory (PTGI)

The PTGI was developed by Tedeschi and Calhoun (1996). This scale was developed to measure posttraumatic growth after an individual experiences trauma. Based on the review of the literature, originally 34 items were picked to reflect on the kind of benefit
that was cited in the literature. Based on the Principal Components Analysis 21 items with highest loading on the five factors, with eigenvalues greater than 1 were selected. These items accounted for 62% of the common variance. The factors were: Relating to others, New Possibilities, Personal Strength, Spiritual Change, and Appreciation of Life. These factors showed a substantial internal consistency ranging in alpha of .67 to .85. There was a Pearson correlation of .98 between the reduced 21 items and the original 34 items, indicating that original information was not lost. The Concurrent and Discriminant validity of this scale was established on undergraduate students by giving them several other personality measures such as: social desirability, NEO Personality Inventory, and Optimism (Life Orientation Scale). The PTGI was not highly correlated with social desirability; however, it was moderately correlated with the personality measure. The PTGI also was positively correlated with optimism and religiosity. The Construct validity of the scale was established by comparing the extent of trauma with perceived benefit amongst Psychology students. The findings showed that individuals experiencing severe trauma reported more benefits than those who did not (Tedeschi & Calhoun, 1996).
CHAPTER 5
RESULTS

Background information about persons that participated in the interviews

Note: All of the following examples use the exact words presented by the men with prostate cancer, my own words for clarification purposes are used only in square brackets. After each example, each person's coded number is given at the end of each example [in square brackets], should someone wish to see how each individual made comments throughout each of the categories. A category was defined as 3 or more individuals making comments with the same theme in their content. When it was less than 3 individuals that made comments in a particular area, that theme was defined as "items" to distinguish it from a "category." The coded number for the qualitative data do not correspond with the code number assigned to individuals in Appendix O because not all the individuals that completed one on one interview also completed a questionnaire. Information about individuals from the South Asian and Chinese background is presented in the italics so that any analyses related to cultural aspects will be easy to carry out.

Moreover, usually the tendency in qualitative research is to cut up the qualitative quotes, and to put them into various subcategories, while leaving out some information that is not pertinent to those subcategories. However, the more I read through individuals' quotes, the more it made sense that things should be taken in their context. I may not see the value of the information that I have left out but an individual who has prostate cancer might. That individual may be interested in the whole story of the person that is presented in the qualitative data. Therefore, I did not cut up people's quotes, and kept them intact.
Keeping quotes intact also has the benefit of different researchers having same access to the data that I did, and this way they can verify the validity and reliability of the information for themselves. For example, person ‘10’ stated that his family relationships had not changed at all but then he went on to talk about how he spends more quality time with his family now then he did before. As a qualitative researcher, I could have taken his first sentence only that there was no change in the family relationships and left all of his other information out. However, I believe that would not do justice to qualitative research. One has to take all of the information in to a “broader” context.

Secondly, another norm in qualitative research is to present only one or two examples from a category, and tell the number of occurrences of similar examples in that category. This assumes that all the other examples are exactly similar to the examples presented by the researcher, and thus there is always some bias on the part of the researcher to choose the examples he/she wishes to choose. Let me illustrate this with the following two examples that talk about the stress of deciding which treatment to choose for prostate cancer:

Example 1: The most stressful time, I would say was trying to figure out exactly what to do, and the doctor gave me a lot of information, not as much as we give out now but, my wife, she went through all the sites on the computer and everything. We pulled everything off, we read it all, together, and we made the decision together too which is a really important thing. We decided to get it taken out even though I knew I’d be in full impotence and I’d have problems with incontinence. Luckily I don’t have any problems with incontinence at all, so, but that was the most stressful thing, I think. I phoned up my uncle, who is a doctor, and he said, what decision did you make, and I said, I decided to have it taken out. He said, good, you do that. He said, I wish I had. He had had prostate cancer and I didn’t know it and he said he just left it in. Now he said he wishes that he’d had it taken out. So, I made the right decision there. [5]
Example 2: Dealing with the medical establishment and with family and getting my family to accept my approach and getting support from the medical establishment for my approach, and the medical establishment wanting me to proceed without giving me, what I consider enough information. In fact, the medical establishment not having enough information within themselves on which for me to make a good decision. [7]

Just to say that both of these individuals in the above two examples felt stress in regards to their medical treatments, leaves out lots of important information. For example, in the first example, the individual had lots of support in making an informed decision and agrees with his decision. In the second example; however, the person has not even made up his decision, and his feelings highlight the stress that is there in his family. He is also stressed out about the medical community not having information themselves on the first place.

Information about the subjects that participated in the interviews is presented in Appendix C.

Interview Questions:

The following section provides results to the interview questions. Please note that only one example comment from each category is featured here in this section; additional comments are contained in the appendices.
Question: In coping with your prostate cancer what would you say has been the most difficult or stressful part for you?

Category: Diagnosis (ratio of the group that used this category: 3/20).

Summary of the comments found in this category: Individuals in this category found the diagnosis to be most stressful. Specific comments of individuals were: when I was told bluntly and brutally that I had cancer, I burst out into tears [14]; it was stressful when I first heard of the news [19]; initial first few weeks were very hard [25]. Only one selected example is featured here. Full comments from which this example is drawn are contained in the appropriate appendix (see Appendix D).

Comments made by individuals:

[What has been the most stressful part for you?] When I was told very bluntly, very brutally that I had cancer and sent out into the street in minutes, by myself, I burst out in tears. So that was very brutal and I discovered it by accident and the doctor says, oh by the way you have cancer, so I don’t need to look at you at this time, you need surgery so we’ll make a reservation for surgery. When I discovered I had cancer, I was very upset because this tumor, I had for nearly six years and then I’d been monitored strictly by DRE during those six years, once a year, and when I suggested, after three years, that we do a PSA test or some other ways we could find out if those tumors were evolving or not, I was told that it was unnecessary and it had grown to the size that was significant enough that my general practitioner said, well now you should have the test and the test revealed that the tumor had become extremely aggressive, the cancer was as aggressive as they come. It scored 5 over 5 at one time and 3 over 5 at another, and that’s, it was growing right into the edge of the prostate and was bursting out and that’s why I was so mad at the system because that could have been detected years before, if they detected it was cancer, it could have been picked up a year or two before. They could have reduced the risk considerably. [Simply by doing the PSA test?] The PSA test and CT scan. At the time, I was not a resident of Canada, therefore, it was at my cost and I understand that the doctor would be reluctant to send somebody to the hospital to have expensive procedures, and x-rays and a CT scan which requires a lot of manpower and a lot of equipment and burdens the system, but the PSA is just a blood test, $30, done at a private lab and I pay for it. It’s my life. I even asked for it but I’m told not to do it. What is she was trying to do, save me $30. So, I guess they thought it would burden the system when it is
not necessary, but $30, it just doesn't make any sense to me, especially when I'm paying for it. So I was mad at the system, I was mad at this doctor, I was mad at, this doctor when she eventually got the result that I received, she got it and never told me I had cancer. That's my GP and the urologist who did the test at her request, found out that I had cancer and he didn't tell me either. So I went on for about, everyone knew I had cancer except me, the GP and the urologist. One day I go back to the urologist at the end of the holidays because he said he wanted to have a look at my bladder, and I come in there, and he said, I don't need to look at it, you have cancer, you have to go to surgery, I will see you on the table. It was too much, and that's when I was out on the street and when I complained to the college. So I filed an appeal with the college and they said, well yes but when we look at it the second time, we think they should have told you that you have cancer. I said, I find this peculiar. So anyways, I'm still mad at the process, at the system, the GP in general and the whole system they seem to be protecting each other. I come from a family of four generations of doctors on one side and three generations of doctors on the other side so I know when things go wrong, my problem is not with the errors with people make, because they will make errors, but it's the fact that they deny making the errors and they are not going to do anything about it, what happened to me. So the next guy who goes to this GP will be treated the same way and their tumor will blow up and it will burst and they will die. I got my, if an error is committed, I have no problem with that as long as it's recognized as long as they apologize and fixes it. [What do you think, if anything, could be done to improve the system?] Well I think the college should be more responsive to the needs of the patients. The problem that the college has is the patients in North America tend to sue. They don't sue as much in Canada as they do in the States, but they sue everybody, so the college is trying to protect its physicians but I, I told them that I had absolutely no interest in suing anybody that's not type. Where I come from in Europe nobody sues anybody, so I would write it on paper, and write it down and confirm it and you know, there's no legal action, I just want the system to improve, and ah, so I think the college, the one that discovered this error should have written to? especially when the patient is paying for this see them once in awhile to make sure the patient keeps the cancer under control. When you have a tumor, you know it's going to grow, the question is when. But apart from that, the treatment I received at the hospital, I would have had to, so there was a little problem with this GP and I think she, because it's a woman, who deals mostly with women, she probably doesn't know that a prostate cancer can be very aggressive especially if it's in a young man. So, that GP needs training. So it's lack of training of the GP. Lack of recognition from the board, the college, they should be attentive to people so that they approve the system, and also, I think the urologist should have taken the time to tell me what this cancer is all about and what options I had, if any, but the man is a surgeon, a highly respected surgeon, and he just said, well you have cancer, you need surgery and I'll make an appoint and you come back in and have the operation. I want to deal with this cancer, I wanted to know what it did or what implication, or where, in the prostate and what it was used for, and I would have liked to be able? and finding out more about and finding out that there are other options besides surgery. [So you didn't?] I didn't know anything about it and I was in such a
shock that I did the surgery and that I didn’t have a choice but to go through surgery. I had to wait four months before I went to surgery, and ah, I have to say, I’m very happy with the surgeon. I don’t like? but I’m still around. The other thing that particular surgeon, when I was told I had cancer, but the day after surgery, he came back to see me at the hospital and I was doing fine, it was a result of the biopsy, so he told me how bad it was. It was very, extremely aggressive right to the edge and ready to bust, and I asked him how long would I last and he said about a year and then he said, goodbye and he went away and that was it. So I was left, I was barely beginning to recover and was told that I would probably be dead in a year from now. [After your surgery?] Yah, this was after the surgery, on average a year and half, but I know that it’s only an average but still, so that doesn’t help with the recovery. I think his bed-side manner has a little bit to be desired, but apart from that he’s a very respected prostate surgeon, urologist. He obviously did a good job because, it’s nearly five years ago and later, I’m still around and still kicking and in good shape, and as far as I’m concerned the cancer is out and I’m very happy about it. [At what point did you find about this support group?] This what? [That there’s a support group.] The support group. I don’t remember. It was after the surgery, long after, much after. [So, you didn’t know anything about it?] No, I didn’t know anything about it. So, I didn’t know what options I had, I didn’t know whether he was a good surgeon or a bad surgeon. I didn’t know who to come ask. I thought if I went to the hospital and asked if he was a good surgeon, they would say, well of course, otherwise he wouldn’t be here, you know that’s what they would have been telling me. I wouldn’t even know, so I don’t know when I knew about the support group, it must have been at least six months after surgery, a long time after, and at the time since I’d been told by the other gentleman, a year and a half, I went to Klaus because the regular one, and you went for advanced prostate cancer, because I thought I was part of a category like that and they after a year I went for a test and realized the PSA level was undetectable. So I didn’t go to the advanced anymore but I still go to the regular meeting so it was nice to meet those guys. No, my main concern with this is the system, again, it was my background with a doctor, and knowing that problems do occur, they make errors, they are tired, or thinking of something else, it’s human, that’s not the problem, but to refuse to admit it, that’s what bothers me. I’m not judging her because it was her fault, I mean incompetence and arrogance of doctors it’s not a matter that the medical profession does not yet protect each other, but apart from that, it’s been a very rewarding experience, a very enjoyable experience. I’m very happy that I went through this experience. I feel much better now. It’s very positive. [14]
Category: Get the cancer out (3/20).

**Summary:** Prior to their treatment, it was stressful for men to have this cancer.

Each person had the anxiety that the cancer is inside, and he wanted to get rid of this cancer. Specifically, the most stressful part was: “It’s in there, get it out [1]; “get rid of it” [4a]”; “I couldn’t stand the thought of having it in my body.” [4b]

**Comments made by individuals**

It’s sort of a big shock when you find out you’ve got the Big C and the first thought that comes into your mind is that, look, I’ve got to look after this and get rid of it and that was my thought as well. [4a]

Category: Deciding which treatment to choose (7/20).

**Summary:** Deciding which treatment to choose was a stressful part of dealing with prostate cancer for many of these men. Specifically, these aspects were stressful: trying to figure out what to do [2, 4a, 5, 8, 15, 16], and the medical establishment doesn’t have enough information within themselves on which I can base a decision. [7]

**Comments made by individuals:**

The most stressful part was deciding on the therapy that I would use both at the primary stage where I decided after a lot of consideration to go with the radical prostatectomy, um, after that it was almost obligatory that I move on since it wasn’t successful, I’d move on to radiation and following that, move on to hormonal therapy. [2]
Category: Having the catheter / incontinence (8/20).

Summary: After treatment, many men found it difficult to carry the catheter. Being incontinent was also found irritating because of having to wear pads. Specifically, the following aspects were stressful for these men: catheter hanging down one’s leg at home is uncomfortable [1]; not being able to control urination is difficult [6]; experiencing incontinence is stressful [11, 13]; getting a good flow of urine is stressful [12]; limited bladder control and wet pants [16,22]; wearing an incontinence pad. [18]

Comments made by individuals:

Most stressful thing in the next 10 to 13 days [after surgery] is when you are at home with the catheter and that catheter is dangling down your leg and it’s a very uncomfortable, not painful, but it certainly is uncomfortable. When the catheter comes out, it’s a period of time of incontinence. In my case, I’ve always had an incontinence problem and I would think that that is the single most irritating thing. Now it’s more like a slow drip, okay, so it depends on what I’m doing. If I’m just sitting here, I don’t need any protection, if I’m going for a walk I need mild protection and if I’m going to be involved in any kind of active sport, I’ve got to have more full protection. Incontinence is the biggest problem followed by impotence. [1].

Category: Erectile dysfunction or not being able to have sexual relationships (7/20).

Summary: Some individuals felt that they did not feel like a man if they couldn’t have an erection. Some also were stressed because of the lack of sexual activity or any sexual relationship. Specific comments made by these men were: not being able to have an erection was stressful [1,22]; sexual aspect was an important part of my life prior to diagnosis [6]; virility has diminished [9]; sexual inactivity is difficult for me and my wife [11]; I am sorry to miss my sex life but I have a good relation with my wife anyway. [12]
Comments made by individuals:

But inactive sexual ability that’s a big problem too. It frustrates me but I think it is more frustrating for my wife. [11]

Category: Not knowing if cancer has been cured or not, and /or whether or not I will live (6/20).

Summary: Whenever any pain was felt, these men found it stressful to wonder whether the pain was related to their cancer or not. Also, there was uncertainty as to whether or not the cancer had gone. Some individuals at an advanced stage of the disease worried about dying. A summary of the specific comments made in this category were: not knowing whether I will live or not [3, 9]; it is stressful not knowing whether or not the cancer is gone [10, 15, 26]; and I am worried about what will happen to my wife. [17]

Comments made by individuals:

Well, I guess the stressful part is the uncertainty about whether the treatment is successful and will continue to be successful. It’s an ongoing stress even though I’ve got pretty good assurances that it’s under control, you never know for sure. [15]

Item: Uncertainty around the procedures at the hospital (1/20).

Summary: It was stressful for this individual not knowing about the treatment procedures that he would be going through at the hospital.

Comments made by the individual:

The uncertainty of not knowing what exactly the procedure would entail that I would go through. I’m an engineer by background. I like to know things and I’ve been very fortunate that I have been very healthy, and ah, I really don’t know, didn’t know a hospital from the inside and everything that is, kind of, very normal to the urologist and the nurses, to me was all new, and the uncertainty of that, to me, was the most stressful thing, and ah, as I said in my little write up, going to the support group, I was able to connect with people and there’s one specifically and we’ve become friends now, we are now socializing together. He went
through this three years ago and I was able to ask him a lot of very personal and very direct questions as to, you know, what’s happening when you get into the hospital and you know, etc., etc., all the little steps and it helped me tremendously to learn, but it is still a different story going through it, you know. So, to me the unfamiliarity and the newness of what I had to go through, to me, was the most stressful part. If, what you possibly expected, you know the fear of dying or so, it never entered my mind. I did a lot of, like I say, I’ve a need to know, I did good reading, I got the two reading books that are on the market, I found the information from our boys very helpful, and um, I read all kind of other stuff on the internet. Eventually it’s information overload. You know there’s just too much out there, but I convinced myself, I became very quickly convinced that this is something I have to go through but it doesn’t mean that’s the end of life. So that is not something that caused me stress, rather the unfamiliarity I’d identify as my biggest concern. [6]

Item: Stress of travelling (1/20).

Summary: With External Radiation, this individual experienced burning and pain.

It was difficult for him to travel for 45 kilometers to Vancouver each day for his radiation treatment.

Comment made by the individual:

One of the stresses was the trip to Vancouver every day, almost every day for six weeks, 32 treatments. After the 10 treatments [external radiation] or so, it started to really hurt, burn. [4b]
Question: Coping with one’s cancer can refer to the mental, physical, emotional, or spiritual part of a person; please tell me what helped you in dealing with your cancer?

Category: Having control over the illness by educating oneself, by accepting it, or by having a positive attitude (7/26). (For additional comments see Appendix E)

Summary: Researching different treatments provided a feeling of control for some of these men. By investigating their treatment options, they had the feeling that they were doing the best that they could do about their prostate cancer. Some of them were able to accept their cancer or develop a positive coping attitude towards it. Specifically, the following aspects emerged in this category: since I did some investigation, that gave me a feeling of control [2, 17]; it helped to understand what the disease was all about [8, 19]; accepting the disease made it easier on me [11]; I had a fighting attitude [13], and information gained from the support group saved my life. [16]

Comments made by individuals:

Well the first thing that helped me a lot, is to understand what it was about. I was ignorant of the fact, you know, and I learned from going to the cancer clinic and talking to different people at the cancer meetings we go to once a month. Understanding what it’s all about, that’s what helped me and helped me to make my decision. [8]

Category: Support from my wife, family and/or friends (14/26).

Summary: Men also spoke about their supportive and encouraging wives and families. They spoke about how some of their friends had been helpful to them. The following specific aspects emerged in this category: my wife was encouraging, capable and supportive [1, 2, 9, 20, 26]; I had a supportive family [4a]; my wife became the driver [4b]; having my wife agree with my decision
about treatment was helpful [5]; support from my friends at the support group was good [6]; support from friends was good [22,25]; I got reassurance from my doctor, family and friends [15]; my wife came with me to visit the doctor [19]; some relatives helped me with coping [21].

Comments made by individuals:

In my case, I had a very, very supportive family and they worked right along with me and ah, you know, I couldn’t have asked for anything better. [4a]

Category: My religious faith provides me with personal strength and with the ability to live day-to-day (12/26).

Summary: These men believed that God has been good to them. They believed that God is a good healer and has made it easier for them to deal with their prostate cancer. Specific aspects related to data from this category are: God can do miracles, and I have a very strong faith. God has sustained me [4a, 4b, 12, 18]; men that have faith in God cope much better [4a’s wife]; God has put me here to do some good [5]; God is in control of everything [10]; it’s been good to spend time with my God [11]; religion has an impact on one’s health [13]; support of my friends at the church has been helpful [15]; One gets to think about mortality more [25]; silent prayer with God has been helpful. [26]

Comments made by the individuals:

What has helped me most is my belief in God. I believe God is in control of everything. I believe that, I don’t know where you are in your religion but I know most people from India are different than my religion. I believe that God created the world, he sent Jesus Christ to die for our sins and I believe that I’m living my life as good as I can for God and when I die, I’ll go to heaven. So if I die when I’m 60 or die when I’m 80, I’ll just get there 20 years earlier and I’ll still go to heaven and that’s helped me a lot. That’s really helped me a lot. I like to stay here because I have five grandchildren. I’d like to see the grandchildren grow up, I’d like to see them graduate from school, I’d like to see them get married and things
like that so that would, I would hate to miss that but at the end of it all, I just see
them in heaven as well so ah, my father has passed away. I believe he’s in
heaven, so I’ll see him again. I think that’s been the greatest strength in coping, is
having this faith in God. I’ve always had that [religious faith]. No it [cancer]
didn’t strengthen or lower it in any way. What it, maybe, did was reinforced it a
little bit more and it made me realize that I am not the tough fellow that I thought I
was. You know, I thought I could handle anything, but I’m just as human as
everybody else, and ah, no that hasn’t changed. No I’ve always had my belief in
God, I always believed that Christ came to this world to die for my sins, and ah,
yah I still believe that, and I guess it just reinforce that a little bit. It hasn’t
changed it. [10]

Category: Prayer was important (6/26).

Summary: These men took time to pray for each other. Some individuals from
their congregation prayed for them as well.

Comments made by individuals:

We depend on our friends and our fellow Christians and their prayers, not only
here with our obligations but throughout North America actually. Friends in
Omaha and Arkansas, everywhere. We depend on that a lot. When someone gets
sick here, we run it home and everywhere and have a chain form and that’s what
happens. We depend on that. I’m looking at the building across there, it has a lot
of columns to support the balcony and what not. Well, that’s the same thing with
us and with everything, one column support is a prayer, the other column is a
support group, another column are your friends and so on and so forth and so a
whole bunch of columns are supporting you to work through what you want to,
not that you want to, it’s most unusual for any person to have cancer. You hope
that you never will have cancer but suddenly the doctor says, hey, you’ve got it,
and you go, What, me? You know, so you need all these columns to support you.
[4b]
Category: No major role played by religion (8/26).

Summary: Religion had not played a major part in some of these men’s coping.

Specific aspects in this category are: I do attend church but I am not devout [2]; I do not go to church and I am not a spiritual person [8, 9, 16, 22]; I believe in the Supreme Being but I do not go to church [17]; my religion is to treat others nicely.

[20]

Comments made by individuals:

Religion or spirituality? No, nothing [no role was played]. No, negative, no [I didn’t go to church prior to my diagnosis either]. [8]

Items: Cancer can be beaten with a life-style change or with one’s values and life experiences (2/26).

Summary: If proper diet is followed, and/or if one’s environment and moral values and beliefs are strong, then cancer can be helped or cured. [1, 7]

Comments made by individuals:

Other than that, I think it’s your lifelong experiences, okay. It’s your moral beliefs, your ethical beliefs, your religious beliefs that will take you through this [1]

Um, I believe that cancer can be cured. You got it naturally or for natural reasons and for the same reason you can cure it naturally. Once I get my environment, my total environment, as I improve my total environment, both the mental, physical and what I consume, I know that my body will start, my immune system will become stronger and I will heal naturally. Whatever fine may be, fine may be not surviving a long time but that’s just the way it’s going to be. It’s kind of just the way things happen. I’m here to live life and I’m not worrying about living x number of years with cancer, I’m worried about living well and um, doing what I can do so that cancer doesn’t make my life unbearable for the time I’m here. So I go to Shamanic healing as well, it’s one of the alternative approaches. I go about once a year. Well it’s basically, you know, like medicine man in the North American Indian culture, I think you probably have something similar to that in India. [7]
Items: Taking on a leadership role to counsel and help others in a religious setting (1/26).

Summary: This individual presented a seminar on prostate cancer, and tried to inform others about prostate cancer at a religious setting. [3]

Comment made by the individual:

I took an active part in the mosque because I am also Muslim and I got on the health board and I was actually put on a seminar on prostate cancer for the mosque and everything. So all of that empowers you, I think. Yes and I actually counseled them [some other individuals with prostate cancer at the mosque]. [3]
Question: With respect to surviving your cancer, have you ever compared yourself to others who might be better off or worse off than you?

Category: Downward social comparison / others have not done as well as me (16/21).

(For additional comments see Appendix F)

Summary: These men believed that others had not done as well as they. Specific aspects about the meaning of this downward social comparison are presented as follows: I learned from others’ experiences [1]; I had good success in my treatments [2]; I consider myself lucky [5, 19, 22, 26]; I am OK because treatments have not worked for others [7]; others may get into worse misfortunes, such as getting into car accidents, so this helps me to deal with the disease [10]; I support others who are worse off [11]; compared to others more worse off, I had little discomfort; I don’t want to have what they have [12, 17]; one feels a loss when he loses somebody because that person had something in common, but one feels lucky at the same time [13]; I came to the realization that there are individuals who are worse off than me or that I had it easy. [16, 20]

Comments made by individuals:

Yes, I do that [compare myself with others] all the time and I consider myself very, very, lucky to be one of the few that they caught it in time and I get to thank my doctor for that. He did the RI exam and digital rectal examination, and ah, he found a slight bump on it and ah, I had no big problems but I did have a few problems that I just thought was going along with old age, you know, coming up. And ah, so I look at the other people that are worse off, and I see them all the time, and consider myself lucky and blessed, as it were, and ah, just count my blessings. [5]
Item: **Upward Social Comparison** (1/21).

**Summary:** When this individual sees others doing well, he has a feeling of encouragement and well-being [3].

**Comment made by individual:**

Well the support group is actually what’s helped most of anything. Well in the sense that I’ve seen and dealt with other fellows in the same situation and I see them surviving and doing well and it gives me that kind of encouragement and a feeling of well-being and that’s helped the most of anything. [3]

Items: **Temporal Comparison** (2/21).

**Summary:** One of these men believed that losing his eyesight was worse than having prostate cancer [8]. Based on his past experiences, another individual thought of himself as a survivor and able to handle difficulties. [9]

**Comments made by individuals:**

My life is my wife, my children and my grandchildren. Those are my priorities and I’m glad I’ve got what I’ve got now, you know. Like you say, it was worse when I lost the eyes, that was the hardest part for me. The prostate cancer was like a breeze. Oh, yah, I lost them [eyes] about five years ago. That was the hardest thing for me to deal with. I consider myself quite lucky to be around, you know, for where I am now, you know, but I like hitting things straight on and then from there continue on with what I have to do. [8]

Yah, yah, you know really, the ah, I have really a whole lot of faith in the urologist that I and I had, the care in the hospital was super and um, I’ve survived so many experiences in my life that you couldn’t ever convince me that I couldn’t handle any problem that came along. I would deal with it, I’m a survivor, I would do it. [9]
Category: No social comparison made on my part (3/21).

Summary: These men believed that they did not make social comparison for their self-enhancement. Specific comments made by individuals in this category were: I have compassion for those that are doing worst off, and I feel happy for those that are better than me [9]; I only look at my situation that it could have been avoided altogether if I had a good doctor [14]; it may be difficult for someone with a lower socioeconomic status to handle it. [25]

Comments made by individuals:

I tried to and I have found that thinking of people who can be worse off does not really happen, whether they are worse off or better off, doesn’t help me so I, yah, I spend a lot of many years? that doesn’t help. [So you only look at your situation?] Yah, I look at my situation and I see that it could have been avoided all together with the proper diet and if the doctor had, at least, sent me to a support group or told me where I could get information but she was ignorant or an incompetent and secondly, once the cancer had started -unclear- so that was, I still have a hard time digesting it because the whole thing was not necessary. The proper diet and the surgery could have been done much earlier with, maybe, less damage and with a sure outcome because if the cancer is very small then the outcome is very straightforward. The whole thing was so dam unnecessary, and at the time, I thought I don’t mind dying as long as people know that it doesn’t have to be that way. [14]

Category: Comparison was made but everyone is unique and has difficulties at certain times (3/21).

Summary: These men believed that we all have our turn at bad times. A summary of the specific comments in this category were: everyone is hurting at one time or another [10]; we share the status of our PSA [15]; we are all part of the same group. [18]
Comments made by individuals:

[In regards to social comparison] In your mind you say, oh that poor guy or that lucky fellow. I guess I have, but everybody is unique, everybody is individual. I have to fight my battles, they have to fight their battles. I know last time there was a guy, there was a new fellow, you try to support him, you tell him, you know, it’s going to be alright and the treatments are good and stuff like that, ah, what was the exact question? I have [compared myself with others] but not that I feel sorry for myself or feel happy about myself, no, no I can’t say that. There are people that have tough times, there’s also people that have struggles with their kids and different things and everybody is hurting one time or another and so I can’t say I’ve every compared myself to others. There’s two kinds of people in the world those that are hurting and those that will hurt. Everybody is going to get their turn and I can’t say that I have compared myself to others very much, no. [10]
Question: Please describe for me what your prostate support group has meant for you?

Category: Getting to know people / emotional aspects (7/24). (For additional comments see Appendix G).

Summary: Men found it helpful to get to know other individuals at the support group. Specific aspects related to this category are: from an emotional aspect, support group has been good [1, 13, 20, 20wife]; there is always someone there to talk to or phone [4b]; I like the group, they do listen and you can ask them questions [8]; and I made lots of friendships at the support group. [16]

Comments made by individuals:

Well a lot of emotional support from other men that went through different types of treatment, okay. The support group will provide you with a lot of information about diseases about what to do about it, what will help you to cope with the different emotional, or psychological or physical or anything like that. As it was, how are you going to cope on your own and what do you do with it, and so, I think the support group has a very important function. That’s why the Canadian Cancer Society organized and supports the support group because they feel that they have a role to play. [13]

Category: Finding out more information to understand prostate cancer / reflective experiences (11/24).

Summary: These men believed that support group made them more reflective and they gained more wisdom from the guest speakers. Specific aspects from this category are: it has helped me in really understanding my cancer [1]; we have good guest speakers there [4a, 14]; support group provided me with technical support [6]; informational aspects and seeing how others are doing was good [7]; I am appreciative of the support group [9]; we get lots of information from doctor at the support group [11, 21]; they [support group facilitators] keep bringing
interesting information [15]; they provided information to confirm what I had
already read, and we got to exchange information with others. [26]

Comments made by individuals:

I think the prostate support has been crucial, you know in both the emotional, but
more in really understanding prostate cancer, in what it is, in the whole spectrum
of knowing what to expect, what to watch for. It can be depressing at times, I
mean, you know, you come here and there are no cures, you know, but most of it
is, it gives you, when I say depressing, I shouldn’t use that word, it should be, it
makes you more reflective, okay are there things you can do, such as, alternate
therapies like changes in diet where you start to know about antioxidants, are they
the thing. It’s not that you start reaching for straws and taking way-out medical
kinds of situations but it does let you know that, hey, your diet, for example, little
things that in the past 40 years, the amount of nutrients and vitamins in vegetables
have decreased by about 70 percent and so without taking vitamins or therapies
you cannot eat enough to feed the body what it would have got, say, just after
World War II. Little things like that [1]

Category: Helps us in coping (3/24).

Summary: These individuals believed that learning from each other’s experiences
helped them to cope better. Some key aspects that emerged in this category are:

it’s a good time to be able to get together and talk [4a]; it helps me in dealing with
my problem [8]; people tell me how they went through it and where to go from
here. [11]

Comments made by individuals:

Well, to me, it’s a good time to be able to get together and talk. We, sort of, split
up into groups and for those that have to go for radiation, that group will get
together, and the one’s that had surgery will get together. We, sort of, share with
each other our thoughts and our feelings and how we cope with it and get through
with it, and ah, I think that a support group is a very important fact in the overall
healing too of getting back on your feet as well.[4a]
Category: Life-style changes (4/24).

Summary: Some individuals had changed their life-styles because of their experience with prostate cancer. Some aspects that emerged from the interviews in this category are: now I eat more vegetables and take supplements [1]; I have changed my diet a bit [3]; I have changed my diet to a certain degree [7]; and I changed it a bit, yes. I eat more tomatoes, more broccoli and beans and you know.

Comments made by individuals:

Oh, I changed it a bit, yes. I eat more tomatoes, more broccoli and beans and you know. That I’ve changed too, I never hardly ever ate that stuff now I’m eating it eh, in fact, every time we go shopping, I insist we buy it and that I have changed, yes.[8]

Category: Helping others (9/24).

Summary: Some of these men believed that it was rewarding to help others by taking a leadership role in a group. Specific examples that emerged in this category are: it has given me a certain sense of satisfaction to help others, especially those that are newly diagnosed [2, 17]; just helping others is the biggest reward [3]; I get a deep sense of satisfaction by being able to share my experiences with others [5, 15]; I have been supportive towards others, and I wish I had that kind of support too [11]; I am in charge of bringing guest speakers; you have to become a whole model [13]; I find it productive and satisfying to take a lead role [16]; and I try to instill a positive attitude. [18]
Comments made by individuals:

Oh, well I think just the reward of helping people, I think is the biggest reward. To be able to talk to people, and ah, for instance, on their first trip into the support group they are always scared, terrified, and at the conclusion of the very first support, they go out feeling much calmer. So that's a reward, helping. [3]

Item: I have not attended support groups (1/24).

Summary: Prior to his treatment, this individual did not know that a support group existed. He was also not sure if he would have benefited by attending it; but, he is helping other individuals with prostate cancer now. [12]

Comment made by the individual:

I didn’t know about [prostate support group], and ah, probably, I suppose, I maybe could have helped others, in fact, right now, the person next to us, his brother is in [name of city withheld] and is going through this and there’s a bit of anguish over this so he talked to me about it and I phoned down to [name of city] and talked to this person and I found out from my neighbor that his brother is going to go through the operation, the surgery that I did. Now he had some concerns, both, sort of, sometimes you perceive something that is going to happen and it really doesn’t and so just talking it out is ah, has a therapeutic affect. So, yah, I don’t mind doing that. As far as going to a group session, I didn’t do it, didn’t know that there was anything such as that that existed, and ah, I’m not sure whether I would have gone. I really didn’t feel I needed that, but the thing is, maybe I could help someone else like I did here, then that’s a different matter too and certainly I’m willing to do that. [12]
Item: Find it depressing to attend the support group (1/24).

Summary: For this individual, surgery has not worked, so he finds it depressing to get pessimistic information at the support group. [10]

Comment made by individual:

I started attending probably September, October of last year. So, I’ve attended, I’ve missed one or two here and there so I’ve probably gone five times and the information there is always very good. It doesn’t always apply to myself and I always leave very depressed because there’s always somebody, one of the medical people or so that says, you know, 30 percent of the guys they live six years. This treatment works for most people but not everybody, and I find myself, a lot of times, the except group that they say, you know except this group or except that group, you know I’m in that group, you know, I was younger so that makes it worse. It got away outside the prostate, that makes it worse. Then they have this scale, you know, 2.6, 7, 8; I was 2.7. I was a high-risk group. I did not react to radiation and they say, once you’re through that, they can’t radiate again so when it comes back, there’s really no cure. I walk out of there every time with some of that kind of input and that, I find that very depressing. So I don’t want to go because I know I’m going to come out of there depressed, but I go because you can put your head in the sand and say, you know, it will be fine, but that’s not right either. I should be educated about it, I should find out more about it and I want to support the group as well, but there’s good information, but I always find it very depressing. [10]
Question: What improvements, if any, do you think need to be made to the medical services and/or other support services that are provided for individuals with prostate cancer in your community?

Category: Provide free PSA testing and encourage PSA testing (8/23).
(For additional comments see Appendix H)

Summary: It was these men’s opinion that PSA tests should be provided free of any charge at all since in the long run it saves government money. Specific aspects mentioned under this category are: PSA tests should be provided free for men just like mammograms are provided free for women with breast cancer [1, 5, 11]; all men should be given free PSA from age 50 [2]; they [the government] should pay for PSA tests [3, 13]; they should encourage men to take the PSA tests [4a]; they would save lots of money in the long run by encouraging PSA tests [4b].

Comments made by individuals:

Well the only thing we want the Ministry of Health to do is to allow men to have a free PSA test, and so far, maybe because of the trend, it’s not accepted, okay. We see that every woman can go and have a mammogram free after a certain age and we want men to have the same access. [13]

Item: Educate doctors about the importance of PSA testing (1/23).

Summary: Doctors need to be better advocates for prostate cancer. Too many physicians are poorly informed about PSA and some don’t believe in it. [6]

Comment made by individual:

Too many physicians are poorly informed. Get the message out there that PSA is strong indicator of potential cancer. I was turned down twice from testing. I would have happily paid $35 dollars if that’s what the issue was. Some other physicians
don’t believe in the PSA. When you are going to do the blood test, why not throw in the PSA anyway? Again, some doctors don’t believe in it. [6]

Category: We need to bring a change in men’s attitude (4/23).

Summary: Men need to go to their doctors on a regular basis from their 40’s onwards. Individuals from early on in their lives also need to change their diet and eat less of fast food. Men also need to learn about their prostate gland. Emphasis should be on the preventive efforts. Specific comments from this category are: we should start looking at preventive efforts and men should start seeing their doctors from their 30’s [1]; men figure the digital rectal exam to be degrading and that’s why they don’t go for a check up [5]; men are either not aware of prostate cancer or they don’t want to face it [8]; I didn’t know that there was a prostate gland and I didn’t know there was a support group for it. [17]

Comments made by individuals:

There’s the thing with the men being too macho to even worry about things like that, you know, it’s funny how men look at it, you know, they ah, especially that DRI exam, or DRE they don’t want to get that done. It’s degrading, they figure, and ah, but ah, that’s about all I can think of. I enjoy helping other people. That’s what the big guy put me here for, I guess. It wasn’t my time to go. So that’s all I can think of. [5]

Items: Cancer researchers should work collaboratively with each other and there should be more funds available for prostate cancer research and there should be more input from the survivors (2/23).

Summary: These men stated that cancer researchers should work together rather than to compete with each other. Specific comments from this category are: there needs to be more communication between the Cancer Agency and the research
departments at the hospitals [3]; there is a big discrepancy between the amount of funding that is available for breast cancer versus the amount of funding available for prostate cancer. [13]

Comments made by individuals:

I would say one, of course, always, is more funding and the second would be more communication between the cancer agency and the research department at the Vancouver Hospital. A little more working together rather than butting heads which they are doing right now and ah, yah, that’s one of the things that would help. Sharing their knowledge a little more rather than competing with each other. [3]

Well, in a scientific point of view there is a lot of research being done, a lot of studies being done and we don’t really have an input in that. We are, through the foundation not through the support group but through the foundation which is also a fundraising organization, we do support certain projects. We provide some money to some study, money to research, otherwise it would not be even starting. So that’s what we can do to improve, okay, but our main function is to help people, the men that are out there, they and their families find the support, find a place. Also, there is millions of dollars spent on breast cancer research and only $300,000 spent on prostate cancer. There’s a very big discrepancy between the two groups. [13]

Item: Be open to doing research about alternative therapies where drug companies do not have a conflict of interest (1/21).

Summary: Physicians need to have an open mind towards clinical trials that are going on throughout the world. Cancer researchers should also do more research on the alternative therapies. [2]

Comment made by individual:

I think that our system is a very slow cumbersome, heavy system that doesn’t take advantage properly of some of the developments around the world. People here are apparently being greatly restricted by what they think would be funded by the healthcare system. That’s one thing, and therefore, to try and bring something innovative or new that seems to have promise, it isn’t accepted and it won’t be used because it isn’t covered by the healthcare, and by the same token, these people that are experts and are specialists in this field are very much funded by the drug companies, so therefore, to try and bring something that’s potentially, well
something which is coming from tests and trials being done elsewhere but is not in
the area of drug products, I'm speaking now of complimentary things such as
[Likopeon?—tomato paste product] and others, but to try and get it accepted here,
at least on a trial basis, is extremely difficult because the doctors here are doing
research on those things and really only those things that are funded and in the
interests of the drug companies and that's a shame. [2]

Item: Speed-up the process for clinical trials (1/23).

Summary: This person believed that treatments that have shown some promise in
other places of the world, should be approved here without cumbersome
procedures that take a long time. [2]

Comment made by individual:

I think they should be willing to investigate, as I said earlier, certain things that
appear to be rather innovative and have good potential even if they aren't all, shall
we say, proven beyond doubt here locally. If it happens to be something which
has been proven in France or Italy or Switzerland or the United States, I think they
should be willing to take some of those results and move forward, if necessary, on
their own investigations here and in that respect, also, I think that the procedures
or the protocols are quite unnecessarily cumbersome. We're speaking now, I can
give you first hand experience of things that even to get a fairly simple clinical
trial through the ethics board can take months and months and months just to have
a person review a piece of paper and what they require for the clinical trial to be,
ah, perceived as being satisfactory and suitable for publication and so on is a
clinical trial is very expensive and very cumbersome and very time consuming
and it's my thought that there are men there that are dying who would be quite
happy to have some shortened path or even they would be willing to take certain
products that had potential proven elsewhere. They would be willing to take those
products without a lot of clinical trials being done right here because my men,
many of them, don't have other options. When they get to the point where it
metastasizes they don't have anything left accept chemotherapy and that's not
been proven very successful for prostate cancer patients. [2]
Category: Focus on treatments that stop metastasis. Meet the needs of advanced patients and find new kinds of treatments that don't have a negative effect on sexuality (3/23).

**Summary:** There needs to be an urgency to stop the metastasis, and this urgency should be present in the research that the cancer researchers carry out. Specific aspects presented in this category are: it is very urgent to reduce the spread of cancer through body but yet cancer laboratories hire Ph.D.'s with a long-term approach; in fact, there should be a better process in place for patients with an advanced disease [2]; they should improve on the techniques of operation for prostate cancer so that sex related nerves can be spared during surgery. [11, 12]

**Comments made by individuals:**

I think that, ah, the urgency of coming up with some means of reducing the tendency of the prostate cancer to spread through the body or metastasize that it's a very urgent and important matter, and yet, I can't instill into the people in the system here that same sense of urgency. They are quite prepared to hire PhD's that have a long-term approach and they hope that their research in five years or ten years might have some beneficial effects, but they really don't have the same sense of urgency that I think there should be. [2]

I think that there could be a little better process than what presently exists for information for people at a more advanced stage because I'm doing a lot of this work, but quite frankly, the number of days I have left will be limited, and ah, there isn't any real source for these men at advanced stages to get information. They go into their specialist, yes, but quite often that specialist is a very overworked person who hasn't actually had a chance to review the literature from foreign medical publications and so on. [2]

**Items:** Provide accurate information about treatment side-effects (2/23).

**Summary:** These individuals claimed that men are not provided with accurate information to the degree of side-effects they will have in regards to their prostate cancer treatments. Key aspects presented in this category are: medical statistics
about treatment side-effects are not accurate and they are misleading [2]; I was not given enough information about treatment related side-effects prior to my operation. [10]

Comments made by individuals:

I’m sure and don’t be fooled by some of the statistics you see that our medical system give as to the percentage of people that are going to be sexually active afterwards or the number of people that are going to be incontinent afterwards, they have their statistics and they call it a successful prostatectomy, for example, even though a person like myself has had to wear pads for incontinence now for seven years and yet I was considered to be quite successful in that respect. So that what, for me, is a real inconvenience, it isn’t even recognized as being serious at all, they considered it quite successful. In the same way the percentage of men that are able to function adequately sexually, their approach is, oh well, a lot of these men are older and wouldn’t be able to function anyway. So the percentages that you get if you take a survey, like you are doing of the patients, you are going to get a different percentage than is given by those people who are advising men what therapies they should use. [2]

No that’s one thing I really feel bad about. I really feel I was not given enough information before the operation, because I did not realize that after this operation my sexual life was totally gone. I wasn’t prepared for that and there’s no way to get it back so it’s finished and that was kind of tough to come to terms with that. Did they prepare me, no, I don’t think they did. Before the operation they prepared me very well. In the hospital they told me exactly how many tubes I would have and what bags I would have and that preparation was really good, but as far as the preparation for incontinence, no. The preparation for sexual activity, no. The preparation for lack of energy and everything, no I don’t think I was totally prepared and I think they did not tell me because then maybe I’d change my mind or maybe I’d get depressed ahead of time or I don’t know what, but no I was not fully informed about any of that kind of stuff. They always kept painting a very nice picture, oh, you’ll be just fine, you know, just a little operation and you’ll be just fine, but they never told me about all the side-effects I could have. I went through the internet a lot but there is so much information out there and so much of it depended on age and how far it spread and it’s so hard to pinpoint what you are going to experience and how far, I did read up on it a bit, but I found it quite depressing too. Sometimes you just hope for the best, because no matter how much you read, it’s not going to change anything, you still have cancer and it still has to be treated, and sure, you can go and try drink a lot of carrots or drink a lot of tomato juice or something like that but you still have cancer, and I just chose to listen to the people that had the most experience and the most knowledge which were the doctors and the surgeons and I went with their advice. You know, people suggest that I go to Mexico and get different medications in Mexico and different things like that. I think that’s kind of silly because these people here,
they do most of the research, they have all the experience and that’s why I went with their recommendations. [10],

**Items:** Provide more support and funds for support groups (2/23).

**Summary:** Support group facilitators would like to do a lot but they are limited by the amount of time it takes, and sometimes they lack appropriate funds to do all the things they wish to accomplish. Specific comments made in this category are: there should be funds for support groups and for advanced support group so that these groups can write information to disseminate to their group members [2]; it would be helpful if support groups were supplied with current reference materials, books, tapes etc. [16]

**Comments made by individuals:**

Well in the sense of information I think there could be funds given for some group whether it be the advanced prostate cancer group to have, for instance, regular newsletters to disseminate this information. I don’t do it because it would take quite a bit, as you know, to prepare the newsletter to make copies, to mail it out to people, but if there were funds to do that, that would be one thing. [2]

Help with funding and also assist in supplying us with very current reference materials, books, tapes and potentially productive speeches. I mean they are scrambling for funds themselves but if you take money out of the equation, like we have, the board gave us $1000 to operate our library so we can’t just go to Chapters and buy the books. What we want is to go for some research at the Center of Excellence, the Cancer Clinic, or whatever, and see if we can’t get an intelligent assessment of what we should purchase to operate our library. We won’t burn the library books we’ve got right now, we’ll send them back to the board, and ah, as the groups across the Province, if they come into being or are relatively new, they will supply some of this reference material to them. So it stays in the cycle. [16]
Items: Give more recognition to the support groups (2/23).

Summary: These people stated that the support groups should be recognized by the urologists and other medical professionals. Also the support groups wanted to receive backup support such as to having a place to meet. Specific comments from this category are: some of the urologists seem to think that the support groups are not important [4a]; the support groups would like the medical community to make sure the patient has the information in his hands before he walks out the door. [18]

Comments made by individuals:

It would be nice if we got some recognition. I know that some of the urologists here don’t seem to think that we’re that important, yet other urologists do, they support us highly, but, you know, I would like to see everybody get on the bandwagon and become a unified group where we could have real caring and sharing and ah, you know, there’s always support that we need for back up for a meeting to be able to have a meeting place and to hold our meetings at and if they would come along side in some supportive way financially as well. We’re not asking for a great big pile of money, but I think, really, what I’m trying to say is that what we’re looking for really is recognition. [4a]

Yes, a lot. We would like the medical community to see the value of support groups and make sure the information is in the hands of the patient when he walks out the door. Getting that to happen is very difficult. Giving the patient a list of materials that he can read, that give him the opportunity to see what other medical people are saying about his particular conditions. I say this for two reasons, at one point in time the doctors were the total source and only source of medical diagnoses and recommended treatment. Any soul today can go to a computer and get any information they want from any place in the world. Any doctor that thinks that he can provide the sole solution to that patient’s problem is not in the twenty-first century. So he can provide himself and his patient with a lot of value by giving that patient the information that the patient can choose to do something with or not. If the patient feels comfortable with this doctor, then fine, they’ll get along well and the patient will accept the recommendations of that particular doctor and proceed. I think we just heard here today, it’s not what treatment you do that is the best treatment, it’s whatever best treatment will work for you, that you can live with. That’s the best treatment. The other ones don’t matter, they are good treatments too, but it’s the treatment that works for you or that you can live with is the right treatment for you. So getting that information in the hands of the patient is, from my point of view, from a medical perspective, really important
to let them know that there’s more than one way to skin a cat and you need to examine those before you make your final decision. I’m quite prepared to help you out and I’ll give you some information as to how you can do that and all that kind of stuff but to walk out of the door with nothing in his hand, I think is a mistake by the medical community. [But what would you say to those—that there might be other magazines sitting around there in the doctor’s offices] Well, let me recite to you a little scene that’s in a video by Mr. Cousins, Norman is his first name. That’s in a video that’s called Belief Becomes Biology, Norman Cousins, is the guys name and he describes a scene in a hospital. The scene in the hospital is the patient is lying in bed and has just gone through a number of tests, and the first scene is the doctor standing at the open door where the patient is and says to the patient, hi, I’m doctor so and so and I’ve just looked at your particular reports and I’m sorry to tell you that you have cancer. Then he says, well, I’d like you to think about this other scene. The same office, or same bed, same patient, same doctor, but this doctor does it a little different. He comes in closes the door and brings the chair up beside your bed, takes your hand and says I’ve got some bad news for you. I want you to know that we are going to do everything possible to help you out. Those medical tests that we had indicate that you have cancer. Which situation is going to make you, as a patient, feel better, and b) how much time difference there is between the two scenes. Zero time difference but the impact on the patient is enormous. That’s what the medical community has to learn is that they can impact a disease tremendously by the way they act. So that’s what the medical community has got to learn. Some of the doctors are pretty good at it and some of the doctors are terrible. We hear all kinds of stories. Imagine getting you diagnosis on your answering service at your home. I had one patient arrive at the Vancouver agency, sent over from Victoria to ride there and back, and I said, what are you here for, and she said, I don’t know, my doctor just sent me over here. She had to make arrangements to look after her children while she came over here, and she had advanced case cancer. The doctor didn’t tell her. Just sent here for somebody else to tell her. That is just terrible. You see, if you think about it another way, hey the doctors are all human beings the same as everybody else, they have a time constraint. Coping with this whole issue is not easy, it’s extremely difficult, and ah, they are afraid to have somebody come and tell them, you know, we can help you out, we’d like to help you out, here’s what we can do for you. You know, I’ve made that offer available to you, all the associations say, can we have a liaison person talk to, we never got a reply. All we wanted to do, as I see, is a role, is to say, look, I’m not talking to you as a patient, I’m talking to you as a representative of the patient and here’s what the patients are telling me about you, not you personally, but, you people as a group, you have one impression of what they are saying about you, I can tell you there’s a very different one. They don’t want to hear that and I’ve heard some of the stories coming back, oh, yah, his incontinence level is this kind of things, so a lot of the guys I’m talking to are having a hell of a time with that. Erectile dysfunction, I haven’t got one person in the group that I’m talking to that has regained any erections. Who are you talking about that says it’s 50 percent, well who are you talking to? Yah, they don’t have all the answers in the world, nobody has. Recognize that that’s the possibility or at least that that’s reality and accept
assistance wherever you can get it. If someone can provide something that will
help other people, take advantage of it. Don’t say that you are God, because you
are not, no one is. We are making small inroads that way and we get, more
brochures are available, some doctors are more receptive. There’s an urologist in
[name of municipality], Dr.[name of urologist withheld], you know him, and he’s
very good. There are some of the doctors here that are very good, getting
information out, the prostate clinic is very good, they refer people, Dr. [name of
doctor withheld] helps out providing information and that’s really, really, really
good. It’s helped out a lot of people, and there’s more work being done in that
area that’s helping. [18]

Item: Need transportation to access clinics (1/23).

Summary: It was difficult for this man to go to clinics without transportation. [4b]

Comments made by individuals:

One of the things that people find problems with, older people, it’s an old man
disease, of course, is to find transportation to go to the hospital and it’s very, very
difficult right now for older people to find transportation to go to the clinics.
Chilliwack is well-organized, Abbotsford is not organized at all in this sense. My
wife and I are doing that kind of work now but as far as I know there’s nothing in
Abbotsford. [4b]

Category: A few Suggestions for improving the support groups (3/23).

Summary: Individuals should be encouraged to share their personal experiences
related to prostate cancer in the support groups. There should be some one-on-one
discussions as well. A summary of the specific comments is as follows: inviting
everyone to share their experiences would make these meetings more beneficial
[9]; our group should open-up more to the members [10]; one-to-one situations
where men could discuss how they dealt with their prostate cancer would be nice.
[11]
Comments made by individuals:

I have one suggestion, I would like to see more time spent individually discussing alternatives how each member dealt with their individual situations. We don’t do enough of that in our group. We bring in specialists, we bring in the doctor, but there’s very little one-on-one. I’d like to see that. I’m dealing with my particular type of, my operation. I don’t know if my situation would relate the same to ?, because he did the penal radiation and he’s on the medication stuff, hormone medication. I can’t relate to that because it’s not something I’m doing so I would like to see how its working. [11]

Items: Provide more medical and educational “tips” to help individuals going through with treatments for prostate cancer (2/23).

Summary: These people ask for more “tips” as to what the medical treatment procedures for prostate cancer will be. They would like specific suggestions for taking care of incontinence, impotence and pain [6]. Support group members believe that a lot of the information about prostate cancer and about support groups is not being given out by the doctors. [17]

Comments made by individuals:

Well, I touched a little bit on my kind of recommendations or observations in my little summary report. There are a few things that aren’t so much the medical system but rather the information that is available. I thought I really read extensively and um, there were still things that I only picked up through friends, like the tip with the stool softener because it’s initially very painful. I mean just on the other side of the bowel is the operating side so obviously things happened there and initially it’s very painful to go and have a bowel movement and it was a tip from my buddy and then I confirmed it with the physician and the nurses and they said, oh, by all means, yah do that, it will make life easier, but I hadn’t read it anywhere. No to me that’s a tip that should be given ahead of time. It should be one of the things, you know, I know our support group, [name of group leader not provided because of privacy] he is kind of the leader for B.C. or one of the leaders and they are working on a brochure. I’ve no idea what that brochure will look like at the end, but to me, it would be nice to have a handout like, “Our Voice” the special issue, to me, is a wonderful publication because it gives you the types of cancers, the treatment options, the likely treatment options to choose from and all that. The next step would be, well if you’re going for surgery, you will go through such and such, and um, one of the items, somewhere it should say, make
sure you take when you start eating again, which is only about a week after the operation, take stool softeners because it will make life so much more painless and bearable, that's one. The other one that impressed me so much, my, and I always had trouble with this word, anesthetist I have really trouble with that word, he was a wonderful person and I told him, I'm a chicken when it comes pain because I have not really had to experience pain in my life. So I'm really afraid of suffering that pain and he said, look don't worry about a thing. Well, that's easily said, I do worry about it but at the end, I had a wonderful experience, and again, I compare myself to me friend who did not have this treatment, I had the epidermal inserted in the back and he explained to me that that was um, not an alternative to being put under but it was pain control and he would do both. I wanted to be under, I don't want to be aware of the doctors talking and hearing scissors and tools or God knows what, you know, just put me out and I don't know what's going on, but in the literature that I read, it talked about the epidermal as one of the options and the way I read it, it was more an option instead of being put under and not as the pain control option, and my experience was so positive, it stayed in for four days and after four days, he said, look, you can now ask the nurses to put something into your IV drip if you have pain, pain control on demand and when you go home you get Tylenol. Well I never experienced pain. I didn't have to ask for anything and I got my Tylenol and never took a single one. Now, if that message can be louder up front, I think it will take a lot of anxiety away from a patient and then I compared notes with my friend and what he went through and especially with Tylenol you get really plugged up, well he didn't have the epidermal and I don't know exactly how the discussion went but I know his anesthetist touched on it, he had heard about it, but he didn't push it, whereabouts, my doctor really pushed, it. He said, don't you worry about it, that's what I'm going to do, not, kind of, this is one of the options, that's what I'm going to do for you and you will like it and you will not suffer and that's exactly how it happened. Why doesn't every one of them, kind of, push it when it is proven to be so successful and the literature dealing with the prostate cancer surgery, the ?, there was very little along those lines. It was just mentioned that sometimes an epidermal is administered without a lot of details, not making the point that I think is very important. I mean I would push it to anybody and say that’s the only way to go. That was one factor, um, the whole bag affair is something that, well the nurses talked to me about it and they explained it in the hospital, they did a good job but there was relatively little, it has been mentioned in the books a, kind of, that you get your day bag and your night bag and all that, but there is very little description in those books as to, yah, and what it means is the side where it comes out, you have to have that hose go down to the side of the bed and you can’t turn around. See, this is the kind of details that again, maybe, it is designed that you talk with others. I picked it up from the chap at the support group who told me that, yah your sleep is not going to be very good because you are connected to this hose and you still have the drains and you can’t turn around and you can’t do this and you have to make sure the bag is always lower and otherwise there is a bit of a vacuum affect and it causes pain inside the bladder and spasms and all that. Well, it shouldn’t be a horror story but I found, despite all my effort to read, there was too little along those, what I call the practical side. There was too little in the
literature, it was as if, oh well, to me it was a pretty nasty thought of having a catheter installed and then actually the one in the penis was blocked off because I was draining through another catheter and that’s the one that, you know, I had to watch so I wouldn’t kink the hose or lie on it or pull it or, you know, put stress between the bag and my body and those kinds of things, again, what probably comes through in my comments is, I’m an engineer. I like to know every little step and every little detail and to me that was something that, well, I struggled with for, it came out after two weeks already. Some people only, my buddy only had it finally out after five weeks because he had complications, it had to stay in. So I was fortunate, I only had to struggle with it for two weeks, but your sleep during those two weeks is of low quality because you tell your body, don’t turn, don’t turn, you know, don’t do anything, so um, you know, you are up and um, the other thing I found is I didn’t bother with a day bag, um, it’s supposed to allow you to walk around and hide it under the long pants. If somebody has it for many weeks, he will have to eventually get out and deal with it, but for me it was just the two weeks so I just stayed at home and didn’t go anywhere and I didn’t switch back and forth because it was easier to cope with, with a night bag, emptying and handling it, you know. I clipped it to my housecoat and put it on the inside of the housecoat with the safety pins and all that. So there are different approaches and maybe everybody has to eventually, kind of, make their own decisions, but for people like me who like to know, I found that was another fact of where there was relatively little in the literature to describe, you know, what’s coming up. Beyond that, well, I found the nurses very informative and competent, my urologist, was excellent, and it’s important, you know, that you trust him. Some people go for a second opinion, basically, because they either don’t have a rapport or they don’t trust them. I haven’t faced a situation like that so, you know, you end up with your urologist just because your GP is recommending somebody, you know, he says, you go there and get some tests done, and eventually the tests confirm it and that’s your surgeon, right, um, that’s how it happens. I haven’t had any problem with it, not actually, I cannot think of any major issues that needs changed. There is a major awareness campaign on the go, and I mean you can only, they say, you can only lead the horse to the trough, but you can’t make it drink. There is a lot of information for people who want to familiarize themselves, it’s not a one-stop, you know, it’s a combination of magazines and associations and books and internet and person contact, you know, its, I had a six-month warning of what’s coming because I had to go onto hormone treatment. So the six months while I went through my hormone treatment getting ready for the eventual surgery, there was a lot of time to do a lot of research and ask a lot of questions. Now some people get diagnosed and they have to be operated on, kind of, within three weeks, four weeks, because of the urgency of their case, they may not quite have that time, and ah, I could see that they don’t quite have either the mental or physical time to do all the research that I did but um, you know, right now I would probably take tidbits from each of the books, some of the internet sites, some of the personal comments I got plus the magazine “Our Voice” and create a pamphlet out of it. No I think Val’s group is working on something like that, I don’t know what will end up in it but um, that’s always, I think, a chance to have a better publication but then that’s my way of looking at it. Maybe somebody
else, there’s different priorities but how do you please everybody, it’s not possible, you know. Fortunately there’s a lot of information out there because so many men, you know, such a high percentage of men get it, so there’s a lot of experience by the medical profession with this cancer and a lot of information is out there so. Now, I um, I mean the Abbotsford Hospital is nothing to write home about, it’s an old timer and they’re working on re-building it. It was interesting for me to get into a somewhat out-dated facility, um, but the care I had, I thought was excellent, you know, the nurses knew what they were doing and they were definitely dedicated. [6]

[So, do you wish to share any other thing that you consider to be important?] Well, there’s a lot of information that is not given by the doctors, an awful lot of information. It’s almost too numerous to mention, just to give you an idea briefly, I’ve been on hormones about four out of five years, although there has been a few things the doctors have told me to look out for, there has been a lot of things that they haven’t told me to look out for. [Like what?] Well, one of them was bone loss, alright, I was on hormones almost three years before the subject came up and it was actually Dr. [name of doctor] brought it up at one of the meetings that when you are on hormones, there’s a good chance that you’ve got bone loss. So I had a bone density, and sure enough, my bones are not as healthy as they should be so I’ve been on Fossilmax which, by the way, the government doesn’t pay for, even though it’s cancer, sort of, related. Um, there’s all kinds of things, very simple things, it’s simply, not much, and I only found out a year ago after four years, I asked because the skin on my penis, actually, I couldn’t pull it back as far, why is that? Well, I found out that when you are on hormones the secretion in there dries up so eventually the skin comes forward and I can’t get the skin back anymore and then I had to get special cream so it wouldn’t get any worse. This was never told to me by a doctor. All these types of things that there should be some sort of an education thing. I think that came up at the meeting today that there should be one central place where you can get all this information, the pros, the cons and all this type of thing. A lot of this stuff that I found out is on the Internet, by researching the Internet but no doctor has every told me that. I’ll give you another example, which I found very interesting and also very disturbing, a couple of years ago there was a seminar over here at the Sheraton Hotel up on whatever street it’s on, on forth or whatever it is, and there was a bunch of doctors from the cancer clinic up there, one of them being Dr. ?, being the head of the cancer clinic and in his speech, he said that every once in a while we get a patient that comes in and all of a sudden the cancer is gone. We don’t understand, why is it gone? So I asked the question, all these people who have the cancer that’s just gone, has there been any discussion with them to find out what they did, to find out a common thread that maybe there’s a common thread here somewhere, whether it be vitamins whether it’s acupuncture or whatever and the answer was no. That disturbed me, because if there is people out there that the cancer has suddenly cured for some reason or other, why not ask a whole bunch of questions as you are and say what have you done for yourself and ask every individual the same question, maybe there’s a common link in there somewhere that we can all use and nobody asks the questions. That disturbs me. [So you
would like to see more active research into some of these things?] Yah. [And
more knowledge being passed out?] Exactly, like how do you research something
that you don’t even know about. So if somebody says you get a dozen patients
and one of the things they are doing is similar, then you have something to
research that particular, similar topic. You say, let’s do some research here. But if
you don’t know about it, how the hell are you going to research it? [Um hmm.]
Anyway it’s just a thought. [17]

Category: Put more emphasis on prevention (4/23).

Summary: There needs to be more emphasis on preventing prostate cancer by
stressing the “whole person” approach, where there is emphasis on one’s
environment. Specific comments are: medical system is great for chasing
symptoms but it doesn’t make people healthy [7]; young individuals should eat
lots of broccoli, tomatoes, beans and other healthy foods [8]; and eat healthy foods.

[10, 13]

Comments made by individuals:

Yah, don’t smoke, don’t drink, their health education. I do think, you know. I’ve
been out of it for so long but I do sense now, see my family is from Holland and
we have Dutch values. My wife is from Holland and sure we were both only four
years old when we immigrated, we met later here. She was from [name of city
withheld], and I’m from [name of city withheld], and we happened to meet when
she was teaching out this way and we both happened to be from Holland but we
have traditional Dutch meals, potatoes, meat, vegetables. I do think that the
average Canadian family, eats a lot fast food, drinks a lot of pop, they probably
don’t get their share of vegetables. They eat a lot of pastas, just fast foods, and I
would really encourage them to get good meals, you know, as far as health
education goes, don’t smoke, don’t drink, just your whole healthful living, but my
outlook on that has not changed because of my prostate cancer, because I really
don’t know what caused my prostate cancer, I don’t know. I, sometimes, in the
back of my mind have thought, in my business we did a lot of work for dairy
farms and build a lot of machinery but we also did a lot of welding of galvanized
pipe which is coated pipe to stop it from rusting. I spent many, many, many hours
welding stall dividers and gates for dairy farms and I think, I often wondered if the
galvanized fumes was a part of it. I’ve asked the doctors and they’ll say, oh no,
no, that’s not part of it, but there’s so much they don’t know. So I don’t know
how that is, you know I haven’t got lung cancer because of it, not yet anyway, but
I often wonder if that hasn’t been the contributing factor. Other than that, I just
don't know, I have no idea, it comes right out of the blue, but as far as advice to young fellows, eat healthy, live healthy, get an education but in relation to my prostate cancer I have no advice. [10]

Item: Post-operative companionship with social-workers or outreach workers would be nice (1/23).

Summary: The following individual stated that some men may need the guidance and support of a social worker or an outreach worker after their surgery or radiation. [12]

Comment made by individual:

Yah, I'm not sure but it seems to me that there is a provision right now for this [professional companionship during and after treatment]. I didn't, I think somebody came to see me in the hospital and talked to me after in my post-operative time. They were a social worker and we were talking about this and we had good conversations. I can't remember that much about, I don't remember her name now, but there was no real follow up because, ah, I don’t think that it, it wasn’t needed, and for people who do require this, I think it's wonderful that that is available. [12]

Item: Encourage young children to have more respect for individuals with illness (1/23).

Summary: Children should be more respectful of their elders especially when they are experiencing trauma in their lives. [9]

Comment made by individual:

As far as the young people are concerned my advice would be to live life to the fullest and be respectful of their elders. I really don’t think that there’s a whole lot of respect today, totally disrespectful society in general and I think um, I’m not looking for sympathy or pity or anything else, but be understanding of people that have had this experience, and I really don’t, like my grandchildren and the rest of it, their attitude towards me hasn’t changed one darn bit and that’s alright by me. I don’t, I’m not looking for sympathy or anything else. [9]
**Category:** Have one medical doctor who had specialization in all the treatments that helps with the decision making process. Presently, there may be some bias in passing out information or in the kinds of treatments that are recommended (4/23).

**Summary:** In spite of doctors’ best intentions, sometimes there is bias when the information comes from one specialist. Specific comments in this category are: I would have liked to have known more about the different kinds of treatments [15]; each speciality of doctor has his/her own bias, and a lot has to do with the mindset of the doctor [20, 20 wife]; “if you are the surgeon and think surgery is good, or the radiation doctor and think radiation is good, so there is a bit of bias there.”

[26]

**Comments made by individuals:**

[Observation: This issue was brought up in different support group meetings for a discussion by two different individuals than the ones presented below]

I think my suggestion is, you go to your doctor, your doctor tells you, your doctor is the one that usually makes the appointment for you about the radiation or whether you go to a surgeon, so I think a lot has to do with the mindset of your doctor, where he’s coming from, we’ve never discussed that with your doctor, have you? Why he sent you to [name of the urologist] and not to a radiologist, but I think we need to have a person out there that is knowledgeable in all the aspects and can talk to you so that they’re not going to be just pushing their schooling. [20 wife].

**Category:** Expert speakers from the South Asian and Chinese community should give more talks to these groups (2/23).

**Summary:** Even before individuals get diagnosed with prostate cancer, they should have some familiarity with it. Specific examples are: expert speakers from the Chinese community should give talks to Chinese men about prostate cancer [21]; the medical community could have a South Asian Health Fair because there are a lot of illnesses and conditions that are specific to South Asians. [25]
Comments made by individuals:

It's probably a good idea to get people to talk about it same as they do with diabetes and high blood pressure and, I think there is not enough awareness [So more awareness?] Um hmm, um hmm. [Do you have any other suggestions for bringing this awareness?] No, how can you do that, maybe through, I'm sure all groups have their own health schemes and rehab. We have health fairs every year and there's always somebody from prostate who talks. So those kinds of things. They could have a South Asian health fair, because there are a lot of illnesses and conditions that are specific to South Asians. So this way they could have a forum. Have you tried any alternative treatment or anything?] No, no. Diet, yes I found out more about what things are important in my diet. [Did you drink or smoke ever?] No, no. [25]
Question: What do you see as some of the challenges in running a support group?

Item: Trying to meet the needs of the individual members: especially those with advanced cancer (1/6). (For additional comments see Appendix I)

Summary: One needs to keep on top of the information about prostate cancer and the clinical trials. The support group leader also has to present this information to meet the individual needs of the men attending the prostate support group. [2]

Comment made by individual:

Trying to determine what would be of the most value and what the people attending would like to have, because needs is a very great deal and that was the reason for starting my group which is an advanced group. Unlike all the other groups which try to cover the complete spectrum, I felt that the needs of people with advanced prostate cancer were not being met adequately by the other regular support groups so I started this special group for advanced patients and I try to, as I say, bring information on the latest clinical trials etc. Now, even within this grouping of advanced prostate cancer patients there are different needs, there are some people who are already focused on palliative care etc. and there’s other people that are still fighting to find the best chemotherapy drug and so on. So I try to find out what the needs are and satisfy them [2].

Category: Motivating individuals to volunteer at the support group (4/6).

Summary: Motivating support group members to take an active part in the activities of the group is a challenge. It’s a challenge to get group individuals motivated to help out in the group. [3, 4a, 16, 17]

Comments made by individuals:

Getting volunteers is one of the big challenges, trying to get the other guys motivated to help out a bit. That’s one of the challenges. [3]
Category: Finding the speakers, finding the time, and getting individuals to come the support group on a regular basis (2/6).

Summary: It takes time to find the appropriate speakers to meet the needs of the support group members. A summary of the comments presented in this category is: one has to bring in different speakers to keep the group members motivated [3]; it is challenging for me as a group leader because I also work full time [3]; getting individuals to attend the support group on a regular basis is also a challenge. [5]

Comments made by individuals:

Getting the guys to come back [is a challenge]. You have to have diversity and a variety of speakers, a lot of new knowledge and a CPS and Canadian Prostate Cancer Network. They send me new stuff almost every month, and ah, the guys come down here quite often, you know, they miss a couple of few weeks but they’ll come for another one to get all the new knowledge etc., and ah, we had a thing up at the showcase here at our, I don’t know what you would call it, where we have our swimming and all that up here, we had a showcase where all the different community services, and that, well we were up there. We had our own booth and all the guys volunteered to help look after it for two or three hours each day. We had it for two days, or two and a half days actually and they all volunteered. Some of the guys were too sick to come down but, ah, they were all happy to help out. So I think the prostate group really helps in that way, togetherness, you know. Gives them a sense of wellbeing and being able to help somebody else. Like when I told them about your papers to send out, oh yah, I’ll help, yah. That’s a good attitude, you know, and there’s a lot of people that don’t come that I know have prostate cancer, and they say, we just don’t need your help, it’s fine. I said, well, if you ever do, give me a call, we’re here every third [name of day]. Tell them what time etc. [5]
Positive aspects of the current medical and support system for treatment of prostate cancer

Item: Satisfaction with the amount of information about prostate cancer that is out there in the doctors’ offices and on the internet (2/18). (For additional comments see Appendix J).

Summary: There is lots of information available about prostate cancer in the doctors’ offices and on the internet. [19]

Comments made by individuals:

I think there’s plenty of information now. Even when you go into your family doctor’s office you’ll see the signs on the wall, you know, information about the prostate. The Web has got more on it and I would think that urologists have to be careful because the patient goes in with a wealth of knowledge, not necessarily put into proper context but with a wealth of knowledge. I think we’ve come a long way. I think the hardest thing is the cost of the medical program and of course we start to become quite selfish but I’d love to see a test for breast cancer like a man has for prostate cancer. A woman doesn’t have a blood test that can tell whether that’s developing. It’s hard to know. [1]

I don’t know if any other improvements could be made better than what they put out in the literature and books and all that, what they say, I don’t know what else they could do better until they discover something new or something that cures it. That’s about the only thing. [19]


Summary: The Prostate Cancer Information Centre is very helpful for individuals at the early stages of their diagnoses. A summary of specific comments is: it is good that there is a Prostate Cancer Information Centre [2]; since 1995, there has been lots of improvements in the province of British Columbia by opening new
cancer centres [4b]; it is good that there is a nurse to give out patient information at the Prostate Cancer Centre. [13]

Comments made by individuals:

Well, I think that recently there has been a good deal that has been done by way of helping at the early stage of diagnosis and the prostate cancer information center which has been set up. [2]

Item: Happiness about the role of the Canadian Cancer Society (1/18).

Summary: Cancer society has taken an active role in providing funds for cancer research and in initiating public forums to provide information about prostate cancer. [3]

Comments made by individuals:

The Cancer Society for instance, phoned me up just last week and asked me to help them put on a prostate cancer forum in September. I put one on about four years ago and they asked me to help out and get some speakers lined up and they are going to pay for the advertising and stuff like that. So they’ve taken on a role to help out. Well what we did last time was, ah, we had a hall rented and we advertised the prostate seminar and we brought in Dr. Art Hister as the MC and I brought in a urologist, an oncologist and a radiologist and these sat up as a panel in the front and each one of them gave a talk and then it was open to questions and answers. [3]

Category: Praise about the cancer related publications and organizations: “Our Voice” magazine, “CPCN” (Canadian Prostate Cancer Network), and Prostate Foundation (4/18).

Summary: A summary of the specific comments in this category are: “Our Voice” is excellent, especially the sharing of the personal stories in it [6, 15 bought some books listed at the back of “Our Voice” [9]; the Prostate Foundation and the
Canadian Prostate Canadian Network are the national organizations that are supporting educational and research activities for prostate cancer. [13]

Comments made by individuals:

Our Voice is excellent. I like the sharing of the personal stories, and what worked and didn’t work [6]

Category: Happiness about the way treatment services were / are provided by doctors, nurses and other professionals (7/18).

Summary: Overall, these people were happy with the way they were provided with their prostate cancer treatments. Summary comments in this category are: I have no complains about the way things are done[10]; I just had an excellent rapport with the medical staff [12]; I couldn’t ask for better treatment, the doctors were fantastic [17]; it was the finest experience, it was 99 percent perfect [20]; I think the doctors and specialists are doing a fine job [26].

Comments made by individuals:

Oh yes, oh yes, I just had excellent care, you know, during my pre-operation, operation, my recovery in the hospital and also afterwards when the health nurse came in for a number of days. I had excellent care and very caring people, you know. It wasn’t something was, oh, this is my job I have to do it, they really cared, and also, when I was in and out of the ambulatory daycare and the day surgery people, they again were just excellent. I was actually going in there so often that they became good friends. I think we did, sort of, touch on the subject by, and you probably from the way that I have been speaking, refer to the kind of quality, and I really mean that, quality care and assistance that is given, that is given to you. I had just excellent rapport with my doctor, excellent rapport with the people at the cancer clinic in Surrey, I thought they were very, very good and thorough, and you know, and when I was going in for all of these pre-operative procedures, scans and whatever, I was really treated with as much dignity as you could and it was caring. [12]
Category: Happiness that a social worker or urologist sits in our meetings. The BC Cancer Agency and the Ministry of Health should make sure that doctors also participate in all of the support groups (4/18).

Summary: Men that made comments in this category were happy that a social worker or an urologist sits in their support group. They also wanted to see this kind of medical professional support for all the support groups throughout Canada. Summary comments for this category are: we have a person who represents the BC Cancer Agency that and he sits in our group and we are happy about that [13]; from last several years, the only time our urologist has missed our support group meetings is when his daughters were graduating [16]; other support groups should be facilitated to have the presence of medical professionals [17]; there should be more medical manpower to help support groups in all areas. [18]

Comments made by individuals:

I think one of the things, we are very fortunate here, we have Dr. [name of doctor] that comes every month and that's one of the reasons that we are the largest support group in B.C., if we lost [name of doctor], we fall flat on our rear-ends because we don't have the knowledge that he has so, yes, we get it together and run a meeting but when it comes to technical support, or whatever, we have Dr.[name of doctor], so I think either the B.C. Cancer Agency or the doctors or whatever, if they could get somebody like a Dr. [name of doctor] and help other support groups around the Provinces, it would be fantastic, a lot more men would be helped in that way. It's only the men here at our group that has a Dr. [name of doctor] that helps them. Every single one. Nobody else in B.C. has that luxury and if we can get that luxury into other prostate groups, it would help a lot of me. [17]
Item: Happiness that the support groups help to collect research funds for cancer and that they are self-supporting (1/18).

Summary: “Do it for Dad run” collected close to $80,000 dollars in donations for cancer research. [13]

Comment made by individual:

Yah, in fact, our group, the regular group, we are self-supporting, we do little things to raise a bit of money. When we have coffee and drinks and so on, we have a little basket where people give a donation and we do a raffle every month. So, again, we earn a little bit of money and some of the money we do, at the end of the year in December, we have a lunch for all the members and we call it a celebration of life, okay, and we also make a donation every year to the Cancer Agency and to the research of prostate cancer. Yah, so we are not taking out money but we want to be able to contribute and give it away. [13]
Advice provided by the survivors for other individuals with prostate cancer

Item: Take responsibility (1/6). (For additional comments see Appendix K).

Summary: Be in charge of your own treatment plan. [2]

Comment made by individual:

I would encourage anybody diagnosed with prostate cancer to take responsibility for learning what’s necessary to make a sensible choice as to what’s necessary to the therapy and to continue to be responsible because an overworked specialist with 10 minutes to spend is not really sufficient. Each individual has to take control of his own situation. [2]

Item: Take a positive attitude, and be happy with the consequences of whatever treatment you choose (3/6).

Summary: Once you have made a decision about the kind of treatment you want, you should not look back. Have a positive attitude.

Comment made by individual:

Have a positive attitude. Make a decision and accept all the consequences and carry on. You only draw yourself down into a hole if you don’t move in that direction. Life is only what you make it, if you choose to make it difficult for yourself, it will be very difficult, if you choose to get everything you can out of it, choose to see all the good things there are, you will have fun and you’ll enjoy, there’s much to enjoy and much to relish in if you want to. Do it. [18]

Now, on the positive side, it hasn’t been all bad. It’s been a life’s experience that, in some cases, has been very good. I’ve become quite well known in the medical fraternity, in the cancer agency, cancer society and the prostate center, and I’ve made some excellent friends out of it, close friends. So, it’s not all bad. There’s positive aspects as well as the negative. [3]

It’s embarrassing, but I think men have to get beyond that point to realize the situation there, if they have to wear pants, so what. You don’t tell the world about that and it’s not that noticeable. I just say, don’t be ashamed of it. You have incontinence, you deal with it. Look positive on life. Attitude is a very big thing.
If you have a positive attitude, you can make things easier for yourself and you can overcome situations. A positive attitude. [11]

Category: Get your PSA done routinely (3/6).

Summary: One way to detect prostate cancer early is to get routine PSA tests.

Specific comments in this category are: get your PSA and DRE done [3]; it's almost criminal that men are dying a horrible death because of not having just one test [4b]; men. get your prostate checked. [5]

Comments made by individuals:

Get your PSA and DRE done that's for sure. [3].
How priorities in life have changed for these men

Item: Trying to keep busy (1/10). (For additional comments see Appendix L).

Summary: I try to keep busy and not think about it. [3]

Comment made by individual:

Golf, tennis, travel, yah, I’m having fun and I don’t spend a lot of time worrying about it, and that’s the truth, although, it’s there, I’m not saying I’m that carefree, I’m not. It still hangs over your head, but I’ve never been in depression, not even close. [3]

Category: I have more appreciation for life and others (3/10).

Summary: Prostate cancer has not stopped these people from doing the activities and things in life that they wanted to do. Specific comments related to this category are: I better appreciate things now [9]; I have become more closer to people [14]; I am more charity minded, and I want to give something back to the support group. [16]

Comments made by individuals:

Eventually you meet so many potential life-taking situations, I had two valves replaced and had Lymphoma three times, so I’m already starting to get an appreciation that life is precious and that’s something that seems to grow as I get older, because really through my adult life, the only hobby I had was business and ah it’s still my hobby but I know now I have some balance. I look at trees in wonderment and the sky etc. I can do those things, like stop and smell the roses, and ah, I work at a much slower pace. I’ve gone out on my own and it’s a much more relaxed pace, much more manageable. I can take control of my time. I’m in a position to retire and I don’t want to and I don’t intend to and from that perspective, ah, it’s different. Also, I’m much more, I call it charity minded in terms of prostate cancer, being active, giving something back. [16]
Items: More appreciation for others with traumatic experiences in their lives (2/10).

Summary: Now, these individuals appreciated more about what others had to go through in their lives while coping with a traumatic event. Summary comments are as follows: I have gained a little more appreciation for those that have gone before me [9]; I am more talkative about other people’s problems now.[15]

Comments made by individuals:

I think maybe I gained a little more understanding and appreciation for those that have gone before, and um, I have a sister-in-law that’s doing really well. She had a radical, both breast removed. They found a malignant tumor in one and she made the decision and had both breasts removed, and I think it’s got to be 15 years and she’s doing well, and I, you know I, you know your reaction in the first place is disbelief, I mean, how could a person do this. Yet you have this female, this image thing with females, and the rest of it, how could she have that and like her husband and their relations and how they deal with this, it’s a big part of this whole sex act and the rest of it, you know. I respect her more today than I ever did. [9]

[The last question is do you feel has it changed your priorities or outlook in life, going through this experience in any way?] I don’t know, maybe a little bit. You know, I’ve slowed down and am trying to enjoy life a little more, not be quite as worried about the little things and try to be a little more talkative about people’s problems. [15]

Items: I spend more quality time with my family (2/10).

Summary: Now these men with prostate cancer took time to slow down, and enjoy some time with their families: I take more time for my family now realizing that later may never come [10]; I take a special effort to snuggle up to my wife now. [14]
Comments made by individuals:

No, I don't think so [in regards to whether or not if cancer has affected family relationships]. We were always a pretty close family. We are still a close family. I do think maybe, myself, I will maybe take a little more time than I did before. I had my own business before and I was always busy, and ah, and I always thought the business comes first and I’ll have time for this later, time for the family later, we’ll do this later, we’ll do that later. I realize now that later might not be that far away so the situation was right, that in 95 I sold the business so I’ve taken on different activities, but I do feel, like I’m involved with the seniors group. My term is up next year in May. I’m not going to get involved that deep again. I think I’ll want to focus more on taking quality family time, but I do take time now, more, for the family. Our relationship is still good but I feel personally, myself, that I take more time and more quality time. Like I used to go to some of these things but in the back of your mind, you are still working on this or working on that or quick make a phone call here or make a phone call there. Now I leave the phone at home and I’m there. So in that regard, it’s changed but my relationship with my family was always good and still is good and they’ve been very supportive. They’re very supportive, but we’re not going to talk about it all of the time. We may not talk about it for months, but last week I went to the cancer clinic for test results and they’ll ask me, how did it go, but it’s not that we talk about it a lot. [10]

[Ah, has it affected your relationship with family in any way, kids?] There was a lot of stress before but it has helped in my relationship with my wife. I always had good relations with my children but with my wife, it hasn’t always been good, although I think that she supports me. I’ve changed my approach to life and I make a special effort now to snuggle up to her and avoid complicating our life, because she has, all of a sudden, become very precious to me. [14]

Category: I have always valued life and I try to get along with others (3/10).

Summary: These people stated that they had lived a good life. Some of the comments were: life has always been precious to me [11]; it certainly is very vivid of a time of appreciating everything that I have, but I have always appreciated everything that I had [18]; I have done what I wanted to do in this world so should I go now, I am not afraid. [19]
Comments made by individuals:

No, I don’t think so. We are still pretty well doing the same. Life has always been precious to me. If I was taken, you know, I’ve had a good life, and I think of all the other people out there who have gone through a lot of crap. So, no, my priorities have not changed. I’ve always been a family man, we’ve always done things together as a family and that was one of the reasons why I was very surprised that I got it. I just didn’t think that I lived the life that would warrant such a thing but, I thought as respectable people, we could handle it. It happens so, and I guess because of my family and my church life, I was able to deal with it, but I felt it anyway. [11]

Item: I have an attitude of helping others even during my work (1/10).

Summary: This person even helped other individuals at his work.

Comment made by individual:

Yah, when you are hit by something like cancer, because I think a lot of people, they don’t just say prostate cancer, the first word that comes to mind is cancer, you know. Cancer that means it can be devastating to a lot of people. Some people they go to the doctor and they say, you have prostate cancer. They don’t hear the word prostate, they hear the word cancer, and they are shocked, you know, and so you say, me, I’m going to fight it and I’m going to survive it and I am going to overcome it, and that, again, is your attitude, you have to have a positive attitude, well this life is work but it is also to enjoy. You have to have time for your family, your friends, your church, your community and so on. You can’t say, I’m just here just to make business. When I see a client, it’s not just to make business, I’m doing the job because I believe I’m doing something important for him and his family so the pay cheque is different. I want to say that we do have people in this office that they will do the business, they don’t care what it is, but you can not do it yourself if you do a job that is important for other people. [13]
Question: If having cancer has changed your relationship with family members, how has your relationship with family members changed?

Item: After cancer, as a family, we have been brought closer together (2/7). (For additional comments see Appendix M).

Summary: A summary of the comments under this category are: I think prostate cancer has brought us closer together [5]; now, I spend more quality time with my family. [10]

Comments made by individuals:

No change whatsoever, if anything, closer. We are a very close-knit family. We get together, probably, maybe, once or twice a week and ah, have breakfast together and whatever. Talk about things that are happening and our grandchildren come over once a week, type thing, and there's four of them so they take up a lot of the week and they come over and stay with grandma and grandpa. No, I think it's brought us closer together. [5]

No, I don't think so [in regards to whether or not if cancer has affected family relationships]. We were always a pretty close family. We are still a close family. I do think maybe, myself, I will maybe take a little more time than I did before. I had my own business before and I was always busy, and ah, and I always thought the business comes first and I'll have time for this later, time for the family later, we'll do this later, we'll do that later. I realize now that later might not be that far away so the situation was right, that in 95 I sold the business so I've taken on different activities, but I do feel, like I'm involved with the seniors group. My term is up next year in May. I'm not going to get involved that deep again. I think I'll want to focus more on taking quality family time, but I do take time now, more, for the family. Our relationship is still good but I feel personally, myself, that I take more time and more quality time. Like I used to go to some of these things but in the back of your mind, you are still working on this or working on that or quick make a phone call here or make a phone call there. Now I leave the phone at home and I'm there. So in that regard, it's changed but my relationship with my family was always good and still is good and they've been very supportive. They're very supportive, but we're not going to talk about it all of the time. We may not talk about it for months, but last week I went to the cancer clinic for test results and they'll ask me, how did it go, but it's not that we talk about it a lot. [10]
Category: No change happened in the family (3/7).

Summary: These individuals stated that their families had stayed intact, and in fact nothing had changed in their families: nothing has changed in our family. [8, 15, 22]

Comments made by individuals:

I had no change in the relations of my family or friends. Some of my friends have gone (passed away) and I miss them. [22]

Item: Children were afraid that dad may die (1/7).

Summary: A diagnosis of cancer is scary, and my children were worried that their dad may die. [11]

Comment made by individual:

Initially, a little bit. The kids, the children, you know, they, cancers scary and they think they are going to lose a parent and there’s a lot of hovering and wanting to do things for you, but once, like I say, two years now, two plus, and things just kind of got back into the norm. We all think dad’s going to be around for awhile so we’re doing everything normal. I would think not to much has changed in our lifestyle and what we do for each other. The youngest [children] is 32 and the oldest is 40. [11]

Items: I want my family to be educated about it (2/7).

Summary: These people believed that they wanted their families to be educated about prostate cancer because they did not want their families to suffer: I am making sure my family members don’t end up on the short end of the stick [11]; I
want to make sure that my sons will be aware of the dangers of prostate cancer.

Comments made by individuals:

It's kind of a negative thing but the beneficial part of it for my family is there, there's not that much information out there, in trying to keep them ahead of it so they don't end up on the short end of the stick, shall we say. I would say that's the best that I got from it. I survived and I am surviving and I'm keeping my family, children, brothers, uncles informed of it and ah, I just give information.

Well, I just want to make sure that my children, especially my two sons, will be aware of the dangers of prostate cancer that they will make sure to check into it and so on. Ah, you want to make sure that you are going to survive and be around for awhile. You want to make sure that you keep in contact with your doctor and get tests and so on, because you want to have your family around and you want to see your family see you and growing.
Two Punjabi sikh individuals who did not have prostate cancer but had prostate difficulties (interviews were done in Punjabi).

Background information about these two men and the "items" that are applicable to them:

Person 23: He is 70 years old. He was born in Pakistan. He is from Punjabi Sikh background. He understands and reads Punjabi. He completed high school. His wife passed away long time ago. He has four children and he is retired. He was diagnosed with prostate difficulty about four years ago. He got operation twice with laser and needle. This man stated that, "They did something to the prostate gland." When he went for the third time to his doctor, his doctor gave him two months to get a surgery done. But, this individual asked his doctor, "Will I get better?" The doctor had told him after his second operation that there was no guarantee. First he got the operation in May 2000, and then in 2002. The doctor asked him to make up his mind. This man told the doctor, "Well the train is going downhill!" He stated that he does not have prostate cancer through. He said he did not know what a PSA level was and his doctor had never told him about it. He said it happens in old age and he had this problem since 3 or 4 years ago. He stated that, "I have no difficulties at night, one usually gets up several times at night anyway."

Person 24: He is 73 years old. He came to Canada 10 years ago. He has 5 children. He has 2 kids in Canada. He lives with his son, wife and daughter-in law here. He stated that he had his laser and needle operation 5 years ago. [This person does not have prostate cancer but instead had prostate difficulties.]
Item: Early wrong doings are the cause of prostate difficulties (1/2).

Comment made by individual:

What causes prostate difficulties? I think it is early wrong doings. For example, I was a truck driver and I stopped urination many times until I was able to find a place to go. For others, I think it may have something to do with not eating prior and after to getting intimate. It may also have something to do old age. It could also be eating meat but I am vegetarian. I have not eaten meat since 1945, and I didn't smoke. [24]

Item: Difficulties in urinating (1/2).

Comment made by individual:

Whatever difficulties I had before, I have them now too. There has been not much change. They said don't drink too much water so you don't have to go to washroom much. [Is there any difficulty psychologically]. No, it has become a routine. When you go outside sometimes, there is difficulty when you have an emergency with urinating sometimes. [23]

Item: I did not get any help from others in coping (2/2).

Summary: These men stated that they tried to deal with their cancer by themselves: Neither I have asked for help from anyone and neither has anyone provided this help [23]; In this world there is no one there to help others, everyone is there to help themselves. [24]

Comments made by individuals:

Neither I have asked help from anyone, and neither has anyone provided this help. Medicines have not helped much either. They always write a medicine that is cheap. They never write a medicine that may be expensive but works well. First I didn't eat some of the medicines that doctors prescribed because I am also a heart
patient, so I eat lots of medicines already. But this time, I did eat medicine from last three or four weeks but it didn't help much. [Who did you communicate with this about your illness in terms of your family or friends?] Sometimes I have talked with others about it but not much. [23]

No, I have never attended any support group. Where do they meet? In this world, no one is out there to help others. Everyone is just there for themselves. [24]

Items: Religion gave me strength (2/2).

Summary: These men prayed themselves for good health: whenever I wake up in the morning, I pray for good health [23]; I keep a diary related to the Sikh holly scriptures and what these scriptures mean to me. [24]

Comments made by individuals:

I believe in God. I have always gone to the temple. Whenever I wake up in the morning, I pray for good health, but everyone does that too. [Has your faith increased or decreased in any way?] No, not at all. I have always had faith. The shortcomings are in us in that whatever we sow so shall we reap. [What do you think is the cause of this problem?] My father had the urine problem too he had aurovedic medicine from Amritsar (city's name in India). Did you ever speak to anyone at the temple about it? There is no sense speaking to anyone at the temple about it. It is a private thing. It is a medical thing and concerns the doctor. I thought surgery would help but it didn't. There are some other individuals who had operations the second time but they have been better. [23]

I will show you what helps me in coping with this. I have the sikh holly scriptures at home, so I read them and I keep a diary about the meaning of the scriptures (individual shares the diary with me: it relates the meaning of scriptures with how to live our life). No, I have not told others about my problems because others cannot help me. Even at the parks or temple the seniors that meet there- What do they do? They talk about propaganda related to others so how is that useful to me? I get my peace from the holly scriptures. I have always believed in God and that's what I rely on now for my true strength. [24]
Suggestions for improving the system

Item: They should keep you longer in the hospital (1/2). (For additional comments see Appendix N).

Summary: An individual gets better care in the hospital.

Comment made by individual:

Yes, they send you home right away after the operation. I think they should keep you there for one or two days for an observation. The kind of care you get at the hospital is not the same at home. For example, at home you have to carry all that system (catheter?) with you. [23]

Items: Provide more education about prostate cancer in Punjabi (2/2).

Summary: These people believed that there needs to be some discussion about prostate cancer in Punjabi language: the medical community should have discussions about this at the Punjabi Senior Centers [23]; the medical professionals should have question and answer sessions about prostate cancer in Punjabi [24].

Comments made by individuals:

They should have discussions about this in Punjabi at the senior centres, where individuals can talk about what has helped them- although I have never attended senior centres. For example, about ejaculation difficulties, the doctor didn’t tell me until I inquired about it after the treatment. [23]

What may help is if there were questions and answers in senior centres in Punjabi language. I have a language problem. [24]
Items: I did not attend a support group (2/2).

Summary: These individuals had very little information about the role of the support groups: I don’t think the support groups can help me [23]; no, I have never attended, where does this group meet? [24]

Comments made by individuals:

No, I never have. There is no time for them. I don’t think they can help me much. I have seen their pamphlets though at the doctor’s office. They collect donations there. Is there any remedy there also, do they tell about treatments too? [Sometimes the have a urologist there and sometimes they have a herbalist that provides information as well].

No, I have never attended. I have gotten an Indian aurovedic medicine (chandarparbhaveti) but I have not used it yet. [Have you read information in Punjabi about it?] Yes, I have and I have read them. [23]

No, I have never attended any support group. Where do they meet? [24]
CHAPTER 6
DISCUSSION AND CONCLUSIONS

Hypothesis 1: Among individuals with prostate cancer, there will be some shift in the meaningfulness of their religious experiences. Some survivors will become more or less religious than before. As an aid to coping, religious beliefs interact with the life-changing events brought on by presence of a serious illness such as cancer, and beliefs themselves may undergo change.

Religion did not play a part in the lives of all of the men with prostate cancer. Most men that were not religious before indicated that they were still not religious. These men stated that they were not devout, but some of them did attend church. None of these men indicated that they had become less religious because of their experience with cancer. The following comment was typical for this group: "I was never much religious. No, I didn't change much in this regard." [22]

On the other hand, some men relied to a large extent on their faith in order to deal with their cancer. These men believed that God had sustained them throughout this ordeal [e.g. 4a, 4b, 12, 18]. They also believed that religion gave them personal strength to deal with mortality, and the support from their friends at church was helpful. Further, these men believed that even though their religious views had not changed because of cancer, these beliefs were reinforced or strengthened in many ways. For example, the following quote indicates how some of these individuals had grown stronger in their faith:
In my case it was my faith. My faith had a lot to do with anything that I, sort of, suffered, you know, I had to deal with this one time before through a very serious car accident and I felt that the Lord brought me through that. So I was putting a lot of dependence on him to bring me through this, this cancer problem. I've always had a strong faith. I came to the Lord back in 1964 when I accepted him as my personal savior and I think as the years grew, I grew stronger in my faith and I've seen where God worked in other lives and had created miracles and this gave me a very strong faith to be able to go through this. I think that, ah, as I went through it, I think it [cancer] probably made me stronger in my faith. Let tomorrow take care of itself. [4a]

Further, many individuals believed that God had put them on earth to do good towards others, and that's why some of them had decided to take on a facilitator role in their support groups [e.g., 5, 10]. Faith also helped these men not to worry about tomorrow and to realize that if they were to die they would be going to heaven. This positive attitude towards death provided by their faith helped them to deal with their prostate cancer in a positive way: "So if I die when I'm 60 or die when I'm 80, I'll just get there 20 years earlier and I'll still go to heaven and that's helped me a lot. That's really helped me a lot." [10] No men from this category lowered their religious beliefs because of cancer; instead, the contrary was found to be true. Pargament et al. (1995) stated that during their coping experience, some individuals may become more or less religious and others may experience a shift in meaningfulness of their experience. This study found that even though having cancer reinforced the religious views that some of these men already had, there were no cases where individuals became less religious because of their experience with prostate cancer.

Another religious aspect that helped some of these men was the praying of others for them, especially the individuals from their own congregation. Person [10] even met
many other individuals with cancer from his congregation, and they worked as a
supportive network for each other. For example, person [10] stated,

“There are other people that have cancer. There’s a lady with breast cancer, there’s a husband whose wife has advanced breast cancer, now it’s all over the place. There’s another fellow who has colon cancer and because people with cancer can more easily talk with other people with cancer, you know, like you’ve been down the same road. You, kind of, talk easier together about your cancer but the rest of the church is very supportive, they’re very, yah, if you need something, they’re there, they hold you up with prayers and I would say they are very supportive.”

Some individuals from the congregation had even visited some members while they were in the hospital [e.g., 12]. Thus, the religious congregation provided a feeling of caring through prayer for some of these men; therefore, these men felt supported.

From qualitative interviews, it was difficult to accurately predict the percentage of individuals who were trying to find comfort in their religion or the percentage that had a stronger faith because of their experience with cancer. However, quantitative analyses were able to help with answering this question. As shown in Table 1, 25.5% of the individuals (N=86) were trying to find comfort in their religion or spiritual beliefs, as stated by them.
Table 1

Percentages of individuals trying to find comfort in their religion or spiritual beliefs (N=86).

<table>
<thead>
<tr>
<th>Variable</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Haven’t been doing this</td>
<td>50.0</td>
</tr>
<tr>
<td>Doing this a little</td>
<td>24.4</td>
</tr>
<tr>
<td>Doing this a medium amount</td>
<td>8.1</td>
</tr>
<tr>
<td>Doing this a lot</td>
<td>17.4</td>
</tr>
</tbody>
</table>

On the Mental Adjustment to Cancer Scale (MAC scale item 12), when asked about whether they had put themselves in the hands of God, 37.5% (N=88) had said that this statement ‘applied’ or ‘definitely applied to them (see Table 2).

Table 2

Percentages of individuals who had put themselves in the hands of God: MAC Scale item 12 (N=88).

<table>
<thead>
<tr>
<th>Variable</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Definitely does not apply</td>
<td>35.2</td>
</tr>
<tr>
<td>Does not apply</td>
<td>27.3</td>
</tr>
<tr>
<td>Applies to me</td>
<td>15.9</td>
</tr>
<tr>
<td>Definitely applies to me</td>
<td>21.6</td>
</tr>
</tbody>
</table>
Therefore, between one-third to one-quarter of the individuals turned to religion in order to cope with their prostate cancer. Further, as indicated by Table 3, 25.6% of the individuals from a total number of 82, indicated that they had actually grown stronger in their religious faith, therefore further validating the results found through the qualitative interview data.

Table 3

Percentages of individuals who had a stronger religious faith because of their experiences with cancer: PTGI scale item 18 (N=82).

<table>
<thead>
<tr>
<th>Variable</th>
<th>%</th>
</tr>
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<tbody>
<tr>
<td>No change</td>
<td>46.3</td>
</tr>
<tr>
<td>Very small change</td>
<td>19.5</td>
</tr>
<tr>
<td>Small change</td>
<td>08.5</td>
</tr>
<tr>
<td>Moderate change</td>
<td>08.5</td>
</tr>
<tr>
<td>Great change</td>
<td>11.0</td>
</tr>
<tr>
<td>Very great change</td>
<td>06.1</td>
</tr>
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</table>

Implications for health professionals and counsellors

It is very important to facilitate the religious support for individuals who have a faith. Therefore, these individuals should be encouraged to keep close ties with members from their congregation throughout their coping experiences with prostate cancer.
Hypothesis 2: Individuals with prostate cancer should be able to describe benefits of their support group in terms of the five dimensions of social support outlined by McCubbin and McCubbin (1989).

McCubbin and McCubbin (1989) outlined five dimensions of social support: emotional (love and care exists); esteem (one is valued); network support (an understanding communication network exists); appraisal support (feedback about how well tasks are being managed); and altruistic support (receiving good will from others for having given something of one’s self). Findings of this study indicate that there is evidence that all of the above types of support were present for support group members. First of all, evidence for emotional, esteem and network support care was apparent by comments such as: “From an emotional aspect, support group has been good.” [1, 3, 20, 20 wife]. Person [8] thought that the support group “listens”, and person [16] had made lots of friendships at the support group. Person [1] was happy that there is always somebody at the support group to talk to, or someone he could phone. Thus, the emotional support was described as talking to or phoning other group members, being listened to, and having an opportunity to make friendships.

There was also evidence for appraisal support but this altruistic feedback was both external and internal and related to these men’s treatments and information about prostate cancer. External altruistic feedback was usually obtained through informal meetings with other individuals, sometimes through the small group discussions. Internal altruistic feedback was related to confirmation of prior information that these men had and towards their reflective experiences related to new information. Person [26] got internal
confirmation feedback from the support group for some of the readings he had done pertaining to prostate cancer. Some individuals also stated that they became more reflective about alternative therapies and diet. Person [7] who did not yet have a treatment was interested in the appraisal related to other individuals rather than to himself. He was curious to know how others, who had treatments, were now coping.

Not all individuals attended a support group only because of emotional, esteem, network or appraisal support. There were many other reasons for attending as well. One individual found it encouraging to listen to the helpful words of the oncologists and urologists [4a]. Another individual was appreciative of what support groups do in general, and he was appreciative of their library and sharing of experiences [9]. Others attended support groups because they were interested in the new information that they gained about their prostate cancer in these groups. For example, person [11] indicated that he liked the advice and education provided by a medical doctor at the support group.

Individuals that attended support groups stated that they got lots of help towards their positive coping from their support group. One theme that emerged from these interviews was that the support group helped these men to realize that they are not alone with this illness, and they enjoyed the sharing of their experiences with others [4a, 8, 11]. They also liked to be in the company of each other. One individual put it this way: “You're not the only one that has the problem, and how to deal with the problem. That’s what I liked the support group for, and you help others who are in my same predicament” [8].
Besides helping individuals in their coping, support groups served as a catalyst for promoting a healthy life-style. Many individuals that attended support groups now claimed that they ate more vegetables, such as broccoli, tomato products and supplements [1,3,7,8]. For example, person [1] stated,

“So you turn around and now you make sure you eat fresh vegetables and you know to supplement that. So what are the vitamins that really help fight cancer after you’ve got it? Okay, so those kinds of things come out of these meetings as well as getting to know people.” Drinking tomato juice and green tea and all that good stuff and lots of fruits and vegetables.

Person [14] put it this way,

“So now I’m on this kind of diet and I’ve said as I did before I haven’t had a cold in four years. So obviously it’s working and doing something for my immune system. So that’s what happened. So to answer your question is that from the information I probably got moral support.”

The “altruistic support” seemed to apply to those who had taken a leadership role in their support groups. Many of these individuals got a sense of satisfaction for helping those that were newly diagnosed with prostate cancer. Some found it productive and satisfying to take on a lead role [8]. Others tried to instill a positive attitude in their membership [18]. For example, person [3] stated,

“Oh, well I think just the reward of helping people, I think is the biggest reward. To be able to talk to people, and ah, for instance, on their first trip into the support group they are always scared, terrified, and at the conclusion of the very first support, they go out feeling much calmer. So that’s a reward, helping.”

Some individuals that had not attended a support group claimed that they did not attend primarily because they did not know that a support group existed, and now since they have had the treatment, they did not see the benefit of going there. One person
wanted to put a closure on his cancer, and did not want to be reminded about a “down point” in his life.

Contrary to the hypothesis in this study, some other individuals also experienced negative emotions about attending the prostate support groups. Some, especially at the advanced stages of their cancer, found it depressing to find pessimistic information related to their condition. For example, person [10] stated it this way: “Surgery has not worked for me, so I find it depressing to get pessimistic information” [10]. Another individual expressed his dilemma about attending support groups by explaining,

“I was a high-risk group. I did not react to radiation and they say, once you’re through that, they can’t radiate again so then it comes back, there’s really no cure. I walk out of there every time with some of that kind of input and that, I find that very depressing. So I don’t want to go because I know I’m going to come out of there depressed, but I go because you can’t put your head in the sand and say, you know, it will be fine, but that’s not right either. I should be educated about it, I should find out more about it and I want to support the group as well, but there’s good information, but I always find it very depressing.” [10]

To sum up, in addition to the five dimensions of social support outlined by McCubbin and McCubbin, prostate support groups provided technical information regarding different treatments and they also promoted positive coping and a healthier lifestyle. Many individuals might have changed their dietary habits because they attended a prostate support group.

To gain a better understanding of the positive coping role that support groups might have played for the support group membership as a whole, various quantitative data analyses were also carried out (see Table 4).
### Table 4

Percentages of individuals indicating support group benefits.

<table>
<thead>
<tr>
<th>Variable</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Educational knowledge</strong></td>
<td>73</td>
<td></td>
</tr>
<tr>
<td>Do not attend</td>
<td></td>
<td>02.7</td>
</tr>
<tr>
<td>Not satisfied</td>
<td></td>
<td>04.1</td>
</tr>
<tr>
<td>Some benefit</td>
<td></td>
<td>23.3</td>
</tr>
<tr>
<td>A lot of benefit</td>
<td></td>
<td>69.9</td>
</tr>
<tr>
<td><strong>Treatment knowledge</strong></td>
<td>73</td>
<td></td>
</tr>
<tr>
<td>Do not attend</td>
<td></td>
<td>01.4</td>
</tr>
<tr>
<td>Some benefit</td>
<td></td>
<td>28.8</td>
</tr>
<tr>
<td>A lot of benefit</td>
<td></td>
<td>69.9</td>
</tr>
<tr>
<td><strong>Emotional support</strong></td>
<td>54</td>
<td></td>
</tr>
<tr>
<td>Do not attend</td>
<td></td>
<td>03.7</td>
</tr>
<tr>
<td>Not satisfied</td>
<td></td>
<td>01.9</td>
</tr>
<tr>
<td>Some benefit</td>
<td></td>
<td>29.6</td>
</tr>
<tr>
<td>A lot of benefit</td>
<td></td>
<td>64.8</td>
</tr>
<tr>
<td><strong>Chance to learn from others</strong></td>
<td>68</td>
<td></td>
</tr>
<tr>
<td>Do not attend</td>
<td></td>
<td>01.5</td>
</tr>
<tr>
<td>Not satisfied</td>
<td></td>
<td>01.5</td>
</tr>
<tr>
<td>Some benefit</td>
<td></td>
<td>22.1</td>
</tr>
<tr>
<td>A lot of benefit</td>
<td></td>
<td>55.4</td>
</tr>
</tbody>
</table>

In the quantitative questionnaire, members from the support group were asked about how satisfied they were with the different benefits they gained from their prostate support group in terms of: educational knowledge, treatment knowledge, emotional support, and an opportunity to learn from experiences of others. Close to 70% percent of the individuals felt that they gained much educational knowledge and treatment knowledge from attending support groups. Further, 75% of the individuals felt that they
had learned much from others. However, 64.4% of the individuals were satisfied with the emotional support offered by the support groups. Interestingly, from a total of 92 individuals (not all were attending a support group), 38 did not respond to the question related to emotional support. But for the educational and treatment support questions, only 19 individuals did not respond to these questions. The above findings indicate that the emotional support was perceived to be lower in the support groups, compared to some of the other kinds of benefits provided. The qualitative interviews indicated that the reason for this may be that some individuals felt that the support groups were not structured to provide them with one-to-one discussions. Also, some individuals felt that it wasn’t the role of the support group to provide emotional support in the first place.

Implications for support groups

As a whole, support groups seem to be doing an excellent job, as perceived by the members that attend these groups. However, if support group facilitators wish to do so, they may seek ways to promote emotional support in their groups by encouraging one-to-one discussions. They may also wish to promote opportunities for a personal touch towards their members. One possibility might be to have more social gatherings where individual members may socialize with one another on a personal level.
Hypothesis 3: Depression level found in these individuals will be lower than those found in previous studies because 95.5% of these men have attended support groups. This support group help may alleviate some of their symptoms of depression.

Hypothesis 4: When asked about stressful aspects, most individuals may talk about their treatment side effects related to incontinence and impotence. Individuals with prostate cancer may talk about incontinence and impotence since these are symptoms resulting from common forms of available treatment.

CES-D (depression) scores for 87 men indicated that only a total of 4.6% of them experienced moderate and major depression. Major depression by itself was 2.3%. However, this finding is different from previous findings amongst men with prostate cancer and elderly men in general. For example, Heim and Oei (1993) found moderate to severe depression only in about 15% of the prostate cancer patients, which was consistent with the depression level generally found in the elderly. However, this study found moderate and major depression of only 4.6%. One explanation for this discrepancy may be that a vast majority of men (84 from 88) were currently attending a support group. Therefore, the benefit gained from the social group may have led to lower results of depression in these men.

Secondly, the relationship between time after diagnosis and mood disturbance is presently not clear for men with prostate cancer. Litwin et al. (1995) indicate that as time after initial diagnosis elapses, mood disturbance decreases (Litwin et al., 1995); however, other authors indicate that mood disturbance increases from the time of diagnosis due to
increasing treatment side effects (Herr, 1994). However, this study’s finding is different from both Litwin et al. and Herr since no significant correlation was found between diagnosis date and the level of depression, $r = .020$, $p = .854$ (two-tailed).

Also, the relationship between symptom distress (treatment side effects) and mood disturbance is presently unclear for prostate cancer individuals, some studies suggesting there may be a correlation (Lubeck et al., 1999). In fact, this study found a significant negative correlation ($r = -.451$ $p < .001$) between depression and quality of life as measured by the total FACT-P (version 4) “additional concerns” score. Given that additional concerns are derived from the treatment side-effects items, there would be a strong positive correlation between depression and treatment side effects.

As was predicted, men with prostate cancer did speak about the stress related to incontinence and impotence. Stress related to incontinence ranged from having to wear pads, limited bladder control, and sometimes having wet pants. Also, some found it difficult to wear the catheter. Impotence was stressful for many men as well. Some men experienced difficulties from not being able to have an active sexual ability. The above findings are consistent with the results obtained by others that often these patients live with pain, incontinence, and sexual dysfunction (Litwin, 1995). These symptoms are the result of common forms of treatments that are available for prostate cancer.

However, in addition to the above mentioned difficulties, going through the diagnosis stage was also very stressful. Some men found that the diagnosis was told bluntly to them, and it was difficult to hear the news [14, 19]. Person [25] found the initial
few weeks after the diagnosis to be very stressful. After the diagnosis, some men [1, 4a, 4b] worried that they did not like the feeling of having cancer inside them. They wanted to get rid of their cancer quickly. Many men not only felt the stress of getting rid of their cancer but also they found it difficult to decide which treatment to choose. Basically, it was difficult deciding what to do [2, 4a, 5, 8, 15, 16]. One man even thought that the medical establishment itself didn’t have enough information within themselves on which he could base his decision [7].

There was also uncertainty around the procedures at the hospital. As an example, person [6] stated, “I’m an engineer by background. I like to know things and I’ve been very fortunate that I have been healthy, and ah, I really don’t know, didn’t know a hospital from the inside and everything that is, kind of, very normal to the urologist and the nurses, to me was all new, and the uncertainty of that, to me, was the most stressful thing, and ah, as I said in my little write up, going to the support group, I was able to connect with people and there’s one specially and we’ve become friends now, we are now socializing together.” Besides an uncertainty around the procedures at the hospital, another individual [4b] found it very difficult to travel to get his treatments, especially when he was having a burning sensation from his radiation treatments. In fact, his wife had to drive him to his treatments.

After the treatment, stress continued for many men who did not know whether or not the treatment was successful or not. As person [10] indicated, the most stressful part is that one never knows where cancer is. Others dealt with issues such as life versus death [3, 9]: “I guess the most stressful part is not knowing how long I’ve got to live because
mine's an advanced case” [3]. The other worry was related to concern regarding family members after one dies.

**Implications for health professionals**

Even though some individuals with high stress level can be distinguished with the CES-D scale, many continue to have on-going stress in their lives. Stress starts from the time an individual is diagnosed, and if continues throughout the lives of these men as some worry about the recurrence of their cancer. Further, this stress not only impacts the patient but his whole family. Therefore, both the men and their spouses should be counselled together about the implications of the treatments. Some of the critical periods for counselling seem to be at the diagnosis stage, and prior to treatment. However, a proper follow-up is also very important, especially for those individuals that may have difficulty accessing medical clinics. Another suggestion would be to have a list of the mentors (survivors) with different kinds of treatments, and to make this list available for those that are newly diagnosed with prostate cancer. These mentors then could help support newly diagnosed individuals with prostate cancer.
Hypothesis 5: Because elderly individuals with prostate cancer may have declining perspective-taking abilities compared with younger individuals (Suls et al., 1991), social comparison would be rare in this older group.

I obtained results totally different from the above hypothesis. In fact, 87.3% (N = 76 from a total valid N = 87) of individuals with prostate cancer claimed that they had made a downward social comparison. It was expected that these men would make a downward social comparison, but such a high percentage of individuals making this downward social comparison was not expected (see Table 5).

Table 5

Percentages of individuals who thought of people who are worse off: Mental Adjustment to Cancer Scale item number 28 (N = 87).

<table>
<thead>
<tr>
<th>Variable</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Definitely no</td>
<td>04.6</td>
</tr>
<tr>
<td>Does not apply</td>
<td>08.0</td>
</tr>
<tr>
<td>Applies to me</td>
<td>60.9</td>
</tr>
<tr>
<td>Definitely applies to me</td>
<td>26.4</td>
</tr>
</tbody>
</table>

Furthermore, according to Buunk et al. (1990), it was expected that only those individuals with high self-esteem may make such comparisons. Thus, I wanted to see if there was a correlation between one's depression level or optimism level and the downward social comparison (item 28 on the Mental Adjustment to Cancer scale). As shown by Table 6,
this study failed to find any significant correlation between social comparison and optimism, or between depression and social comparison.

Table 6
Correlation between downward social comparison and depression (N=86), as well as correlation between downward social comparison and optimism (N=83).

<table>
<thead>
<tr>
<th></th>
<th>CES-D Total score</th>
<th>LOT-R Total score</th>
</tr>
</thead>
<tbody>
<tr>
<td>I think of other people who are worse off.</td>
<td>.052</td>
<td>.051</td>
</tr>
<tr>
<td>Sig. (2-tailed)</td>
<td>.633</td>
<td>.649</td>
</tr>
</tbody>
</table>

Further, I wanted to investigate if these individuals only make downward social comparisons, and what might be their motivation for making downward social comparisons. To answer the above questions, I turned to qualitative interview data. By making a downward social comparison, these individuals felt lucky [5, 9, 22, 26] or thought that they were comfortable [16, 20]. Others felt good because their treatment had worked [7], and some wanted to support those who were worse off [11]. Many also felt a personal loss for the deceased individual members in their groups. Some also made comparison with other diseases, rather than with other individuals. For example, person [6] stated that it would be worse to have Alzheimer's.

One individual made an upward and a downward social comparison [3]. Even though he was envious of others who had done well, he had a feeling of encouragement and well-being to see that one could do better. For example, person [3] stated,
Well, when I look at some guys that are a lot worse off than me, I feel better and I see some guys that actually got cured and I’m envious of them because I won’t be cured, you see, but I’m not popping off tomorrow, I mean I’ll be around for a while yet but, yah, so there’s envy for the guys that have done well and a little bit of feeling not too bad when I see the others...Well the support group is actually what’s helped most of anything. Well in the sense that I’ve seen and dealt with other fellows in the same situation and I see them surviving and doing well and it gives me that kind of encouragement and a feeling of well-being and that’s helped the most of anything.

A few of the individuals also made temporal comparisons. For example, person [8] felt that it was worse when he lost one of his eyes, and person [9] stated that he was a survivor at handling difficulties in his life. In fact, person [8] found his prostate cancer to be a “breeze” compared to the eyesight that he had lost.
Hypothesis 6: Because information regarding the coping strategies that survivors of prostate cancer use is currently lacking, the results of this study should describe the kinds of coping strategies that facilitate positive coping.

As mentioned previously, religious prayer and personal strength gained from religion played a role in the positive coping of these men with prostate cancer. Another aspect that facilitated positive coping was being a member of the prostate support group. Other positive coping aspects mentioned by these individuals were: (1) having control over one’s illness by educating oneself; (2) accepting one’s illness; (3) reframing the illness in a positive way. Persons [2, 17] indicated that researching their problem provided them with a feeling of control. Being educated about one’s illness also eliminated one’s ignorance about prostate cancer. The strategy of accepting one’s illness made it easier on the individual to deal with it constructively [11]. It was also the fighting and positive attitude that helped:

“Well attitude is one, I think it is very important that you say, well, there is a condition and I’m going to fight it. Second is to acquire knowledge about how to cope with it and third the group is a really important element, because you find emotional support, you find people with the same condition and how to deal with it and so on and so you try to make yourself able to cope a little better.” [13]

As stated above, it was many of these coping support elements working synergistically that promoted positive coping in men with prostate cancer. Support from spouses, family and friends was another important element. Family and friends provided reassurance that things will work out, and many spouses also went along to visit the doctor and to the support groups. For person [4b], his wife drove him to another city for
radiation treatments. Men were also pleased when they and their spouses had reached the treatment decision together. Therefore, coping involved both problem-focused and emotion-focused strategies.

**Implications for health professionals:**

In order to facilitate positive coping in men with prostate cancer, it is very important to encourage their spouses to take an active role throughout their medical treatments and coping processes. Individuals with prostate cancer should also be encouraged to take control over their illness by educating themselves about prostate cancer, and by reframing their cancer in a positive way.
Hypothesis 7: Even though some survivors of cancer experience psychological growth, not much is known about the details of this psychological growth. This study presumes that psychological growth from the experiences of survivors of prostate cancer. This study predicts that survivors of prostate cancer should experience psychological growth. This study also suggests that posttraumatic growth might be related to one’s coping processes, depression and quality of life.

Perceived growth is believed to occur in three domains: changes in the perceptions of the self, changes in relationship with others, and changes in one’s philosophy of life, with new life directions and priorities (Tedeschi & Calhoun, 1996). In this study, one of the ways in which individuals indicated a change in life priorities was that now some persons were trying to keep themselves busy so that they will not think about their prostate cancer. The following comment from person [3] illustrates this point: “Golf, tennis, travel, yeah, I’m having fun and I don’t spend a lot of time worrying about it, and that’s the truth, although, it’s there, I’m not saying I’m that carefree, I’m not. It still hangs over your head, but I’ve never been in depression, not even close.” So, some individuals had changed their life through self-distraction strategies.

Some others stated that now they were able to have more appreciation of life and others, especially the ones that needed help. There was some change in their relationship with others, as predicted by Tedeschi and Calhoun. A summary of the comments in this category were: I better appreciate things now [9]; I have become closer to people [14]; I am more charity minded, and I want to give something back [16]. Further, following
comments provided by the survivors indicate that posttraumatic growth does not result from cognitive distortions or illusions:

Eventually you meet so many potential life-taking situations, I had two valves replaced and had Lymphoma three times, so I'm already starting to get an appreciation that life is precious and that's something that seems to grow as I get older, because really through my adult life, the only hobby I had was business and ah it's still my hobby but I know now I have some balance. I look at trees in wonderment and the sky etc. I can do those things, like stop and smell the roses, and ah, I work at a much slower pace. I’ve gone out on my own and it's a much more relaxed pace, much more manageable. I can take control of my time. I’m in a position to retire and I don’t want to and I don’t intend to and from that perspective, ah, it's different. Also, I’m much more, I call it charity minded in terms of prostate cancer, being active, giving something back. [16]

You know, I’ve slowed down and am trying to enjoy life a little more, not be quite as worried about the little things and try to be a little more talkative about people’s problems. [15]

These individuals’ written comments (see Appendix O) about how they perceived changes in their priorities of life also echoed similar themes as found in the qualitative interviews. These themes were: each day is a gift; now I have greater appreciation for life; greater appreciation for health; greater appreciation for relationships; lesser significance for material things; greater compassion for people dealing with life issues, and strengthened faith in God. Some individuals helped out at the prostate support group, whereas others changed their diet. Other comments were: people should live their lives with less concern for material things, and I still feel lucky compared to people who have more serious illnesses, such as blindness, and MS. However, not all men experienced changes in their priorities of life.

Some men’s comments about the changes in their families were consistent with ‘The Dialectic of Maintaining Hope.’ While there continued to be some stress in the families, these families were also strengthened because of their experience with this
illness. The stress and strengthening seem to coexist in these families. This coexistence of stress and getting closer together are illustrated by the following example:

There was a lot of stress before but it has helped in my relationship with my wife. I always had good relations with my children but with my wife, it hasn't always been good, although I think that she supports me. I've changed my approach to life and I make a special effort now to snuggle up to her and avoid complicating our life, because she has, all of a sudden, become very precious to me. [14]

Persons [5, 10] indicated that cancer had brought their families closer together and now they spent more quality time with each other. However, there were some individuals who said that they had no change in their families because of their experiences with cancer [8, 15, 22]. Further, a diagnosis of cancer was worrisome for some children as they feared that their dad may pass away [11]. Some other individuals also indicated that now they wanted their own sons to be educated about prostate cancer so that they don't end on the short end of the stick [11, 13].

To find out the kind of posttraumatic growth that occurred the most, I looked at the frequencies of the responses to various individual items that make up the posttraumatic growth inventory (see Table 7 below).
Table 7

Percentages of men with Prostate Cancer showing Posttraumatic Growth on the items of the Posttraumatic Growth Inventory

<table>
<thead>
<tr>
<th>Posttraumatic Growth Inventory Item *</th>
<th>Total N</th>
<th>Valid N</th>
<th>Valid % with “Great” and “Very Great” change</th>
</tr>
</thead>
<tbody>
<tr>
<td>I changed my priorities about what is important in life</td>
<td>92</td>
<td>82</td>
<td>28</td>
</tr>
<tr>
<td>I have a greater appreciation for the value of my own life</td>
<td>92</td>
<td>83</td>
<td>38.6</td>
</tr>
<tr>
<td>I developed new interests</td>
<td>92</td>
<td>79</td>
<td>5</td>
</tr>
<tr>
<td>I have a greater feeling of self-reliance</td>
<td>92</td>
<td>80</td>
<td>8.8</td>
</tr>
<tr>
<td>I have a better understanding of spiritual matters</td>
<td>92</td>
<td>81</td>
<td>14.2</td>
</tr>
<tr>
<td>I more clearly see that I can count on people in times of trouble</td>
<td>92</td>
<td>81</td>
<td>22.2</td>
</tr>
<tr>
<td>I established a new path for my life</td>
<td>92</td>
<td>80</td>
<td>13.8</td>
</tr>
<tr>
<td>I have a greater sense of closeness with others</td>
<td>92</td>
<td>80</td>
<td>22.5</td>
</tr>
<tr>
<td>I am more willing to express my emotions</td>
<td>92</td>
<td>81</td>
<td>26</td>
</tr>
<tr>
<td>I know better that I can handle difficulties</td>
<td>92</td>
<td>81</td>
<td>29.6</td>
</tr>
<tr>
<td>I am able to do better things with my life</td>
<td>92</td>
<td>80</td>
<td>18.8</td>
</tr>
<tr>
<td>I am better able to accept the way things work out</td>
<td>92</td>
<td>82</td>
<td>28</td>
</tr>
<tr>
<td>I can better appreciate each day</td>
<td>92</td>
<td>83</td>
<td>38.6</td>
</tr>
<tr>
<td>New opportunities are available which wouldn’t have been otherwise</td>
<td>92</td>
<td>79</td>
<td>13.9</td>
</tr>
<tr>
<td>I have more compassion for others</td>
<td>92</td>
<td>83</td>
<td>30.1</td>
</tr>
<tr>
<td>I put more effort into my relationships</td>
<td>92</td>
<td>80</td>
<td>23.8</td>
</tr>
<tr>
<td>I am more likely to try to change things which need changing</td>
<td>92</td>
<td>81</td>
<td>22.2</td>
</tr>
<tr>
<td>I have a stronger religious faith</td>
<td>92</td>
<td>82</td>
<td>17.1</td>
</tr>
<tr>
<td>I discovered that I am stronger than I thought I was</td>
<td>92</td>
<td>81</td>
<td>27.1</td>
</tr>
<tr>
<td>I learned a great deal about how wonderful people are</td>
<td>92</td>
<td>82</td>
<td>29.3</td>
</tr>
<tr>
<td>I better accept needing others</td>
<td>92</td>
<td>82</td>
<td>28.1</td>
</tr>
</tbody>
</table>

* Copyright 1996, Tedeschi & Calhoun. Used by permission.
The top five percentages based on table 7 above are: (1) I have a greater appreciation for the value of my own life; (2) I can better appreciate each day; (3) I have more compassion for others; (4) I know better that I can handle difficulties; (5) I learned a great deal about how wonderful people are. Interestingly, during the qualitative interviews there were only about two individuals who indicated that now they could better handle difficulties, so that is one aspect that was not apparent during the interviews. Also, during the interviews, men generally talked about the various helping roles that had been taken to help other people, and they had appreciated the help that they got from others; but they did not specifically mention learning about how wonderful people are. However, one-third of these men with prostate cancer saying that they had a ‘great’ or a ‘very great’ change in the posttraumatic growth aspects indicates that their perception about posttraumatic growth may be real. This posttraumatic growth was supported both by the qualitative interviews and the quantitative data (see Appendix O)

Moreover, I wanted to investigate how posttraumatic growth was related to one’s coping processes, depression, and quality of life, as measured by the FACT-G, and FACT-P scale. To answer these questions, many correlational and Multiple Regression Stepwise were carried out, and a summary of these regression analyses is presented below in Tables 8 through 12.
Table 8

Spearman’s rho 2 -tailed zero-order correlations for Posttraumatic Growth (PTGI-total score) with other variables from the Brief Cope and the Mental Adjustment to Cancer coping scale.

<table>
<thead>
<tr>
<th>Variable Name</th>
<th>PTGI total score</th>
<th>N</th>
<th>Sig. Level</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Significant Correlations</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MAC factor 1: Fighting Spirit</td>
<td>.315</td>
<td>79</td>
<td>p&lt;.005</td>
</tr>
<tr>
<td>MAC factor 2: Anxious Preoccupation</td>
<td>.310</td>
<td>79</td>
<td>p&lt;.005</td>
</tr>
<tr>
<td>Brief Cope: Self-distraction</td>
<td>.303</td>
<td>79</td>
<td>p&lt;.007</td>
</tr>
<tr>
<td>Brief Cope: Active Coping</td>
<td>.331</td>
<td>79</td>
<td>p&lt;.003</td>
</tr>
<tr>
<td>Brief Cope: Denial</td>
<td>.233</td>
<td>79</td>
<td>p&lt;.039</td>
</tr>
<tr>
<td>Brief Cope: Use of emotional support</td>
<td>.309</td>
<td>79</td>
<td>p&lt;.006</td>
</tr>
<tr>
<td>Brief Cope: Use of instrumental support</td>
<td>.222</td>
<td>79</td>
<td>p&lt;.049</td>
</tr>
<tr>
<td>Brief Cope: Religion</td>
<td>.316</td>
<td>79</td>
<td>p&lt;.005</td>
</tr>
<tr>
<td><strong>Non-Significant Correlations:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MAC factor 2: Helpless / Hopeless</td>
<td>-.004</td>
<td>79</td>
<td>p&lt;.974</td>
</tr>
<tr>
<td>MAC factor 4: Fatalism</td>
<td>.089</td>
<td>79</td>
<td>p&lt;.437</td>
</tr>
<tr>
<td>Brief Cope: Substance Use</td>
<td>.053</td>
<td>79</td>
<td>p&lt;.641</td>
</tr>
<tr>
<td>Brief Cope: Behavioral Disengagement</td>
<td>.120</td>
<td>79</td>
<td>p&lt;.291</td>
</tr>
<tr>
<td>Brief Cope: Venting</td>
<td>.206</td>
<td>79</td>
<td>p&lt;.068</td>
</tr>
<tr>
<td>Brief Cope: Positive Reframing</td>
<td>.181</td>
<td>79</td>
<td>p&lt;.111</td>
</tr>
<tr>
<td>Brief Cope: Planning</td>
<td>.241</td>
<td>79</td>
<td>p&lt;.059</td>
</tr>
<tr>
<td>Brief Cope: Humor</td>
<td>.120</td>
<td>79</td>
<td>p&lt;.294</td>
</tr>
<tr>
<td>Brief Cope: Acceptance</td>
<td>.129</td>
<td>79</td>
<td>p&lt;.257</td>
</tr>
<tr>
<td>Brief Cope: Self-blame</td>
<td>-.031</td>
<td>79</td>
<td>p&lt;.786</td>
</tr>
</tbody>
</table>

Table 8 indicates the factors that were both significantly and non-significantly correlated with the Posttraumatic Growth score.
Table 9
Spearman's rho zero order correlations between Posttraumatic Growth (PTGI-total score) and Religious variables

<table>
<thead>
<tr>
<th>Variable Name</th>
<th>PTGI total score</th>
<th>N</th>
<th>Sig. Level</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Significant Correlations:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DUREL item 3-5: Intrinsic religious motivation</td>
<td>.230</td>
<td>79</td>
<td>p&lt;.042</td>
</tr>
<tr>
<td>DUREL item 1: Organized religious activities</td>
<td>.379</td>
<td>79</td>
<td>p&lt;.001</td>
</tr>
<tr>
<td>DUREL item 2: Non-organized religious activities</td>
<td>.335</td>
<td>79</td>
<td>p&lt;.003</td>
</tr>
</tbody>
</table>

Table 9 shows that the religious items in the DUREL scale were positively correlated with the total Posttraumatic growth score.

Table 10
Spearman's rho zero order correlations between Posttraumatic Growth (PTGI-total score) and some other variables

<table>
<thead>
<tr>
<th>Variable Name</th>
<th>PTGI total score</th>
<th>N</th>
<th>Sig. Level</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Significant Correlations:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>FACT general factor 2: Social / Family wellbeing</td>
<td>.327</td>
<td>79</td>
<td>p&lt;.003</td>
</tr>
<tr>
<td><strong>Non-significant Correlations:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diagnosis Date</td>
<td>-.010</td>
<td>79</td>
<td>p&lt;.930</td>
</tr>
<tr>
<td>Sense of Coherence factor: Meaningfulness</td>
<td>.041</td>
<td>78</td>
<td>p&lt;.724</td>
</tr>
<tr>
<td>Sense of Coherence factor: Manageability</td>
<td>-.048</td>
<td>78</td>
<td>p&lt;.679</td>
</tr>
<tr>
<td>Sense of Coherence factor: Comprehension</td>
<td>-.085</td>
<td>78</td>
<td>p&lt;.458</td>
</tr>
<tr>
<td>Sense of Coherence: Total score</td>
<td>-.045</td>
<td>78</td>
<td>p&lt;.694</td>
</tr>
<tr>
<td>LOT-R total score: Optimism</td>
<td>.128</td>
<td>75</td>
<td>p&lt;.275</td>
</tr>
<tr>
<td>Depression (CES-D)</td>
<td>.095</td>
<td>78</td>
<td>p&lt;.407</td>
</tr>
</tbody>
</table>

Table 10 indicates that social / family wellbeing (factor 2 of the FACT scale) was positively and significantly correlated with the total PTGI score. On the other hand, Sense of Coherence factors, depression, and Optimism were not significantly correlated with the total PTGI score.
Table 11

Spearman’s rho zero Sense of Coherence zero order correlations with some other factors

<table>
<thead>
<tr>
<th>Variable Name</th>
<th>Sense of Coherence Total score</th>
<th>N</th>
<th>Sig. Level</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Significant Correlations:</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>LOT-R Total score (Optimism)</td>
<td>.235</td>
<td>82</td>
<td>p&lt;.033</td>
</tr>
<tr>
<td>CES-D Total score (Depression)</td>
<td>-.516</td>
<td>85</td>
<td>p&lt;.001</td>
</tr>
</tbody>
</table>

Table 11 indicates that the Sense of Coherence was positively and significantly correlated with the LOT-R total score.
Table 12

Multiple regression stepwise for Posttraumatic Growth (PTGI) and for the Quality of Life Measure (FACT-G, FACT-P scale).

<table>
<thead>
<tr>
<th>Analysis No.</th>
<th>R square</th>
<th>Dependent Variable</th>
<th>Independent Variable</th>
<th>Model Factors</th>
<th>Standardized Beta Values</th>
<th>T</th>
<th>Sig. Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>.319</td>
<td>PTGI Total score</td>
<td>Mac factors 1-5:</td>
<td>Religion,</td>
<td>.32</td>
<td>3.2</td>
<td>p&lt;.002</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Fighting Spirit,</td>
<td>Self-</td>
<td>.196</td>
<td>1.86</td>
<td>p&lt;.067</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Helpless /</td>
<td>distraction</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Hopeless,</td>
<td>Mac factor 3:</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Anxious Preoccupation</td>
<td>Anxious</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Fatalism,</td>
<td>Preoccupation,</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Avoidance /</td>
<td>Mac factor 1:</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Denial,</td>
<td>Fighting</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Brief Cope Factors:</td>
<td>Spirit</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Self-distractions,</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>Active coping,</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Denial,</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Substance Use,</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>Use of Emotional</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>support,</td>
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<td></td>
<td></td>
<td></td>
<td>Use of instrumental</td>
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<td>support,</td>
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<td></td>
<td></td>
<td></td>
<td>Behavioral</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>disengagement,</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>Venting,</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>Positive Reframing,</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td>Planning,</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Humor,</td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>Acceptance,</td>
<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Religion,</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td>Self-blame</td>
<td></td>
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</tr>
</tbody>
</table>
Analysis Number 1: In analysis number one, the significant independent variable for the final multiple regression stepwise model were religion, self-distraction, anxious preoccupation, and fighting spirit. The R square value of .319 indicates that 31.9% of the variance in the PTGI total score (dependent variable) was predicted by the independent variables of religion, self-distraction, anxious preoccupation and fighting spirit.

<table>
<thead>
<tr>
<th>Analysis No.</th>
<th>R square</th>
<th>Dependent Variable</th>
<th>Independent Variable</th>
<th>Model Factors</th>
<th>Standardized Beta Values</th>
<th>T</th>
<th>Sig. Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>.296</td>
<td>PTGI Factor 1: Relating to others</td>
<td>Brief Cope Factors, DUREL items 1-5, FACT components: Physical well-being, Emotional well-being, Social / Family well-being, Optimism (LOT-R), Mac Factors: Fighting Spirit, Anxious Preoccupation,</td>
<td>FACT Factor: Social / Family well-being, Mac Factor 3: Anxious Preoccupation, Denial</td>
<td>.385</td>
<td>3.75</td>
<td>p&lt;.001</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.289</td>
<td>2.80</td>
<td>p&lt;.007</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.209</td>
<td>2.01</td>
<td>p&lt;.048</td>
</tr>
</tbody>
</table>

Analysis Number 2: In this multiple regression stepwise analysis, PTGI factor 1: Relating to others, was predicted by the significant independent variables social / family wellbeing (FACT factor), anxious preoccupation (MAC factor 3), and denial (Brief Cope factor). The R square value of .296 indicates that 29.6% of the variance in the PTGI factor 1: Relating to others was predicted by the independent variables of social / family wellbeing, anxious preoccupation and denial.
Analysis Number 3: In this multiple regression stepwise, appreciation of life (PTGI factor 5) was predicted by the significant independent variables (Brief Cope factors) religion and use of emotional support. In fact, 18% of the variance in PTGI factor 5 was predicted by the independent variables of religion and use of emotional support.
Analysis Number 4: In this multiple regression stepwise, spiritual change (PTGI factor 4) was predicted by the significant independent variables religion (Brief Cope factor), self-distraction (Brief Cope factor) and social / family wellbeing. A large variance of 57.6% in PTGI factor 4 (spiritual change) was predicted by religion, self-distraction and social / family wellbeing.
Analysis Number 5: In this multiple regression stepwise, personal strength (PTGI factor 3) was predicted by significant independent variables (Brief Cope factors) fighting spirit, denial, religion, and FACT factor physical wellbeing, when taken together with a negative significant value of functional wellbeing.
<table>
<thead>
<tr>
<th>Analysis No.</th>
<th>R square</th>
<th>Dependent Variable</th>
<th>Independent Variable</th>
<th>Model Factors</th>
<th>Standardized Beta Values</th>
<th>T</th>
<th>Sig. Level</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.260</td>
<td>2.50</td>
<td>p&lt;.015</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.238</td>
<td>2.21</td>
<td>p&lt;.030</td>
</tr>
</tbody>
</table>

Analysis Number 6: In this multiple regression stepwise, new possibilities (PTGI factor 2) was predicted by the significant independent variables Brief Cope self-distraction, DUREL item 1-religion organized activities, and MAC factor -anxious preoccupation. A 26% of the variance in New Possibilities (PTGI factor 2) was predicted by distraction, religious organized activities and anxious preoccupation.
<table>
<thead>
<tr>
<th>Analysis No.</th>
<th>R square</th>
<th>Dependent Variable</th>
<th>Independent Variable</th>
<th>Model Factors</th>
<th>Standardized Beta Values</th>
<th>T</th>
<th>Sig. Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>7</td>
<td>.388</td>
<td>PTGI all factors</td>
<td>Brief Cope Factors,</td>
<td>Social / Family well-being,</td>
<td>.344</td>
<td>3.68</td>
<td>p&lt;.001</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>DUREL items 1-5,</td>
<td>Anxious preoccupation</td>
<td>.269</td>
<td>2.80</td>
<td>p&lt;.007</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>FACT components:</td>
<td>Physical well-being,</td>
<td>.314</td>
<td>3.37</td>
<td>p&lt;.001</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Emotional well-being,</td>
<td></td>
<td></td>
<td></td>
</tr>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>Social / Family well-being,</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>FACT-G total without the additional concerns,</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>FACT-P additional concerns total,</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Optimism (LOT-R),</td>
<td>Self-distraction</td>
<td>.245</td>
<td>2.56</td>
<td>p&lt;.013</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Mac Factors: Fighting Spirit,</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Analysis Number 7: In this multiple regression stepwise, PTGI all factors were predicted by the significant independent variables social / family wellbeing, anxious preoccupation, religion and self-distraction. A 38.8% of the variance in PTGI all factors was predicted by the above mentioned independent factors.
In the following analyses, the dependent variable was Quality of Life. Quality of Life can be represented by the total FACT-G score which does not include the “Additional Concerns,” which are specific to Prostate Cancer. One can also represent Quality of Life score FACT-G with the additional concerns. The Brief Cope was not chosen as a dependent variable because this study was interested only in the kinds of coping strategies that would predict posttraumatic growth and the quality of life.

<table>
<thead>
<tr>
<th>Analysis No.</th>
<th>R square</th>
<th>Dependent Variable</th>
<th>Independent Variable</th>
<th>Model Factors</th>
<th>Standardized Beta Values</th>
<th>T</th>
<th>Sig. Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>8</td>
<td>.657</td>
<td>FACT-G: total score + Additional concerns</td>
<td>Brief Cope Factors, DUREL items 1-5, Optimism (LOT-R), Mac Factors: Fighting Spirit, Helpless / Hopeless, Anxious preoccupation, Fatalism, Avoidance, Depression (CESD-total) Sense of coherence (soc total)</td>
<td>Depression Fighting spirit, SOC total score</td>
<td>-.562</td>
<td>-6.47</td>
<td>p&lt;.001</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.332</td>
<td>4.57</td>
<td>p&lt;.001</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.191</td>
<td>2.23</td>
<td>p&lt;.029</td>
</tr>
</tbody>
</table>

Analysis Number 8: In this multiple regression stepwise, FACT-G total score and “Additional concerns” from FACT-G related to prostate cancer – were positively predicted by the independent variables fighting spirit and sense of coherence total score. The quality of life was negatively predicted by depression. In fact, 65.7% of the variance in quality of life could be accounted by the independent variables depression, fighting spirit, and sense of coherence.
Analysis Number 9: In this multiple regression stepwise, FACT-G total score and additional concerns related to prostate cancer on the FACT scale were positively predicted by the fighting spirit and negatively predicted by self-distraction and anxious preoccupation. A total variance of 32.2% in the quality of life measure could be accounted by the fighting spirit, self-distraction, and anxious preoccupation.

Analysis Number 10: In this multiple regression stepwise, FACT-G without the additional concerns related to prostate cancer was positively predicted by the fighting spirit as well as by use of instrumental support, and negatively predicted by self-distraction, and helpless / hopeless. A total of 44.3% of the variance in the quality of life could be accounted by the independent variables of fighting spirit, use of instrumental support, self-distraction, and helpless / hopeless.
Discussion

Findings from tables 8 to 12 are discussed here. The variables that correlated significantly with the posttraumatic growth score were used for further analyses with the multiple regression stepwise. The coping, quality of life and other psychosocial variables that came up repeatedly in the multiple regression stepwise final model for posttraumatic growth and its factors were: social/family wellbeing; religion; anxious preoccupation; self-distraction; use of emotional support; fighting spirit, and denial. Findings indicate that 38.8% of the variance in posttraumatic growth was predicted by social/family well-being, anxious preoccupation, religion and self-distraction.

The positive association of religion with posttraumatic growth is not surprising given that qualitative interviews indicated that religion was one of the coping strategies that was utilized by close to one-third of the individuals. The positive association of social/family wellbeing with the posttraumatic growth was also expected since many individuals stated in their interviews the importance of their families and friends towards positive coping. It is somewhat surprising to see the positive association of anxious preoccupation with the posttraumatic growth because one would think that active coping would have played a greater positive role. However, because many of these men in this sample attended support groups, they were trying to get information about their prostate cancer; therefore, the association of these men in these support groups might account for anxious preoccupation being associated significantly with posttraumatic growth. The qualitative interviews data also indicated that many men engaged in self-distraction by
engaging in other activities that distracted them from thinking about their prostate cancer. However, one would not expect denial to be positively associated with posttraumatic growth. Although one must remember, that in a multiple regression, not all the factors that make up the final regression model for significant independent variables are equally constituted towards posttraumatic growth, and some significant independent variables may contribute more towards posttraumatic growth than other significant independent variables.

It is also important to note that many coping aspects such as helpless/hopeless; fatalism; substance use; behavioral disengagement; venting; positive reframing; planning; humour, and self-blame were not associated positively with posttraumatic growth in the multiple regression stepwise model. Many of these factors such as helpless/hopelessness and substance use were not expected to have an association with posttraumatic growth. However, I was surprised to find that in the multiple regression model of significant independent variables, positive reframing and planning were not clearly associated with posttraumatic growth. Although when I looked at the qualitative interview data, I also did not find positive reframing and planning to be a major part of the positive coping efforts in these men with prostate cancer.

Interestingly, many of the variables that were part of the final multiple regression stepwise model of significant independent variables in linear regression for posttraumatic growth were also part of the quality of life model. This is interesting because I did not find a significant correlation between posttraumatic growth and the total quality of life score (with and without additional concerns). However, posttraumatic growth was positively correlated with the social / family wellbeing component of the quality of life.
for individuals with prostate cancer. One of the variables that was common in the multiple linear regression stepwise models for quality of life and posttraumatic growth was the fighting spirit. These findings indicate that many of the variables that have a positive impact on posttraumatic growth also have a positive impact on one’s quality of life. In fact, 65.7% of the variance in the total quality of life score (inclusive of additional factors) on the FACT-G scale could be accounted for by positive association with fighting spirit; positive association with sense of coherence, and with a negative association with depression. Therefore, those men who saw their illness as a challenge, and in a meaningful and positive way, had a higher quality of life. As indicated by analysis 10, interestingly, self-distraction, planning, and helpless/hopelessness were negatively associated with these men’s quality of life. It is important to note that even though self-distraction was positively associated with posttraumatic growth, it was negatively associated with one’s quality of life. This indicates that even though posttraumatic growth may have much in common with quality of life, it is not the same as quality of life; instead, it constitutes a unique element that has much in common with many of the positive coping strategies such as religion, fighting spirit, and social/emotional wellbeing.
Hypothesis 8: Individuals with prostate cancer from Eastern cultures may not have more extended family involvement than those survivors from the Western cultures.

Given the small number of individuals with Punjabi, Muslim and Chinese backgrounds involved in this study, the following results only shed preliminary light into some key areas that need to be investigated further by elaborative studies in this area. This study found that the extended families did not play much of a role towards promoting positive coping in these individuals’ lives. These men did not want to involve their extended families because they did not want to give these family members anxiety. Some of these individuals feared that their extended families may not understand that prostate cancer is a slow cancer, unlike many other cancers. One individual from a Chinese background did not even tell his daughters that he had prostate cancer.

Implications for health professionals

Health care professionals should work towards educating the families and men from South Asian and Chinese families about what prostate cancer is, and how it differs from other cancers. When these families get more education, they will not associate prostate cancer with the “Big C” fear, and would be better able to help their loved ones with coping with prostate cancer. It is clear from the data that some of these men did not confide even in their immediate families because they feared that these family members would worry too much.
Hypothesis 9: Prostate cancer survivors of cancer from Eastern cultures will emphasize more interdependence in their coping than independence. Interdependence coping implies greater emphasis on the social and cooperative aspects of coping than does independence.

The hypothesis was that prostate cancer survivors from Eastern cultures will emphasize more interdependence in their coping than independence. In fact, in this study, quite the opposite was found to be true. Individuals from Western cultures were able to make friendships at the prostate support groups and were able to talk openly about their prostate cancer experiences with individuals from their churches. However, individuals from the Punjabi, Muslim and Chinese cultures did not have friendships at the support groups, and did not discuss their diagnosis at their religious gatherings. Two of the Punjabi individuals who have prostate difficulties indicated that they did not see how the Temple could play a coping role for them. However, both of these Punjabi individuals prayed at home and used their holy scriptures as a positive coping strategy. One individual from a Muslim background only attended the prostate support group (with some hesitation) based on the invitation of his friend who was a facilitator for a support group. This Caucasian facilitator was a Muslim. This Caucasian facilitator had also presented a workshop about prostate cancer at the Mosque.
CHAPTER 7
GENERAL CONCLUSIONS AND RECOMMENDATIONS

It is apparent from the findings of this study that prostate cancer support groups provide a key link towards positive coping in individuals with prostate cancer. Close to seventy-five percent of the individuals that attended these groups found them very meaningful. In fact, some of these persons claimed that it was the support groups that really saved their lives. However, only 64.4% of the individuals were satisfied with the emotional support offered by these groups. Therefore, emotional support was perceived to be lower in the support groups, compared to some of the other kinds of benefits, although some individuals felt that it wasn’t the role of the support group to provide this emotional support in the first place.

Support groups may provide many other benefits as well. Interestingly, prior to their diagnosis, 42.5 % of the individuals had smoked; however, after their diagnosis, only 2.2 % of the individuals continued to smoke. Therefore, there was a significant reduction in smoking after treatment for prostate cancer. Many of these men also stated that they had changed their dietary habits. However, since this study does not have a large sample of individuals that did not attend support groups, it is difficult to say whether support groups contributed towards reducing smoking or not. But, one could certainly conclude that such a benefit was possible for those who did attend support groups.
Also, moderate and severe depression was lower in these men compared to the findings of other studies. The CES-D scores for eighty-seven men indicated that only a total of 4.6% experienced moderate or major depression. Major depression by itself was 2.3 percent. However, this finding is different from previous studies of men with prostate cancer and elderly men in general. For example, Heim and Oei (1993) found moderate to severe depression in about 15% of the prostate cancer patients, which was consistent with the depression level that is generally found in the elderly. One explanation for this discrepancy may be that a vast majority of men (84 from 88) were currently attending a support group. Therefore, the benefit gained from the social group may have led to lower results of depression in these men. Again, this finding should be investigated by further studies.

Further, the relationship between time after diagnosis and mood disturbance is presently not clear for men with prostate cancer. Litwin et al. (1995) indicate that as time following initial diagnosis elapses, mood disturbance decreases (Litwin et al., 1995); however, other authors indicate that mood disturbance increases from the time of diagnosis due to increasing treatment side effects (Herr, 1994). However, the finding of this study is different from both Litwin et al. and Herr's findings since no significant correlation was found between diagnosis date and the level of depression, $r = .020, p = .854$ (two-tailed).

Moreover, the relationship between symptom distress (treatment side-effects) and mood disturbance is presently unclear for men with prostate cancer, some studies suggesting there may be a correlation (Lubeck et al., 1999). In fact, this study found a
significant negative correlation ($r = -0.45, p<0.001$) between depression and quality of life as measured by the total FACT-P (version 4) “additional concerns” score. Because additional concerns are derived from the treatment side-effects items, there is thus a strong positive correlation between depression and treatment side effects.

This study also investigated posttraumatic growth. Linear Regression analysis indicated that the coping, quality of life and other psychosocial variables that came up repeatedly in the model for posttraumatic growth and its factors were: social/family wellbeing; religion; anxious preoccupation; self-distraction; use of emotional support; fighting spirit, and denial. In fact, 38.8% of the variance in posttraumatic growth was shared with social/family well-being, anxious preoccupation, religion and self-distraction. A positive association of religion with posttraumatic growth in this study is not surprising because qualitative interviews indicated that religion was one of the coping strategies utilized by close to one-third of these men.

Moreover, the positive association of social/family wellbeing with the posttraumatic growth was also expected because many individuals stated in their interviews about the importance of their families and friends towards positive coping. This study also found that many coping aspects such as helpless/hopeless; fatalism; substance use; behavioral disengagement; venting; positive reframing; planning; humor, and self-blame were not positively associated with posttraumatic growth.

Further, many of the variables that were part of the model in linear regression for posttraumatic growth were also part of the quality of life model. Posttraumatic growth was positively correlated with the social/family wellbeing component of the quality of
life for individuals with prostate cancer. One of the variables that was common in the multiple regression stepwise models for quality of life and posttraumatic growth was the fighting spirit. This overlap of variance between posttraumatic growth and quality of life matters because it indicates that some of the variables that are associated with posttraumatic growth are also associated with one’s quality of life. In fact, 65.7% of the variance in the total quality of life score (inclusive of additional factors) could be accounted by positive association with fighting spirit; positive association with sense of coherence; and negative association with depression. Therefore, those men who saw their illness as a challenge, and in a meaningful and positive way, had a higher quality of life.

To conclude, based on the patterns that emerged in the implications sections of this study and the written comments provided by the prostate cancer survivors, there are many recommendations that can be made for support groups, educators, health professionals, and policy makers. These recommendations are summarized below:
Recommendations for support groups

Encourage more one to one or small group discussions to promote emotional support.

As a whole, support groups seem to be doing an excellent job, as perceived by these group members. However, if support groups wish to do so, they may seek ways to promote emotional support in their groups by encouraging one-to-one discussions.
Recommendations for Educators

Educate about the bad effects of smoking and alcohol early in the lives of students.

Seventy-six percent of the individuals started smoking when they were between the ages of twelve and nineteen. Therefore, this data indicates that any preventive efforts toward drugs in schools should be aimed at both elementary and secondary students. It is best to educate students about the negative effects of tobacco before they go into junior high school; however, this emphasis should be maintained throughout the high school years. Moreover, 42.2% of the individuals also stated that they had consumed alcohol in a “significant way.” Thus, preventive efforts against alcohol drinking should also be directed towards youngsters.

Encourage young children to have more respect for individuals with illness.

Children should be more respectful of their elders, especially when their elders are experiencing trauma in their lives.
Advice provided by prostate cancer survivors for newly diagnosed individuals with prostate cancer

These men gave the following advice for others with prostate cancer:

- Take responsibility. Be in charge of your own treatment plan.

- There is hope, take a positive attitude. You should accept your condition. Be thankful there are treatments for prostate cancer.

- Busy yourself with things you feel are important and have a lasting value. Make your life count.

- Be prepared to live with the side-effects. Ask about the side-effects of various treatments.

- Have faith in God.

- Seek out support at a support group. Pick up on practical tips from others.

- Take one day at a time.

- Don't look back at your decisions. Be happy with the choice of treatment that you have made.

- There are worse things in life than prostate cancer.

- Quit smoking and using alcohol and eat a properly balanced diet.

- Discuss your illness openly with your spouse.

- God / Spirituality, family, and friends are important for coping.

- Get your PSA done routinely / get checked.
**Recommendations for health professionals**

Spouses should be encouraged to take an active role throughout the treatment plan. Also, mentors should be provided for those that are newly diagnosed.

Many individuals with prostate cancer continue to have on-going stresses in their lives. This stress starts from the time an individual is diagnosed, and continues throughout the lives of these men, as some worry about the recurrence of their cancer. Further, stress not only impacts the patient but also his whole family. Therefore, both the men and their spouses should be counselled together about the implications of the treatments. Some of the critical periods for counselling seem to be at the diagnosis stage, and prior to the treatment. However, a proper follow-up is also very important, especially for those individuals that may have difficulty accessing medical clinics. Another suggestion would be to have a list of the mentors (survivors) with different kinds of treatments, and to make this list available for those that are newly diagnosed with prostate cancer.

**Facilitate religious/spiritual support for those that seek it**

It is very important to facilitate religious support for individuals that have a faith. Therefore, these individuals should be encouraged to keep close ties with members from their congregation throughout their coping experiences with prostate cancer.
Educate the families and men from the South Asian community about prostate cancer

Health care professionals should work towards educating the families and men from South Asian and Chinese families towards what prostate cancer is, and how it differs from other cancers. When these families get more education, they will not associate prostate cancer with the “Big C” fear, and would be able to better help their loved ones with coping with prostate cancer. It is clear from the data that some of these men did not tell even their immediate families because they feared that these family members would worry too much. Expert speakers from the South Asian and Chinese community should give more talks to these groups.

Provide free PSA testing and encourage PSA testing

It was these men’s opinion that PSA tests should be provided free of any charge at all since in the long run, the government will save money.

Educate doctors about the importance of PSA testing

Doctors need to be better advocates for prostate cancer. Too many physicians are poorly informed about PSA and some don’t believe in it.

Provide accurate information about treatment side-effects

Men need to be provided with accurate information about the degree of side-effects of their prostate cancer treatments.
Work towards bringing a change in some men’s attitude

Many men need to learn about their prostate gland. Emphasis should be on preventative efforts.

Provide more medical and educational “tips” to help individuals having treatments for prostate cancer

These men ask for more “tips” as to what the medical procedures will be. They would like specific suggestions for taking care of incontinence, impotence and pain. Research indicates that individuals with prostate cancer can decide on a treatment option that is appropriate for their needs if their doctor provides information that they can understand and remember. In one small U.K. study that examined the knowledge of twelve patients with prostate cancer that had been diagnosed but not yet treated, semi-structured interviews indicated that patients were aware that they had incomplete understanding but no one asked for information to be provided in a language that they understood (McGregor, 2002). McGregor found that most men agreed with the treatment even though they didn’t understand why a specific treatment was recommended. Furthermore, from a cohort of ten healthy individuals of an age similar to the prostate cancer individuals, only one man knew the position and function of the prostate gland. The study concluded that even though urologists had provided the information they felt was sufficient, patients only remembered and understood a little of it. McGregor stated that, “The information is often complex, vocabulary foreign and hospital noisy. A video that could be taken home, viewed as often as required and
in the company of choice would enable information to be gathered in a more relaxed environment” (p.283).
Recommendations for Prostate Cancer Researchers

Cancer researchers should work collaboratively with each other and there should be more funds available for prostate cancer research and there should be more input from the survivors.

These men stated that cancer researchers should work together rather than compete with one another. There is a big discrepancy between the amount of funding that is available for breast cancer versus prostate cancer.

Be open to doing research about alternative therapies where drug companies do not have a conflict of interest.

Physicians need to have an open mind towards clinical trials that are going on throughout the world. They should also do more research on the alternative therapies.

Speed-up the process for clinical trials.

Treatments that have shown some promises in other places of the world should be approved here without cumbersome procedures that take a long time.

Category: Focus on treatments that stop metastasis. Meet the needs of advanced patients and find new kinds of treatments that don’t have a negative effect on sexuality.

There needs to be urgency to stop the metastasis, and this urgency should be present in the research that researchers carry out.
Recommendations for the Ministry of Health / BC Cancer Agency and other such national / community agencies

Provide more support and funds for support groups

Support group facilitators would like to do a lot but they are limited by time, and sometimes they lack appropriate funds to do all the things they wish to accomplish.

Give more recognition to the support groups

These men stated that support groups should be recognized by urologists and other medical professionals. Also, receiving backup support, such as having a meeting place would be desirable.

Provide transportation to access clinics

It is difficult to go to clinics without transportation. Appropriate arrangements should be available in all communities.

Put more emphasis on prevention

There needs to be more emphasis on preventing prostate cancer by stressing the "whole person" approach, where there is emphasis on one's environment.

Post-operative companionship with social-workers or outreach workers would be helpful.

Some men may need the guidance and support of a social worker or an outreach worker, after post-operative time.
Have one medical doctor who has had specialization in all the treatments that help with the decision making process. Presently, there may be some bias in passing out information or in the kinds of treatments that are recommended.

In spite of their best intentions, sometimes there is bias when information comes from one specialist. Also, after diagnosis, often patients experience significant anxiety, which can limit their ability to absorb medical information and engage in decision-making (Spiegel, 1995). In fact, prostate cancer treatments may be dictated largely by which specialist a patient sees, as opposed to his/her personal preference (Fowler et al., 2000). Sepucha and Mulley (2002) further state that patients also should be provided with adequate help in preparing for decision making and in implementing their choices.
Some of the challenges in running a support group:

By becoming more aware of these challenges, medical professionals, community organizations, governments and individual prostate cancer members may help to overcome some of the challenges faced by the support group facilitators.

Trying to meet the needs of individual members; especially those with advanced cancer.

One needs to keep on top of the information and the clinical trials, and then present this information to meet the individual needs of the men attending the prostate support group.

Motivating individuals to volunteer at the support group

Motivating support group members to take an active part in the activities of the group is a challenge.

Finding the speakers, finding the time, and getting individuals to come to the support group on a regular basis.

It takes time to find the appropriate speakers to meet the needs of the support group members.
Positive aspects of the current system for treatment of prostate cancer:

Most individuals were very happy with the kind of treatment and support they had received from nurses, doctors and other medical professionals. Following is a summary of these positive findings associated with the current medical system for treating individuals with prostate cancer.

Satisfaction with the current amount of information.

There is much information available about prostate cancer in doctors’ offices and on the Internet, although many men thought that doctors should take a more active role in passing out some of this information to their patients. Also, medical professionals should inform all newly diagnosed men about the prostate support groups in their communities.

Satisfaction with the prostate cancer information centre, Vancouver, B.C.

The Prostate Cancer Information Centre is very helpful for individuals at the early stages of their diagnoses.

Happiness about the role of the Canadian Cancer Society

The Cancer Society has taken an active role in providing funds and initiating public forums to provide information about prostate cancer.
Praise about the cancer related publications and organizations: “Our Voice” magazine, “CPCN” (Canadian Prostate Cancer Network), and Prostate Foundation

Several individuals had found “Our Voice” magazine and other prostate cancer national organizations to be useful.

Satisfaction with the way treatment services were / are provided by doctors, nurses and other professionals

Overall, these men were happy with the way they were provided with their prostate cancer treatment, although they did have some reservations.

Happiness that a social- worker or urologist sits on our meetings. The BC Cancer Agency and the Ministry of Health should make sure that doctors also participate in all of the support groups

Men that made comments in this category were happy that a social worker or a urologist sits in on their support group. They also wanted to see this medical professional support for all the support groups throughout Canada.

Happiness that the support groups help to collect research funds for cancer and that they are self-supporting.

“Do it for Dad run” collected close to $80,000 dollars in donations for cancer research. [13]
Finally, as the baby boom generation ages, more men will be at risk for prostate cancer, and health care demands will exceed available resources (Koenig, 1999). It is hoped that the above recommendations will help to better serve the coping, psychosocial and quality of life needs of individuals with prostate cancer. Hopefully, with more emphasis on prevention, some men may never need these treatments.

Limitations of this study

One of the drawbacks of the qualitative interview methodology might be memory selectivities derived from an individual’s attempts to attribute a meaning to what has happened to him. Rutter (2000, p.376) indicates that “people who are functioning well tend to underreport adverse experiences in the past because these no longer seem pertinent.” However, the strength of this study is that both qualitative and quantitative analyses were carried out. The data of this study was also collected over many localities throughout Canada. Further the subjects that participated in this study did so freely and with no monetary incentive.

To conclude, support groups can promote to and build emotional strength by encouraging small group discussions. Furthermore, educators need to teach children and youth to respect individuals with cancer or any kind of illness. And finally, there is also a real need to educate families and men who belong to the South Asian Community about prostate cancer.
REFERENCES


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October 2, 2003

Mr. Jasdev Makkar
Graduate Student
Faculty of Education
Simon Fraser University

Dear Mr. Makkar:

Re: Positive coping in individuals with Prostate Cancer: The effects of Prostate Support Groups, social comparison and religious resources

The above-titled ethics application has been granted approval by the Simon Fraser Research Ethics Board, in accordance with Policy R 20.01, "Ethics Review of Research Involving Human Subjects".

Sincerely,

Dr. Hal Weinberg, Director
Office of Research Ethics
Appendix B

Qualitative Interview

1. I would like to take this opportunity to thank you for giving your time to help other individuals with prostate cancer by sharing your personal experiences. This information will be kept confidential and your name will not ever be published. If it’s ok with you, I will be audio-taping this interview so that it can be transcribed later.

2. Please tell me a little bit about your treatment history (PSA scores, Gleason score, age, children, when diagnosed, and the kind of treatments you have had)

3. In coping with your prostate cancer, what would you say has been the most stressful part for you...

4. Coping with one’s cancer can refer to the mental, physical, emotional or spiritual part of a person. Please tell me what has helped you in dealing with your cancer...

5. [If not already talked about] Did religion or spirituality play a role in your coping with cancer? Please explain, what role if any, that religion or spirituality played in your coping...

6. [If not already talked about] Did religious preachers or church play a role in your coping?

7. Do you attend a prostate support group? Please describe for me what your prostate support group has meant for you...
8. [If not] If you have never attended a prostate support group, what are some of the reasons as to why you have not attended.

9. [For group facilitators] What do you see as some of the challenges in running a support group?

10. What steps, if any, do you feel Ministry of health, B.C. Cancer Agency or other such agencies may take to help facilitate the role of a prostate support group leader?

11. If having cancer has changed your relationships with family members, how have your relationships with family members changed [Do not ask this question if the interview is being taken at someone’s home as their would be bias in answering this question in the presence of family members]

12. With respect to surviving your cancer, have you ever compared yourself with those who may be worse off or better off than you?

13. What improvements, if any, do you think need to be made the way medical services and other support services are provided for individuals with prostate cancer in your community?

14. Please feel free to share any other information that you consider to be important.

Thank you so much for your time. I appreciate it very much.
Appendix C

Information about the subjects that participated in the interviews.

**Person 1:** He is 61 years old. He was diagnosed in February, 1997 and had Radical Prostatectomy in June, 1997.

**Person 2:** He is 73 years old, and he was diagnosed in July 1994. He had Radical Prostatectomy in May 1995. He had External Beam Radiation in December 1995. He also had hormone pills and has been on hormone therapy (off and on) since 1994.

**Person 3:** He was diagnosed in 1994. He had Radical Prostatectomy in May, 1995. When they did the pathology they discovered that it had advanced. So, that was followed up by six weeks of radiation in December of 95. Four years ago, he had to go back on the hormonal treatment and he was on that for about nine months and then his PSA went right down to .04 and it stayed there for about a year and half, and then about six months ago, he went onto treatment again. Initially, when he was diagnosed, his PSA was at 24 and his Gleason score was 7. He’s back on hormones now until September.

**Person 4a:** He was first diagnosed in June 1994. He had Radical Prostatectomy in February, 1995.

**Person 4b:** He is 74 years old. He was first diagnosed with prostate cancer in October, 1994. He had External Beam Radiation in 1995.

**Person 5:** Had surgery to remove his prostate gland. He is 60 years old. He was first diagnosed with Prostate Cancer in June, 1997. He had his Radical Prostatectomy in July 1997.

**Person 6:** He is 63 years old. He was first diagnosed in October, 2002. He had Radical Prostatectomy in May, 2003.

**Person 7:** He was diagnosed 3 years ago with prostate cancer. He is 57 years old. He was diagnosed in May, 2000. He has not had any treatments yet.

**Person 8:** He is 63 years old. He was diagnosed last year and he had his surgery to remove the prostate last year in April, 2002. His Gleason score prior to surgery was 5 or 6. His PSA score after the surgery is .05. He lives with his wife and has two children and two grandchildren.

**Person 9:** Had surgery to remove prostate 9 months ago. He is 77 years old. He was diagnosed in June, 2002. He had Radical Prostatectomy in November, 2002.
Person 10: He is 55 years old. He was first diagnosed in February, 2002. He had Radical Prostatectomy in June, 2002. He has been on Hormone Deprivation shots, Lupron, since February to June, 2003.

Person 11: He is 64 years old. He was first diagnosed in August, 2000. He had Radical Prostatectomy in October, 2000.

Person 12: He is 73 years old. He was diagnosed in March, 2001. He had Radical Prostatectomy in May, 2001.

Person 13: He is 72 years old. He was first diagnosed in September, 1993. He had Radical Prostatectomy in September, 1993.

Person 14: He is 63 years old. He had Radical Prostatectomy in 1999.

Person 15: He is 67 years old. He was first diagnosed in February, 2000. He had Radical Prostatectomy in May, 2000.

Person 16: Now, he is 62 years old. He was diagnosed with prostate cancer 4 years ago. He had his removal of testicles and he also had 33 treatments of radiation. He wasn’t eligible for a Prostatectomy and obviously wasn’t eligible for Brachytherapy. In 1999, his Digital Rectal Exam was fine, but his doctor said maybe we should do the PSA but it costs money. This person said that’s ok, “let’s be thorough.” When the results came back his PSA was 58, and his Gleason score was 7. His cat-scan confirmed that his cancer had not escaped the prostate but it was close. His grandfather had Leukemia and he had Lymphoma three times.

Person 17: He is 66 years old, and he was diagnosed with prostate cancer when he was 59. He had problems urinating and went to his doctor. His PSA was 6.2 and the biopsy came out as 5 out of 6 being positive with a Gleason score of 9, so the cancer was already outside the prostate. In 1998, he had External Beam Radiation, and stayed on hormones for 3 years. Then he stayed off hormones for one year but the PSA started going up again. In February of 1999, he had to go on hormone pills. His cancer had metastasised to the bone and to his spine. They recently did some radiation on his spine to stop the pain.

Person 18: He is 69 years old. He was diagnosed in 1992. His employer’s doctor did not find anything with him. However, he decided to go to his family doctor, and was referred to an urologist. He had PSA at 4.65 and went through a biopsy. None of his general practitioners discovered he had prostate cancer through the digital exam. His biopsy confirmed that he had some cancer present. He said at that time he did not know what the symptoms of prostate cancer were but he only recognizes now that he had those symptoms then. The only cancer in his family was that his mother
had died of stomach cancer. He had Radical Prostatectomy because he wanted to know how much cancer he really had. Also, if that option failed then he could get radiation. At that time, he did not know that there was something called Hormone therapy.

**Person 19:** He is a Chinese Canadian born in Canada. He is 83 years of age. He started his treatment in January, 2002. His PSA was 12.8. Because of his age, he couldn’t have the operation, so they gave him hormone therapy through the injections, Lupron. His PSA went down to 1.48 as of July 2003. In May, 2003, his PSA went down to .48. He has two children. He is not associated with any of the Chinese cultural or religious groups. He doesn’t know how cancer is viewed from a Chinese perspective. The symptom that he had was that he found it hard to urinate. His enlarged prostate was pinching against his urethra. He has completed high school education.

**Person 20:** He is 68 years old. He was diagnosed in November, 2000. He had Radical Prostatectomy in July, 2000.

**Person 21:** He is Indonesian Chinese. He is 64 years old. His PSA before the treatment was 5 and his Gleason score was 6. He had Brachytherapy one and a half years ago. He was born in Indonesia, and came to Canada 25 years ago. He has no children. His sister also died of colon cancer. He attended College.

**Person 22:** He was born in Alberta, and is 77 years old. His recent PSA was 0.8. He was diagnosed 13 years ago. He couldn’t pass water, and went to emergency. They did a biopsy, cleaned urethra, and he had 20 treatments of External Radiation. Since then, urinating has been easier. He has two sons aged 50 and 41 and 2 grandchildren. His wife died in 1973 because of cancer. He had a son who was 11 years old and he also died because of cancer. His son’s abdomen was swollen up. This man is the middle one from a family of 9. He has lived alone since 1970. In 1960, some lumber came on top of him. He walked with crutches. He had back operated on, and has been in wheelchair since. However, he drives a van with a lift.

**Person 25:** He is 65 years old and a Muslim. His PSA was 6.6 and his Gleason score, when they did the biopsy, was 6, 3 plus 3. When he went to enquire about brachy therapy, initially, they repeated the whole thing and they reviewed the report and they upgraded his Gleason score to 7. He has not had any treatment yet. He only had the hormone treatment to shrink the prostate. He is planning to have the Brachy therapy done.

**Person 26:** He is 71 years old and states his culture to be Chinese. He has been in Canada from 10 years. He has the equivalent of high school. He was diagnosed with prostate cancer about three years ago and had his prostate removed two and a half years ago. According to him, he had his
last PSA done about an year ago. He has a son who is in [name of a state], and he has a daughter who is in Malaysia. He is living with his wife. He believes that cancer is caused by preserved food, like spices to keep things fresh.
Appendix D

Question: In coping with your prostate cancer what would you say has been the most difficult or stressful part for you?

Category: Diagnosis (ratio of the group that used this category: 3/20).

Summary of the comments found in this category: Individuals in this category found the diagnosis to be most stressful. Specific comments of individuals were: when I was told bluntly and brutally that I had cancer, I burst out into tears [14]; it was stressful when I first heard of the news [19]; initial first few weeks were very hard [25]. Only one selected example is featured here. Full comments from which this example is drawn are contained in the appropriate appendix.

Comments made by individuals:

[What has been the most stressful part for you?] When I was told very bluntly, very brutally that I had cancer and sent out into the street in minutes, by myself, I burst out in tears. So that was very brutal and I discovered it by accident and the doctor says, oh by the way you have cancer, so I don’t need to look at you at this time, you need surgery so we’ll make a reservation for surgery. When I discovered I had cancer, I was very upset because this tumor, I had for nearly six years and then I’d been monitored strictly by DRE during those six years, once a year, and when I suggested, after three years, that we do a PSA test or some other ways we could find out if those tumors were evolving or not, I was told that it was unnecessary and it had grown to the size that was significant enough that my general practitioner said, well now you should have the test and the test revealed that the tumor had become extremely aggressive, the cancer was as aggressive as they come. It scored 5 over 5 at one time and 3 over 5 at another, and that’s, it was growing right into the edge of the prostate and was bursting out and that’s why I was so mad at the system because that could have been detected years before, if they detected it was cancer, it could have been picked up a year or two before. They could have reduced the risk considerably. [Simply by doing the PSA test?] The PSA test and CT scan. At the time, I was not a resident of Canada, therefore, it was at my cost and I understand that the doctor would be reluctant to send somebody to the hospital to have expensive procedures, and x-rays and a CT scan which requires a lot of manpower and a lot of equipment and burdens the
system, but the PSA is just a blood test, $30, done at a private lab and I pay for it. It's my life. I even asked for it but I'm told not to do it. What is she was trying to do, save me $30. So, I guess they thought it would burden the system when it is not necessary, but $30, it just doesn't make any sense to me, especially when I'm paying for it. So I was mad at the system, I was mad at this doctor, I was mad at this doctor when she eventually got the result that I received, she got it and never told me I had cancer. That's my GP and the urologist who did the test at her request, found out that I had cancer and he didn't tell me either. So I went on for about, everyone knew I had cancer except me, the GP and the urologist. One day I go back to the urologist at the end of the holidays because he said he wanted to have a look at my bladder, and I come in there, and he said, I don't need to look at it, you have cancer, you have to go to surgery, I will see you on the table. It was too much, and that's when I was out on the street and when I complained to the college. So I filed an appeal with the college and they said, well yes but when we look at it the second time, we think they should have told you that you have cancer. I said, I find this peculiar. So anyways, I'm still mad at the process, at the system, the GP in general and the whole system they seem to be protecting each other. I come from a family of four generations of doctors on one side and three generations of doctors on the other side so I know when things go wrong, my problem is not with the errors with people make, because they will make errors, but it's the fact that they deny making the errors and they are not going to do anything about it, what happened to me. So the next guy who goes to this GP will be treated the same way and their tumor will blow up and it will burst and they will die. I got my, if an error is committed, I have no problem with that as long as it's recognized as long as they apologize and fixes it. [What do you think, if anything, could be done to improve the system?] Well I think the college should be more responsive to the needs of the patients. The problem that the college has is the patients in North America tend to sue. They don't sue as much in Canada as they do in the States, but they sue everybody, so the college is trying to protect its physicians but I, I told them that I had absolutely no interest in suing anybody that's not type. Where I come from in Europe nobody sues anybody, so I would write it on paper, and write it down and confirm it and you know, there's no legal action, I just want the system to improve, and ah, so I think the college, the one that discovered this error should have written to? especially when the patient is paying for this see them once in awhile to make sure the patient keeps the cancer under control. When you have a tumor, you know it's going to grow, the question is when. But apart from that, the treatment I received at the hospital, I would have had to, so there was a little problem with this GP and I think she, because it's a woman, who deals mostly with women, she probably doesn't know that a prostate cancer can be very aggressive especially if it's in a young man. So, that GP needs training. So it's lack of training of the GP. Lack of recognition from the board, the college, they should be attentive to people so that they approve the system, and also, I think the urologist should have taken the time to tell me what this cancer is all about and what options I had, if any, but the man is a surgeon, a highly respected surgeon, and he just said, well you have cancer, you need surgery and I'll make an appoint and you come back in and have the operation. I want to deal with this cancer, I wanted to know what it did or what implication, or where, in
the prostate and what it was used for, and I would have liked to be able? and finding out more about and finding out that there are other options besides surgery. [So you didn’t?] I didn’t know anything about it and I was in such a shock that I did the surgery and that I didn’t have a choice but to go through surgery. I had to wait four months before I went to surgery, and ah, I have to say, I’m very happy with the surgeon. I don’t like? but I’m still around. The other thing that particular surgeon, when I was told I had cancer, but the day after surgery, he came back to see me at the hospital and I was doing fine, it was a result of the biopsy, so he told me how bad it was. It was very, extremely aggressive right to the edge and ready to bust, and I asked him how long would I last and he said about a year and then he said, goodbye and he went away and that was it. So I was left, I was barely beginning to recover and was told that I would probably be dead in a year from now. [After your surgery?] Yah, this was after the surgery, on average a year and half, but I know that it’s only an average but still, so that doesn’t help with the recovery. I think his bed-side manner has a little bit to be desired, but apart from that he’s a very respected prostate surgeon, urologist. He obviously did a good job because, it’s nearly five years ago and later, I’m still around and still kicking and in good shape, and as far as I’m concerned the cancer is out and I’m very happy about it. [At what point did you find about this support group?] This what? [That there’s a support group.] The support group. I don’t remember. It was after the surgery, long after, much after. [So, you didn’t know anything about it?] No, I didn’t know anything about it. So, I didn’t know what options I had, I didn’t know whether he was a good surgeon or a bad surgeon. I didn’t know who to come ask. I thought if I went to the hospital and asked if he was a good surgeon, they would say, well of course, otherwise he wouldn’t be here, you know that’s what they would have been telling me. I wouldn’t even know, so I don’t know when I knew about the support group, it must have been at least six months after surgery, a long time after, and at the time since I’d been told by the other gentleman, a year and a half, I went to Klaus because the regular one, and you went for advanced prostate cancer, because I thought I was part of a category like that and they after a year I went for a test and realized the PSA level was undetectable. So I didn’t go to the advanced anymore but I still go to the regular meeting so it was nice to meet those guys. No, my main concern with this is the system, again, it was my background with a doctor, and knowing that problems do occur, they make errors, they are tired, or thinking of something else, it’s human, that’s not the problem, but to refuse to admit it, that’s what bothers me. I’m not judging her because it was her fault, I mean incompetence and arrogance of doctors it’s not a matter that the medical profession does not yet protect each other, but apart from that, it’s been a very rewarding experience, a very enjoyable experience. I’m very happy that I went through this experience. I feel much better now. It’s very positive. [14]

Well, I don’t know if that’s stressful or not, but when I first heard of the news that I had prostate cancer probably that’s the concern there, that’s all. [19]
The stressful part was just the initial first few weeks that were very stressful for my family and myself but we did get over it fairly quickly the more I learned about it. The thing is to learn as much as you can so the Internet helped a lot and then I met John [name changed] and through John I met another cancer survivor and we just started talking and finding out more and more and it becomes accepted. [So you had that through your Mosque?] Yes, yes.

[You, like a prostate support group, have you been to it?] This is the first group that I have attended. [First time?] Yah first time. [When did you find out, when did they do a biopsy, like how long ago?] The biopsy was done, first of all, I had no symptoms at all, and at the routine examination the PSA was fine, but my doctor does a rectal examination, the finger, the rear, and that's when it was noticed, a slight lump. So she referred me to a urologist and then he also confirmed, yes, straight away, biopsy and he told me right in his office and that's when it hits you. [And that was in?] In March. Yes, and then after that, surgeons want to cut you up so I investigated alternatives and found out about brachiotherapy so it's quite a decision, you have to make a decision. [Any history of prostate cancer in your family?] No, now we have history. [Did you know that there was a support group before?] Every disease has support groups right? So, I knew there would be a support group, yah. [Can I ask you why you didn’t want to come to it right away or you wanted to deal with it?] No, I just, no you are right, this is the first time, a couple of meetings I avoided. You want to forget about it, you try to push it, it's there but you don't want to think about it. [So, you wanted to take your private time to look into it?] Yah, yah, yah. [25]

Category: Get the cancer out (3/20).

Summary: Prior to their treatment, it was stressful for men to have this cancer.

Each person had the anxiety that the cancer is inside, and he wanted to get rid of this cancer. Specifically, the most stressful part was: “It’s in there, get it out [1]; “get rid of it” [4a]”; “I couldn’t stand the thought of having it in my body.” [4b]

Comments made by individuals

Actually when I found out I had cancer I was numb. It took, the anxiety was, get it out, okay, and at the time there was no choices between brachiotherapy. You either had external beam radiation or you had radical surgery and I think, even had brachiotherapy been available, it was get it out. So it wasn’t, it was like you had cancer and it struck you with, it didn’t set with you, you know it’s a completely different experience from when you, from before you were told. So the most stressful thing was, it’s in there, get it out [1].
It’s sort of a big shock when you find out you’ve got the Big C and the first thought that comes into your mind is that, look, I’ve got to look after this and get rid of it and that was my thought as well. [4a]

My first thought was to get rid of it as soon as possible, that was my first thought. There was no rush, really, to get rid of it, but I could not stand the thought of having that thing growing inside me so I said get rid of it now. [4b]

**Category:** Deciding which treatment to choose (7/20).

**Summary:** Deciding which treatment to choose was a stressful part of dealing with prostate cancer for many of these men. Specifically, these aspects were stressful: trying to figure out what to do [2, 4a, 5, 8, 15, 16], and the medical establishment doesn’t have enough information within themselves on which I can base a decision. [7]

**Comments made by individuals:**

The most stressful part was deciding on the therapy that I would use both at the primary stage where I decided after a lot of consideration to go with the radical prostatectomy, um, after that it was almost obligatory that I move on since it wasn’t successful, I’d move on to radiation and following that, move on to hormonal therapy. [2]

I guess the stress was just, more or less, sitting down with the doctor and talking about it and getting a really clear picture on what I had to do.[4a].

The most stressful time, I would say was trying to figure out exactly what to do, and the doctor gave me a lot of information, not as much as we give out now but, my wife, she went through all the sites on the computer and everything. We pulled everything off, we read it all, together, and we made the decision together too which is a really important thing. We decided to get it taken out even though I knew I’d be in full impotence and I’d have problems with incontinence. Luckily I don’t have any problems with incontinence at all, so, but that was the most stressful thing, I think. I phoned up my uncle, who is a doctor, and he said, what decision did you make, and I said, I decided to have it taken out. He said, good, you do that. He said, I wish I had. He had had prostate cancer and I didn’t know
it and he said he just left it in. Now he said he wishes that he’d had it taken out.
So, I made the right decision there. [5]

Dealing with the medical establishment and with family and getting my family to accept my approach and getting support from the medical establishment for my approach, and the medical establishment wanting me to proceed without giving me, what I consider enough information. In fact, the medical establishment not having enough information within themselves on which for me to make a good decision. I guess it was bad at the beginning because they wanted me to have traditional treatment, especially since my mother was treated with a mastectomy successfully and others in my family who had cancer, different types of cancer, have been treated successfully but nobody had had prostate cancer like I had before, and so that was a bit of ah, and after awhile they understood more and a lot of people were basically going the alternate route, and it caused me to have some very frank discussions with my family about life and death and this is the way it’s going to be and I’m not going to, It’s my life and I’m taking charge. So from that point of view it was good it cleared that up.And then also people, I think people realize in my family, it’s my life, just like I’m not telling you how to live your life, except give you advice or help you and support you, it’s my life and I’m going to live it this way. It’s sort of like breaking it, but in many ways, things [?] Maybe but it gives you the opportunity to become a true adult and take charge of yourself. [7]

I would say, well, for me I’d say right now there is none. I go in for my regular test, I asked the doctor, I’m always interested about my PSA. I ask him about it and he tells me. Dr. [name left out for confidentiality] is pretty good at that, and I went to the cancer clinic and they gave me the three options, the hormone pills, the seed implant and the other one there, ah, surgery, and he was saying to me that he, ah, would give me 90 percent with the surgery, so I took the surgery. It was stressful but I’m the kind of guy, I look for the best percentage-wise, not afraid to go with whatever I can. [8]

Yes that was a fairly, [deciding about which treatment to have] it was a stressful time that didn’t last very long because I basically made the decision very quickly and it seemed that most of the people that I went to talk to for advice or information and, kind of, came up with the same conclusions that surgery was the best approach for me so there wasn’t much ambiguity in the advice that I was getting. So, it was stressful but it didn’t last long because everybody seemed to agree that surgery was the right approach for me. [15]

Post the diagnostics, deciding on the treatment alternatives was the most difficult, and ah, also the lack of knowledge about the disease and the implications of it and the treatment. Everybody will tell you, the doctor will say, you have to decide your own treatment, and ah, so you have to spend time getting a good taste of understanding. That was difficult. [16]
Category: Having the catheter / incontinence (8/20).

Summary: After treatment, many men found it difficult to carry the catheter.
Being incontinent was also found irritating because of having to wear pads.
Specifically, the following aspects were stressful for these men: catheter hanging
down one’s leg at home is uncomfortable [1]; not being able to control urination is
difficult [6]; experiencing incontinence is stressful [11, 13]; getting a good flow of
urine is stressful [12]; limited bladder control and wet pants [16,22]; wearing an
incontinence pad. [18]

Comments made by individuals:

Most stressful thing in the next 10 to 13 days [after surgery] is when you are at
home with the catheter and that catheter is dangling down your leg and it’s a very
uncomfortable, not painful, but it certainly is uncomfortable. When the catheter
comes out, it’s a period of time of incontinence. In my case, I’ve always had an
incontinence problem and I would think that is the single most irritating thing.
Now it’s more like a slow drip, okay, so it depends on what I’m doing. If I’m just
sitting here, I don’t need any protection, if I’m going for a walk I need mild
protection and if I’m going to be involved in any kind of active sport, I’ve got to
have more full protection. Incontinence is the biggest problem followed by
impotence. [1].

We’ll, start with incontinence. I knew it would be one of the side-effects at the
end. I’m not dealing with it. It is, again, a very new experience, not being in
control, um, however, I like to remain optimistic. Most of the literature that I read
said, kind of, one to three months, you kind of, have a real problem and then it
gets better. Most men have it under control within a year and I had some
interesting advice from the homecare nurse that came here. It was a gentleman
and he said, don’t make the mistake in monitoring your progress from day-to-day,
monitor it from week-to-week. Look back after a week, do you think it is better,
and now it is seven weeks, today is Tuesday, so seven weeks since the operation,
and whereabouts, after three or four weeks, it was a very serious problem. I
would say it’s already a lot better, I see the progress and I’m optimistic that after
three months, I will have it under control to such an extent, like I wear, now, the
Depends which is really the full garment, you know, because there are many
moments when I have absolutely no control, it just happens, and ah, I still catch
myself in, kind of, shouting surprise to my spouse and say, it’s happening. You
know, I’m so surprised by it because I had no warning and there was no feeling that something was going to happen, it just starts coming. So this is, yah, not, kind of, a comfortable, psychologically, not a comfortable situation, but at the same time, I’m a realist and um, I say there’s worse things in life than struggling with some dribbling there, that hopefully, eventually I can just use a pad instead of a full garment which is what my friend told me that the time will come where I feel comfortable just putting a pad into the underwear, and well, so you have to change it, so what, and my spouse says look, now you finally find out what every women had to go through all her life. So, you know, and it’s a lot worse really. So, I think it’s important to be a realist and say, well, something happened and it’s a small price to pay. I don’t think it is a major price to pay and again I’m optimistic that, in time, I will have it fully under control, interesting enough, the other gentleman that I referred to you to send him a questionnaire, he had this operation just three weeks before me. We are friends, he’s my computer man and he had a number of complications after the operation, but, when he got rid of all his catheters and plumbing and all that, he has full control. So, to me, that’s wonderful that the only person that I really know, very closely, had absolutely no side-effects. So it is possible to get it under control. So, again, you know, certain maturity and outlook, not feeling sorry for yourself but rather say, give it a bit of time and it will be under control. [6]

Incontinence along with ah, that’s probably No. 1 [11]

I think, probably the most stressful part was in the post-operative period of time when I had difficulty with getting a good flow of urine. I had a swelling down there so it used to create a blockage and I would have to go in and get another catheter put in to relieve myself. That was the most stressful and that was a physical stress, it certainly wasn’t a mental stress, but it was a physical stress. [12]

Well, side-effects okay. I believe it doesn’t matter which direction you go, there is side-effects. They will affect, impotence, that will be our No. 1 problem and another little problem is incontinence, but it’s gone so I don’t have a problem but there are other things that, there is nothing you can do to go back, so you just say, okay, are you going to be potent and be sexually active the way you were before or you don’t live. So I chose life, right. This is an effect. For people in their 40’s and 50’s or younger, then it is a big problem because maybe they are going to have a family and so on and it can affect them. [13]

After my treatment, I had wet pants with limited bladder control, and wore a catheter a few times.[16]

I think the most stressful part for me is the incontinence I have. That means I have a condition called stress incontinence. That means I have to wear an incontinence pad the whole time. [18]
After my treatment, I had wet pants with limited bladder control, and wore a catheter a few times. I can’t get erection. The cancer clinic prepared me well for the catheter use. [22]

Category: Erectile dysfunction or not being able to have sexual relationships (7/20).

Summary: Some individuals felt that they did not feel like a man if they couldn’t have an erection. Some also were stressed because of the lack of sexual activity or any sexual relationship. Specific comments made by these men were: not being able to have an erection was stressful [1,22]; sexual aspect was an important part of my life prior to diagnosis [6]; virility has diminished [9]; sexual inactivity is difficult for me and my wife [11]; I am sorry to miss my sex life but I have a good relation with my wife anyway. [12]

Comments made by individuals:

The hardest thing for a man that follows this, is not having an erection, not sex, it’s that all your life you wait, you know like from puberty on and so the most stressful thing, I think, is you just don’t feel complete anymore, you know, you can’t have that erection. As far as not having sex, that’s not a big thing. When you reach my age you, um, in fact I think my wife and I have gotten closer. We are more friends, I don’t think we ever argue, you know, we’re ticked off now and then as all friends do, but sex is something that is for the teens, the 20’s, the 30’s, the 40’s, it begins to die out in the 50’s and with me having prostate surgery when I was 55, the lack of sex sometimes becomes a problem but the biggest one is the incontinence and to some degree not being able to have an erection. [1].

For impotence, again you have to be realistic. I was married 27 years and then I was widowed in 99, so that’s four years ago, and ah, realistically any relationship that lasts that long, things, kind of, become less important as related to sex. Not many couples that are married that long have a very active sex life so it wasn’t, let say, that big of a thing in my life anymore. Then I was widowed and then I was alone for awhile and I’m not one to go to nightclubs to have an affair, so eventually I connected with another widow, we were neighbours here in [name of city] on another street, and ah, yah the kind of excitement of a new partner and a new approach. We had a fairly active sex life again, and both enjoyed it, and so it became actually, just recently, again a more important part of my life but ah, we both, I think we are realists and say well, if that is the price to pay, obviously
nothing is happening at this time it’s far too early, and um, the literature tells me after about a year when a certain number of patients will regain control and have an erection and be able to have sex again, and ah, like my other friend from the support group said to me before the operation, he says look, you just have to accept that’s over, you know, having a good relationship doesn’t rely entirely on sex, you know, it’s kind of the mental relationship and the hugging and the kissing and the closeness and doing things together. At this stage of our life and going into the mid-sixties, um, I don’t think it’s that crucial. I mean there are sweet memories, and so be it, but we are all getting older, you know, we lose our hair, we lose our teeth, whatever, so I’m a realist, I decided many, many years ago, I will age gracefully and not, kind of, harp on the things that I can no longer do when it happens, and if this is one of the things that I may not regain within a year, then so be it. I’ve heard others at the support group talk about that being a major crisis in their life. My outlook is more, kind of, you probably had your fun in your 20’s and 30’s and 40’s and 50’s and now that you are in your 60’s or 70’s even, get with it, there are certain things we just don’t do or can’t do into our 80’s and 90’s, and if in this case, the prostate cancer was the cause, accept it, you know, be practical, be realistic. So, yah, I know, I’ve heard other people talk as it being a major crisis in their lives and I say, oh well, again there are worse things to happen to me that would be a much, much bigger crisis than anything a prostate cancer will ever experience, and you know, I would be a lot more fearful of coming down with Alzheimer’s one day as we get older, which is a typical illness, you know, that people might experience in their old age, so, you know, kind of, count your blessings and realize there are a lot of worse things around than what I’m right now experiencing, you know. [6]

That’s right and the results of the treatment. I mean, you have to face the fact that your virility and the rest is not going to be the same. Your sex life is going to change and the rest of it, but you know I was talking, I’ve got a younger brother, he’s up in [name of place withheld because of confidentiality], in the middle of [name of place withheld] and the rest of it and he was the first one treated, and he had brachi therapy by the chap that was at the last meeting. Yes, and he raves about this fellow, you know what I mean, and ah, he’s happy with the treatment, he has a lot of other problems besides his cancer and the rest of it. He had a genetic problem in his youth and the rest of it that saw him with pain, like we never experienced as siblings and the rest of it, you know, and so he developed a different way than we did, and um, so, if you went back in this genetic chain and the rest of it then maybe you’d find something else, some other basis for the problem, I really believe it’s genetic, the cancer and the problem is genetic. My dad had um, gallstones, every other kind of, kidney stones and he had other operations. I don’t know that he had his prostate removed, I don’t believe he did. His dad died, I think before he was 40, something like that, but that was back in 1930, before they had all the medical, and um, you know, the treatments and the technology that they have today, so he died very young, and um, so I guess, my dad lived to 88 and my mother lived to nearly 92 so they are long-lived people but there’s some genetic, I guess the basic thing, way back then, was the genetic thing. We have, the genetic thing is pretty amazing, like, um, dyslexia and I’m mildly
dyslexic but I never knew. Dyslexia wasn’t diagnosed and very difficult. It’s still not diagnosed, you know, very well, but um, these are things that you deal with in your life and you develop around these problems, you know. [9]

But inactive sexual ability that’s a big problem too. It frustrates me but I think it is more frustrating for my wife. [11]

No, I don’t think my family, as such, certainly not my children or my grandchildren. My grandchildren were quite fascinated when grandpa was carrying this bag around, you know when I had the catheter in and they were, of course, very curious as young children would be and I didn’t try to hide anything from them. I think it’s wise to keep the family members informed. So they saw that. Certainly, prostate cancer, one of the after effects of this is that your sex life suffers, and you know, that is something that I’m sorry to miss but I have such a positive and good relationship with my wife anyway, and ah, so this is just one thing that if ah, good memories. [12]

Well, side-effects okay. I believe it doesn’t matter which direction you go, there is side-effects. They will affect, impotence, that will be our No. 1 problem and another little problem is incontinence, but it’s gone so I don’t have a problem but there are other things that, there is nothing you can do to go back, so you just say, okay, are you going to be potent and be sexually active the way you were before or you don’t live. So I chose life, right. This is an effect. For people in their 40’s and 50’s or younger, then it is a big problem because maybe they are going to have a family and so on and it can affect them. [13]

I can’t get erection. [22]

Category: Not knowing if cancer has been cured or not, and /or whether or not I will live (6/20).

Summary: Whenever any pain was felt, these men found it stressful to wonder whether the pain was related to their cancer or not. Also, there was uncertainty as to whether or not the cancer had gone. Some individuals at an advanced stage of the disease worried about dying. A summary of the specific comments made in this category were: not knowing whether I will live or not [3, 9]; it is stressful not knowing whether or not the cancer is gone [10, 15, 26]; and I am worried about what will happen to my wife. [17]
Comments made by individuals:

I guess the most stressful part is not knowing how long I’ve got to live because mine’s an advanced case. So I guess that’s a little stressful, but to be honest, I haven’t had a lot of stress. I’ve taken it okay. I keep busy. [3]

When I had the biopsy done or whatever, when they said that I had prostate cancer, I told the urologist when we were conferring in the first place that the sex life that was enjoying at the time was the best, I guess of the age and the experience and the rest of it, made me appreciate the fact that we were having a good sex relation and so I was concerned when I was maybe going to give that up, and um, so you know that’s the most stressful part to me, um, I mean death, the fact that cancer could kill you and the rest of it was obviously a stressful thing, and anybody hears the Big C has this, um, impression that they weren’t going to last very long. Several of my close friends were gone within six months or a year or whatever of the ah, of cancer being diagnosed, and I, of course, was concerned with that but I guess, being the male, a virile male, kind of thing, and having chased the business of ? and supporting this male thing through life, the scale was like this. Like death or my sex relation, or whatever, you know.[9]

The most stressful part is you don’t know where it is [cancer]. Like, now that it’s gone. Every time I have a pain somewhere, you think, oh, I wonder what that is, you know. It’s just hard to say. I don’t really know how to answer that. I guess just the stress of not knowing. Yah, I guess that’s the most stressful.[10]

Well, I guess the stressful part is the uncertainty about whether the treatment is successful and will continue to be successful. It’s an ongoing stress even though I’ve got pretty good assurances that it’s under control, you never know for sure. [15]

Probably the most stressful point to me was making sure the family, worrying more about the family than myself because I think when I was first diagnosed which is ah, just a few months before I turned 60, I dealt with it at that point because I thought, not knowing the situation, I thought I was going to die pretty soon because it was a very aggressive form and the way the doctor told me was very blunt. I asked him how long I might have, and he says, well I had a patient like you and he was younger than you and he only lasted less than a year. [That was your general practitioner?] That was my GP and I thought, that’s it, you know. After the initial shock, I dealt with it and I have no fear of death and I guess the thing that worries me the most is probably my wife, because I have taken care of everything else, everything is in order. So, I’m ready to go when the time has come and it doesn’t bother me. The fear that I have is not death, I do not fear death, what I fear most is the way I’m going to get there. The pain and all the
things that I'll probably have to go through before I get there. That's probably my biggest concern.[17]

_Well, the after surgery, the surgery itself, whether it was going to be successful or not and also the hospitalization, you know, I don't like being hospitalized so I feel happy to be away from that, to dealing with that place, especially a hospital with other patients around, I cannot sleep the sounds in there and what's happening, so that was my worry._ [26]

**Item:** Uncertainty around the procedures at the hospital (1/20).

**Summary:** It was stressful for this individual not knowing about the treatment procedures that he would be going through at the hospital.

**Comments made by the individual:**

The uncertainty of not knowing what exactly the procedure would entail that I would go through. I'm an engineer by background. I like to know things and I've been very fortunate that I have been very healthy, and ah, I really don't know, didn't know a hospital from the inside and everything that is, kind of, very normal to the urologist and the nurses, to me was all new, and the uncertainty of that, to me, was the most stressful thing, and ah, as I said in my little write up, going to the support group, I was able to connect with people and there's one specifically and we've become friends now, we are now socializing together. He went through this three years ago and I was able to ask him a lot of very personal and very direct questions as to, you know, what's happening when you get into the hospital and you know, etc., etc., all the little steps and it helped me tremendously to learn, but it is still a different story going through it, you know. So, to me the unfamiliarity and the newness of what I had to go through, to me, was the most stressful part. If, what you possibly expected, you know the fear of dying or so, it never entered my mind. I did a lot of, like I say, I've a need to know, I did good reading, I got the two reading books that are on the market, I found the information from our boys very helpful, and um, I read all kind of other stuff on the internet. Eventually it's information overload. You know there's just too much out there, but I convinced myself, I became very quickly convinced that this is something I have to go through but it doesn't mean that's the end of life. So that is not something that caused me stress, rather the unfamiliarity I'd identify as my biggest concern. [6]
Item: Stress of travelling (1/20).

Summary: With External Radiation, this individual experienced burning and pain. It was difficult for him to travel for 45 kilometers to Vancouver each day for his radiation treatment.

Comment made by the individual:

One of the stresses was the trip to Vancouver every day, almost every day for six weeks, 32 treatments. After the 10 treatments [external radiation] or so, it started to really hurt, burn. [4b]
Appendix E

**Question:** Coping with one’s cancer can refer to the mental, physical, emotional, or spiritual part of a person; please tell me what helped you in dealing with your cancer?

**Category:** Having control over the illness by educating oneself, by accepting it, or by having a positive attitude (7/26).

**Summary:** Researching different treatments provided a feeling of control for some of these men. By investigating their treatment options, they had the feeling that they were doing the best that they could do about their prostate cancer. Some of them were able to accept their cancer or develop a positive coping attitude towards it. Specifically, the following aspects emerged in this category: since I did some investigation, that gave me a feeling of control [2, 17]; it helped to understand what the disease was all about [8, 19]; accepting the disease made it easier on me [11]; I had a fighting attitude [13], and information gained from the support group saved my life. [16]

**Comments made by individuals:**

- Probably the fact that my nature is that of doing investigation and to take responsibility for my own decisions and once I had done some research and explored various possibilities and even right to this day, I still feel that this gives me some control that has been upheld instead of sitting back and feeling powerless. By investigating it makes you have a feeling that you are doing the very best you can. [2]

- Well the first thing that helped me a lot, is to understand what it was about. I was ignorant of the fact, you know, and I learned from going to the cancer clinic and talking to different people at the cancer meetings we go to once a month. Understanding what it’s all about, that’s what helped me and helped me to make my decision. [8]

- No. 1 is accepting it. It was hard at first but accepting it, having a supportive family, the support group and just going on with everyday life. I don’t worry
about it anymore. Most of the time I don’t even think about it. There are times when you are by yourself and you remember what it was a few years ago what you could do verses now, but accepting the fact and just saying, it happened, deal with it. It’s changed my life. Oh yah, oh for sure, you know, the not knowing and not having control is very frustrating and after you’ve had the experience and time to understand your capabilities, limitations, you get better with it. So, yah, I’m coping a lot better now. [11]

Well attitude is one, I think it is very important that you say, well, there is a condition and I’m going to fight it. Second is to acquire knowledge about how to cope with it and third the group is a really important element, because you find emotional support, you find people with the same condition and how to deal with it and so on and so you try to make yourself able to cope a little better.[13].

The [name of city withheld] support group. I think the [name of group 1] support group saved my life. I was floundering, not knowing where to go. I went to [name of another support group] support group, and ah, it was a group of about 10 much older gentlemen, and ah, it was local here and they sat around and spent most of the time just talking. You wouldn’t say it was an organized program. On a couple of occasions they brought in a guest speaker. My doctor, Dr. [name] was treating me and did the operation and also a naturopath and so I was pretty lost about where I was, and then somehow, I learned about the [name of support group 1] support group, and I therefore got there and found it extremely excellent. The executive were good, it had a great library, a great film library, every other month we had a great speaker. There was about 250 members so we had a good turnout so. It was only through that that I really, after that session, I really, a couple of those sessions, I was really able to think through the course of action I should take, and ah, and I chose the course I did and I became so impressed with the support group that I joined the committee and I also ended up joining the board in order to give something back, but I no longer am a board member because I ran into all these health problems. I didn’t have the staying power to stay out until 10:30/11:00 o’clock once a month. So, I’m on a committee now and I’ll continue to be on the committee. Listening to Dr. [name of doctor] field questions from the floor was extremely productive. [16]

Taking control. I haven’t, although the doctors have been fantastic, I’ve researched every step of the way. I researched it to make sure that this is the route that I wanted and I was lucky enough to have good doctors that were willing to discuss everything with me and they concurred or I concurred with them, or one way or the other, but we both agreed on the treatment that I would receive. [17]

*I don’t know most helpful, I just read up all I can on it, all the information and books on it so I start to understand it. [So, then finding information on your own?]* Yah, most of it, I got in there too, but mostly on the books. I read up on. [19]
Category: Support from my wife, family and/or friends (14/26).

Summary: Men also spoke about their supportive and encouraging wives and families. They spoke about how some of their friends had been helpful to them. The following specific aspects emerged in this category: my wife was encouraging, capable and supportive [1, 2, 9, 20, 26]; I had a supportive family [4a]; my wife became the driver [4b]; having my wife agree with my decision about treatment was helpful [5]; support from my friends at the support group was good [6]; support from friends was good [22,25]; I got reassurance from my doctor, family and friends [15]; my wife came with me to visit the doctor [19]; some relatives helped me with coping [21].

Comments made by individuals:

Wife was encouraging and did not accept negative behavior. [1]

I have a very confident, capable, supportive wife. I have family members that have also been very supportive. [2]

In my case, I had a very, very supportive family and they worked right along with me and ah, you know, I couldn’t have asked for anything better. [4a]

My wife became the driver to take me to Vancouver every day, for 32 trips. That was really stressful, really, really stressful for her, but the support from the family, and like we were saying, the prayers are there and the phone calls and the cards and so on and so forth. There’s no problem there whatsoever. [4b]

Okay being the prostate support group facilitator from [a municipality] and seeing other people with the same problems as I had and being able to alleviate their problems from my knowledge, and ah, having the wife agree with me in the decision that we made. Those were two big, stressful things and that’s pretty well all it is. It makes a difference, a big difference to have somebody supporting you, and even the guys here, we’re giving them our support and they appreciate this, and people that we’ve talked to, we can’t give any information medically but we can tell them what to have done, and ah, from what I see, most people have decided to get it taken out so they can live another 10, 15, 20 years, whatever, rather than maybe five, if they’re lucky, with cancer. My whole family helped, you know, they supported me in my decision. [5]
Well obviously you know the family connection and the friends, that's very important. Nobody wants to be alone at a time of physical crisis, you know, I think it's very important to feel that others care and typically it starts with your family, now in my case, the family is my spouse's family because I didn't have family and whatever family I have left, I have one sister left, she's in [country's name taken out for privacy] in but immigrated so, whatever little bit, cousins or so that I really have no contact with, my family is overseas and that's very little contact but my new spouse, you know, she has three children, you know, five grandchildren and there's an extended family and then we both have a substantial circle of friends, and you know, we have kept contact with them and that is maybe even, in prioritizing, that's a more important support and then the new support through the support group that, to me, was initially more technical support, you know, medical terminology, medical procedures and well, you know, we developed a close contact with one couple out of that support group, but um, you know, prioritizing it's obviously family and friends, (a) it's a much bigger group and (b) it's a stronger group because you go back many years. I have a very good friend in [city name taken out for privacy] who suffered cancer many years ago, a different cancer, but I was with him at that time, before either one of us married, and ah, we kind of bummed around together and I was kind of support for him and ah, you know, he was very, very, strong support for me, and again, what I kind of stressed in my answers to your questionnaires, prostate cancer, fortunately, has a very, very high success rate especially if caught relatively early or at a relatively young age because later on, as you know, they don’t do the full surgery anymore and um, treatment options are more limited later on for older patients but um, you know, it's not a death sentence. It is an unfortunate something that one has to go through and you know get through it and be done with it and more on so that' how I would look at it. [6]

Um, my wife, my partner, has been unbelievable, just totally unbelievable, so understanding, so, um, it’s hard, I think for the male to understand that, um, you know the male instinct and the rest of it is to get on with the sex and have sex and enjoyment and the rest of it and um, you know, it's like women are from Venus and men are from Mars or something like that but my wife can do without it, and you know, the male, I think the male thing is, you know I have to treat this lady, I have to show her some male expertise and the rest of it, you know, I have to hang on to her because this is how, you know, you grow up and you mature in life and this is the goal, the male goal, is keep the female happy and the rest of it. She's the sole best thing for me, over this. You know, we converse about these things and I told her the inability to get an erection is really, destroys the male esteem. You know what I mean, you, I guess it's a fact with every male being, I would say, is you know, I mean, if you can get it up, it means you're still a male, if you can't you're something else, but anyway, I was saying to my wife the other night, I mean we still have special moments and I'm able to experience an organism, and thankfully, she can as well and that’s great, but I was saying that I have injections to enhance so that I can get an erection on and the rest of it, but we have beer and wine and I think beer and wine and the injection don't work too well together, this is not too effective, it just doesn't work somehow. It's there, but not long enough
and you know, anyway. So maybe I have to up the dose or give myself two injections or something like that but I’m thinking that maybe a better way around it is to have this prosthesis fitted in there and so I’ll an erection anytime I want it, just turn it up and away we go. Anyway, so that’s where we are at. [9]

Well, I guess it’s the fact that the reassurances that I’ve gotten from my doctor and the tests I’ve had that the treatment has been successful is the most reassuring thing. If it had been some other result it would have been very stressful anyway, so I guess, I had excellent support from my friends and family and so on, but ah, it seems to work. [15]

_My wife comes along with me every time I go visit a doctor. So that’s all the family, I don’t even tell my daughter or son about it. It’s no use letting them worry about it._ [19]

My wife did [helped me in coping] [20]

_I have been dealing it by myself. I do have some relatives that live here, and I did tell some of them. First they were more afraid and more worried than me. But you know I think I would have been ok if I didn’t even have a treatment. Research says that it is diet that causes this problem, I believe in research. I don’t take an active part in my culture so I have no help from my culture. I am not religious either. It was a shock for me for a week or so; however, information helped. Before I was diagnosed, I had no information about this. That made it really hard. I had to go to washroom._ [21]

My friends have helped me cope with it. I take it day by day, slow grind you know. I try to keep occupied and work on the garden. I have never attended a support group. At first I didn’t have information about it but I found out after the treatment but then I never felt the need for it. [22]

_The stressful part was just the initial first few weeks that were very stressful for my family and myself but we did get over it fairly quickly the more I learned about it. The thing is to learn as much as you can so the Internet helped a lot and then I met John [name changed] and through John I met another cancer survivor and we just started talking and finding out more and more and it becomes accepted. [So you had that through your Mosque?] Yes, yes._ [25]

_[How about your family, were you able to open up to them?] Yes, of course, straight away, the very first day. That’s my immediate family. I haven’t discussed this with my extended family yet, but you know, in our culture the minute you mention the word cancer, that’s it, you’re dead. [It was very stressful for your family then, even your immediate family?] Yah, my wife, but again, you know, you talk about, you talk about it. She comes with me to all the visits to the doctors and oncologists so. It’s difficult to find others. It’s good to be able to talk to other prostate survivors and other people who have been in your community but_
everybody is so tight, nobody talks about it. [Were you able to find some people from your community?] I met one person here eh, yah. [And how was that?] Oh, excellent but that was my main source of information. [How did you find out about him?] Through John, but John first asked him if it’s okay. John didn’t give me any names or so. [Okay, so far your support has been your family and the person that you talk to, has there been any other support for you?] No, no but it’s nice to come to meetings like this. You open up and it becomes easier to handle. [25]

Um, just not to worry, I’m pleased because that was the advice given to me, to undergo a surgery instead of hormone or radiation, and I think that I like the decision that I made. But in terms of who has given you the most support and helping you to deal with it, like, your family, friends, support worker? Okay, my wife supported me. Helped me also to make my decision. [26]

Yah, I started to give them some worry. [Were you able to communicate with them openly, your feelings with your family?] Ah, yes and no, but ah, I don’t we – unclear- so if they don’t ask and if I don’t feel like talking then I don’t. [So beside your family, have there been any other family members you’ve talked to about your problem? Oh, yah, my sister, my nephew, my nieces and some very old friends. [Have they been much support to you, the extended family?] Well yes, of course, they show they are supporting and wish me well. [And the very last question, has your cultural community, have they played any part?] They don’t know about it so I don’t expect them to play a role. I mean, they did not know about my problem, I didn’t expect them to know, I do not talk close to them, so they didn’t not know about it because I did not want to share it with them. So, I don’t expect them to provide any support. [26]

Category: My religious faith provides me with personal strength and with the ability to live day-to-day (12/26).

Summary: These men believed that God has been good to them. They believed that God is a good healer and has made it easier for them to deal with their prostate cancer. Specific aspects related to data from this category are: God can do miracles, and I have a very strong faith. God has sustained me [4a, 4b, 12, 18]; men that have faith in God cope much better [4a’s wife]; God has put me here to do some good [5]; God is in control of everything [10]; it’s been good to spend time with my God [11]; religion has an impact on one’s health [13]; support of my
friends at the church has been helpful [15]; One gets to think about mortality more [25]; silent prayer with God has been helpful. [26]

Comments made by the individuals:

In my case it was my faith. My faith had a lot to do with anything that I, sort of, suffered, you know, I had to deal with this one time before through a very serious car accident and I felt that the Lord brought me through that. So I was putting a lot of dependence on him to bring me through this, this cancer problem. I’ve always had a strong faith. I came to the Lord back in 1964 when I accepted him as my personal savior and I think as the years grew, I grew stronger in my faith and I’ve seen where God worked in other lives and had created miracles and this gave me a very strong faith to be able to go through this. I think that, ah, as I went through it, I think it [cancer] probably made me stronger in my faith. Let tomorrow take care of itself. [4a]

I’ve noticed the difference between the men that have cancer and the ones that have faith live day-to-day and enjoy it, the ones that have no faith will try to get more into their lives, they go everywhere, they try to see the things they’ve never seen and they are trying to make a long life into a short life. You know, like there’s fear there, but the one’s that have faith live day-to-day as if someday they’re going but it’s not important to them. [4a’s wife].

In all our reflections, even in our good things that we enjoy, we depend on the Lord so greatly for our lives. Whether the faith grew during that time or not, well it’s hard to say, but I know very well that if I hadn’t been Christian and had him on my side with me, it would have been much more difficult to go through and to endure what I did afterwards after the treatments. Faith in the Lord has a lot to do with our healing. Our healing, I believe he has a lot to do with it and so we depend on him, you know, in whatever we face we depend on the Lord to help us, to be beside us and with us. We don’t worry too much about tomorrow. [4b]

Well, once I found out that ah, when I had it taken out and everything and they had got everything and when I was on the operating table my heart stopped and my doctor said I lost four liters of blood and my doctor brought me back again and I figured there’s got to be a bigger reason for me being here so I figure the Lord has put me down here to do some good to help out with other people with prostate cancer. That’s why I’m here working for, I work for the cancer society in doing what I can to alleviate the problems of others also. So that’s about it. No, I think it’s [my faith after cancer] remained the same I would say, yah. [5]

What has helped me most is my belief in God. I believe God is in control of everything. I believe that, I don’t know where you are in your religion but I know most people from India are different than my religion. I believe that God created
the world, he sent Jesus Christ to die for our sins and I believe that I'm living my life as good as I can for God and when I die, I'll go to heaven. So if I die when I'm 60 or die when I'm 80, I'll just get there 20 years earlier and I'll still go to heaven and that's helped me a lot. That's really helped me a lot. I like to stay here because I have five grandchildren. I'd like to see the grandchildren grow up, I'd like to see them graduate from school, I'd like to see them get married and things like that so that would, I would hate to miss that but at the end of it all, I just see them in heaven as well so ah, my father has passed away. I believe he's in heaven, so I'll see him again. I think that's been the greatest strength in coping, is having this faith in God. I've always had that [religious faith]. No it [cancer] didn't strengthen or lower it in any way. What it, maybe, did was reinforced it a little bit more and it made me realize that I am not the tough fellow that I thought I was. You know, I thought I could handle anything, but I'm just as human as everybody else, and no that hasn't changed. No I've always had my belief in God, I always believed that Christ came to this world to die for my sins, and ah, yah I still believe that, and I guess it just reinforce that a little bit. It hasn't changed it. [10]

Oh yah, I think that a person that does not have a religious background has a hard time coping with the things that are strange to them. I know that when I was going through the recuperation period and you're by yourself and you are just healing, you spend a lot of time, I spend a lot of time in meditation and I came to deal with it a lot better. I won't say I understood it any better, but I was dealing with it better and I'd say religion had a big deal for me. Not really [speaking about change in religious views], other than, I spend more time in meditation. No, once I got it in my brain that no matter what happened, it happened, you deal with it. It worked for the best and you can thank the Lord that you came through it and it's been good to spend time with me and my God. [11]

Well, I think my faith, my religion. It has, certainly, sustained me. I always felt that I was certainly prepared. I’m prepared for life, I’m also prepared for death, and having that, you know, there wasn’t anguish on my part. Certainly that doesn’t mean that I look forward to death, but because I have such a good relationship with my family and my friends and you don’t like to leave them but I also know that there is an inevitability that we will, someday, die and I think we should be prepared. So I was pretty good about that, I think. No, no, I think I was steady through all of this [in my religious faith], yah, yah, because I did have a belief before, during and after and I don’t think there were any fluctuations. [12]

It probably makes you religious, a little bit more. [But you always attended the synagogue?] Yes, yes. I come from a background of people that belong to a certain community and one way to express your community is belong to something. We know that people that do belong to any affiliation, or religious group, that they even find that they live even longer. They find that there are like stronger family ties and stronger? You set aside, there is one day of the week or a certain time of the year where you are devoted to spiritual things and spiritual things play a role in our life. [So you’ve become more religious through this
experience and believe more?] Yes, yes, yes, I think religion is also a way to give you direction in life, what you do, what not to do, and how to live with your friend and your neighbour and so on, and that's important. I think those who honestly believe in something become better people, because you would have some more values, some ethics that they would follow. [13]

I belong to the United Church and have strong beliefs so that's helped me. Also the support of my friends at the church. [So you were going to church before as well too?] Yes. [So, do you feel you had a change in your religious outlook at all, like, going through this experience or, like did it make you more or less religious?] I don’t think so. [15]

Yah, what I found in talking to the people, those people that have a faith tend to do better than those that don't. My analysis of that is that people have something to hang on to more so than those people who don’t have a faith. They don’t have a path to follow. The future is not as clear to them as for other people, something along that line. People feel more secure, that kind of thing. Certainly in my case the congregation was very supportive and very helpful and my ministry at the time, was very helpful, those kinds of things. Ah, my colleagues at work and those kinds of things, because I was very open about it, I found a few other people who were not. Those people, who are more open about it, tend to find more comfort I think and talk about it more easily and that kind of thing. I would never have talked about prostate cancer in my life if I hadn’t of had the cancer myself and a lot of the things that happened with it. You wouldn’t get me to talk about it at all, not at all, particularly the sexual side of it. It’s very private for me. I would never, never, never have talked about it. Not at all.

[Do you feel it changed your beliefs in any way?] Oh yes, I think so. I had some very interesting things happen to me in the course of having the surgery. The anesthesiologist came to see me the evening before the surgery. I really don’t know what the procedure is now, but at that particular time, you went in the hospital the day before and they prepared you for the surgery the following day. Anyway, in the evening he came in to tell me about what was going to happen and that kind of thing, and as he was leaving, I said to him, good luck. He turned around rather abruptly and said, it’s not good luck, and that was a very profound statement for me. I realized that none of this was good luck, it is all upon knowledge, skill and faith. If you have no faith within yourself, there’s no way that you can proceed with anything, nothing. So it has given me a deeper understanding, faith in myself, and I’ve discussed that with a number of people and I’ve even been invited to give a sermon on this, at one time, and I said, oh, I’m not ready to do this yet, but I’m ready to do it now. I’ve given a bit of a talk, talking about faith and how faith is within a person and how you have to have faith in everybody else too or you can’t move a finger and I can demonstrate how that works. So that’s awakened me in that sense that I didn’t have that before. I had it before, but, and we all had it, what it did for me was awaken me to the reality of it. To allow me to express it in a different way and show people how it works and my minister at the time, talked a lot about this, about God being with yourself and the spirit is within us, those kinds of things. I couldn’t really figure
out what he was talking about, you know, I thought it’s very, very, you know, it’s out there someplace, but that statement made me realize where it is. So I can talk about it now and more comfortably and I feel more confident about it, that type of thing. [18]

[Has spirituality played any role so far?] Yah, yah. [Would you explain it?] Well, it’s, you, I think in any business like this, you know, it can be terminal or you know your life is going to be shortened and you internalize a lot and you gain a lot of spiritual strength. [So you became more of a believer in your faith?] I was a believer in my faith but more so. You know questions of mortality and start thinking about it more.

[More about the meaning of life?] Yah the meaning of life, death, family and the short time we have in this world and you know eventually you are going to die but when it gets, you know it’s going to get closer it’s what you think about. [Ah, did the Mosque leader or congregation play any role?] No. [Did you discuss it with them?] No, no. It’s a private thing, no. It doesn’t bother me, really. [25]

Yes to some extent. [Like what, have you been going to some sort of temple or church or something like that?] Well we pray for recovery, we pray for speedy recovery, we pray for a successful surgery. [Like do you pray privately or do you pray publicly somewhere?] Well in church I don’t know if that qualifies as publicly or privately, but you pray silently by yourself. [Which religion do you belong to if you don’t mind telling me?] I belong to a denomination of the Catholic Church. [So, did your congregation know about it that you had a problem?] No, no, except for maybe one or two close friends, other than that, only certain people know. [Is it easy to open up in your culture to talk about it with your family and friends?] It’s not too bad, there’s people who prefer we not mention it, but we don’t go out of our way to do so. [26]

Category: Prayer was important (6/26).

Summary: These men took time to pray for each other. Some individuals from their congregation prayed for them as well.

Comments made by individuals:

Um, religion played a small part, yes, um hmm. No, no. [cancer did not change my religious views at all] It’s a Mosque actually and they were supportive and I got involved with the health board there. [They would] just ask me always, how are you feeling and praying for you and in that sort of respect, that’s how they helped out, yah.[3]
We depend on our friends and our fellow Christians and their prayers, not only here with our obligations but throughout North America actually. Friends in Omaha and Arkansas, everywhere. We depend on that a lot. When someone gets sick here, we run it home and everywhere and have a chain form and that’s what happens. We depend on that. I’m looking at the building across there, it has a lot of columns to support the balcony and what not. Well, that’s the same thing with us and with everything, one column support is a prayer, the other column is a support group, another column are your friends and so on and so forth and so a whole bunch of columns are supporting you to work through what you want to, not that you want to, it’s most unusual for any person to have cancer. You hope that you never will have cancer but suddenly the doctor says, hey, you’ve got it, and you go, What, me? You know, so you need all these columns to support you. [4b]

The preachers in our church, in our particular church at this time, the preachers have not been much support, no. I’m very disappointed in the preachers but the people, in general, my friends in the church are very good. They’re very good, they’re very supportive, they’re very interested. There are other people that have cancer. There’s a lady with breast cancer, there’s a husband whose wife has advanced breast cancer, now it’s all over the place. There’s another fellow who has colon cancer and because people with cancer can more easily talk with other people with cancer, you know, like you’ve been down the same road. You, kind of, talk easier together about your cancer but the rest of the church is very supportive, they’re very, yah, if you need something, they’re there, they hold you up with prayers and I would say they are very supportive. [10]

Other than support, no, what can you do, you just, just the support that they are there, they pray for you, you know, you are put on a prayer list. That’s basically what the church role is for, just the family church group for support and for prayers. [11]

Well they [religious preachers] visited me in the hospital and I’ve talked to them on the phone when I was at home here recuperating, recovering from this, and yes, and certainly they prayed for me in the church and I was aware of that and they also told me. They’re just wonderful people and so to know that you have people caring for you, that’s a comfort, sure.[12]

I think of religion has something to do, because if you do have faith, if you do believe in something, okay, it gives you the strength to believe that we are here to live and God will decide whether I’m going to stay alive or not, but that will make you a stronger person, okay, you have something to rely on, something to pray for, and ah, generally when they are religious, they are a part of a certain community,
and again, it’s a community that is not always supportive for cancer but you have a social connection and that’s important.[13]

Category: No major role played by religion (8/26).

Summary: Religion had not played a major part in some of these men’s coping.

Specific aspects in this category are: I do attend church but I am not devout [2]; I do not go to church and I am not a spiritual person [8, 9, 16, 22]; I believe in the Supreme Being but I do not go to church [17]; my religion is to treat others nicely.[20]

Comments made by individuals:

Not a major role. I do attend church but I am not as devout as some people and I guess I don’t get the same comfort support as some people would but I do certainly have beliefs of that kind but it wasn’t a major factor.[2]

I guess, not in terms of formal religion, not in terms of formal spirituality, I don’t meditate per say though I’m familiar with all of its forms or whatever. I would say that I know where horoscopes and all that good stuff fits in the scheme of things, but it seems to me that I’m my past and what is laid out from the start, or what is reported after the fact, in other words, I don’t read the horoscopes to see what I’m going to do tomorrow but at the end of the week or the end of the month, I will read the horoscopes for what is just past, and say, gee, it’s exactly how it worked out. So and they’re always good things so I know that down the road things are going to work out fine and I have confidence.[7]

Religion or spirituality? No, nothing [no role was played]. No, negative, no [I didn’t go to church prior to my diagnosis either]. [8]

No neither of us [is religious], my wife is um, my wife is not religious at all, and um. We were married before a Justice of the Peace and we had witnesses there and the rest of it, and um, I think today she said, or yesterday I’m not sure, but she said marriage is that piece of paper, there’s no binding thing on it. I’m you, you know, my wife, I was concerned 35 years ago or 40 years ago, she was hooked on Yoga and the Guru and she would go and not come back for some time and get away on, like a sabbatical and I was concerned, I thought, what’s going on? This is her religion, she doesn’t practice yoga now, she has a weight problem and she’s gotten away from it, but at a point, she instructed in yoga postures and the rest of it, what do you call it, Hatha Yoga or something like that, but she is the most honest and considerate person that I know and I guess that’s, it’s truly respected...
by, me and for that reason, I don’t believe I need it any more than she does, you know, to practice, you know, going to church or, whatever, or praying, whatever, this is it. [9]

Not really. I wouldn’t say, I am not a overly spiritual person. I believe in God and live a God-like life in terms of values but I don’t attend church. [And you didn’t do it before either?] No, I did when I got married. We got married in the United Church but we got away from it. No, I can’t say, it was not a factor, not a factor. I felt ? and that position remains today. [16]

No, no, but um, I’ve gone through virtually, to take some control of myself, I’ve just about done everything. I’ve gone through meditation, herbs, Chinese medicine, acupuncture, meditation, diet. So, my taking control, myself, I feel has helped me. I don’t think I would be in such good condition now as I am, if I hadn’t helped the doctors along the way by doing things that I thought would help me. [So, I suppose you weren’t that religious or whatever before?] No, I’m not a religious person. You know, I believe there’s probably a supreme being there, but ah, I’m not, I don’t go to church, it’s not something that I believe in, I may believe, somewhat, in a bit of religion but I don’t believe in church. I think there is too much corruption in the church. My feeling is that whether it be Buda or Mohammad or whether it’s God, we are following the chief teachers rather than the Supreme Being himself. [17]

I’m not a religious person [20] He has a religion. [20 wife] Church, I think if we got rid of all the religions, the world would straighten up. Just get rid of them all and we wouldn’t have a conflict. You have a religion, [name of husband], it’s do onto others as you’d have them do unto me and that’s what we live by, that’s what we live by. [20wife]

I was never much religious. No, I didn’t change much in this regard. [22]

Items: Cancer can be beaten with a life-style change or with one’s values and life experiences (2/26).

Summary: If proper diet is followed, and /or if one’s environment and moral values and beliefs are strong, then cancer can be helped or cured. [1,7]

Comments made by individuals:

Other than that, I think it’s your lifelong experiences, okay. It’s your moral beliefs, your ethical beliefs, your religious beliefs that will take you through this [1]
Um, I believe that cancer can be cured. You got it naturally or for natural reasons and for the same reason you can cure it naturally. Once I get my environment, my total environment, as I improve my total environment, both the mental, physical and what I consume, I know that my body will start, my immune system will become stronger and I will heal naturally. Whatever fine may be, fine may be not surviving a long time but that's just the way it's going to be. It's kind of just the way things happen. I'm here to live life and I'm not worrying about living x number of years with cancer, I'm worried about living well and um, doing what I can do so that cancer doesn't make my life unbearable for the time I'm here. So I go to Shamanic healing as well, it's one of the alternative approaches. I go about once a year. Well it's basically, you know, like medicine man in the North American Indian culture, I think you probably have something similar to that in India. [7]

**Items:** Taking on a leadership role to counsel and help others in a religious setting (1/26).

**Summary:** This individual presented a seminar on prostate cancer, and tried to inform others about prostate cancer at a religious setting. [3]

**Comment made by the individual:**

I took an active part in the mosque because I am also Muslim and I got on the health board and I was actually put on a seminar on prostate cancer for the mosque and everything. So all of that empowers you, I think. Yes and I actually counseled them [some other individuals with prostate cancer at the mosque]. [3]
Appendix F

Question: With respect to surviving your cancer, have you ever compared yourself to others who might be better off or worse off than you?

Category: Downward social comparison / others have not done as well as me (16/21).

Summary: These men believed that others had not done as well as they. Specific aspects about the meaning of this downward social comparison are presented as follows: I learned from others’ experiences [1]; I had good success in my treatments [2]; I consider myself lucky [5, 19, 22, 26]; I am OK because treatments have not worked for others [7]; others may get into worse misfortunes, such as getting into car accidents, so this helps me to deal with the disease [10]; I support others who are worse off [11]; compared to others more worse off, I had little discomfort; I don’t want to have what they have [12, 17]; one feels a loss when he loses somebody because that person had something in common, but one feels lucky at the same time [13]; I came to the realization that there are individuals who are worse off than me or that I had it easy. [16, 20]

Comments made by individuals:

These meetings [Prostate support group] help, okay, because you always know somebody is worse off than you and it also lets you know what kind of treatments you can do so you can meet people here and kind of share your experiences. So those are the most important, what has not been important is kind of religious experience, okay. It’s been basically, I think through every transition you go through and I think when you become a cancer patient, it’s all the things you’ve done before hand that you take into that that’s important. So if you haven’t done anything and you haven’t made your risks with your God or your religious beliefs, if you haven’t experienced those things, this might be quite traumatic and I’ve seen that here. If, on the other hand, you’ve lived a life where you have no regrets, then you take that with you into this experience of having cancer. [1]
Sure, very much so and I think that I benefited by getting on hormonal therapy quickly when the other primary treatments such as surgery and radiation, when they were not successful, I jumped on hormonal therapy and I have been very careful monitoring the situation and even changing the drugs used for the hormonal therapy so I’ve had reasonable, good success compared to my support group members who pass away. [2]

Well, when I look at some guys that are a lot worse off than me, I feel better and I see some guys that actually got cured and I’m envious of them because I won’t be cured, you see, but I’m not popping off tomorrow, I mean I’ll be around for a while yet but, yah, so there’s envy for the guys that have done well and a little bit of feeling not too bad when I see the others. [3]

Yes, I do that [compare myself with others] all the time and I consider myself very, very, lucky to be one of the few that they caught it in time and I get to thank my doctor for that. He did the RI exam and digital rectal examination, and ah, he found a slight bump on it and ah, I had no big problems but I did have a few problems that I just thought was going along with old age, you know, coming up. And ah, so I look at the other people that are worse off, and I see them all the time, and consider myself lucky and blessed, as it were, and ah, just count my blessings. [5]

So, yah, I know, I’ve heard other people talk as it being a major crisis in their lives and I say, oh well, again there are worse things to happen to me that would be a much, much bigger crisis than anything a prostate cancer will ever experience, and you know, I would be a lot more fearful of coming down with Alzheimer’s one day as we get older, which is a typical illness, you know, that people might experience in their old age, so, you know, kind of, count your blessings and realize there are a lot of worse things around than what I’m right now experiencing, you know. [6]

[In comparison to other individuals]: Well only in reminding myself that there are worse things in life than what I had to experience, you know, in that sense, count your blessings that it isn’t worse because there are many forms of cancer. My wife died of cancer, my spouse, her husband died of cancer. We have both been through a cycle of caregiving that ended up in death and so we have both seen, you know, very, very close in our relationship how the cancer can be terminal and that is not a very, very kind of good experience, it’s a very, very destructive experience, but um, we have come through that and ah, I sometimes think the experience as a caregiver, for a case that was terminal, gave me some insight and strength to look at my situation and say, well this is not one of those, this is something that is manageable and controllable and maybe I handle it better because of that. I sometimes think that. That without the experience of having cared for my wife, I might have being more negative in my outlook, so similarly, my spouse, having gone through a very similar parallel with a different cancer again but similar experience, an experience like that helps you to mature and that
maturity you can draw on when the next crisis comes and in this case it was my crisis so, yah. it would be worst off to have Alzheimer [6]

The fact that matters is they had the operation, in my opinion, it may come back, and then the guys that had the operation, they had the hormones, I guess you could say I’m better off than they are. [7]

Oh my, ah, it’s my nature I’m fairly optimistic, I do not walk around feeling sorry for myself. Oh, I have cancer, you know you have to treat me gently or I need favors, no, I don’t have that at all. I go through life not thinking about it, and the times I think about it is, when I get my blood test done which is about once every three or four months, and I when I go into the doctor’s office and you sit with all these other fellows and think, oh all you guys have cancer, you know, and then you realize, oh yah, you’ve got it yourself too but you can’t feel it. So I get a little down when I go in for reports and stuff like that, but lately the reports have been very good so I feel really good. I go to these support groups and for about two or three days afterwards I feel down because you hear of all of these statistics that are not in your favor and sometimes you figure, you hear that, sometimes you figure, you hear that people with your symptoms and your treatment and your reaction will live three years and sometimes they live as long as six years, that’s not very long, when you think about that, six years is not very long, and you think that maybe you’re not here anymore in six years, I don’t even think about that because that would get so depressing. I just keep praying to God that he will heal me because I know he can do that, and ah, I just pray for strength. I pray to him to help me through this and keep me having a good attitude to help me use the time that I have the best way possible, and ah, just to help society, but ah, other than that, other suggestions I can’t think of any at all. Just make the most of every day. Like I feel fortunate, I have cancer so I have notice that I will not become an old man by the same token, a lot of young people may not even be getting home today, they could get into an accident or get another disease so I just received notice and I’ve been made aware that I won’t become an old man so I’ve just got to make it count and I would suggest to everybody, make it count. You know, whatever you do, don’t waste your time, you know, just live life to the fullest, that’s the best way you can serve your family and your community and serve God and make the most of everyday. I guess that’s about the bottom line. [10].

You can’t help but do that. I know that I have a friend at church that was diagnosed after I was, he’s an older gentleman and he has terminal prostate cancer. So I relate to him and I support him as much as I can. In our group, there is such a variety or different options of therapy. Some have just the needle, some go on with the pills, some just do radiation chemo. There’s not too many of us there that actually had the radical. So I don’t think I’ve really compared myself too much to them. I didn’t think I was in the same kind of, feel the same. I believe there’s only two that I know of, three, [name of a friend with prostate cancer, name withheld for confidentiality], I was very supportive of him and
there’s another older gentleman there, but ah, generally, no I don’t compare. I try to deal with myself. [11]

Well it’s certainly in the back of my mind, when I go into the hospitals and the ambulatory daycare or surgery or just when I was in the hospital itself and I saw other people that were certainly much worse off than I was. I think that, if you didn’t know, you probably wouldn’t even realize that I’d had that kind of surgery. I had an ephemeral that was given to me and I tell you, I didn’t suffer any pain, you know, just on the post-operative recovery period, they would ask me on a scale of one to ten what do you feel. Well one time I said, and I think it was on the second day, I said, maybe a two, but all the rest of the time it was one, one, one, one, one. So in other words, I just felt good and I would be walking around and ah, talking to people and no, I was amazed myself, personally, that there was as little discomfort during my post-operative time [12].

Yes, better off I don’t know because I have been lucky, maybe. I have been able to survive nicely and so on, but yah, mostly affected when, once in awhile, we lose one of our members, you know, you just have to spread out and you feel a real loss. Like the people who belong to that group and especially some people who were active in our group. We just lost a member a month ago and he was also an active member, you know, for a number of years and so over the years you develop some kinds of friendships, some connection with some of the people and the loss is like you lost a friend. You’ve lost somebody that you have something in common with [13].

Well, it isn’t a question of comparisons, it’s a question of realizing as it’s difficult for you, there are others that are worse than you. There’s a committee member his has metastasized and it’s painful watching him go through it. He’s on Morphine and he knows there’s time limits on his life and not a happy thing to carry around you know. I would say the worse thing about being a member of a support group is every meeting there’s an announcement that we have lost one, two, three people or what have you. People I have known and I knew two guys who were good, really good guys. [16]

[As you’ve been going through this ordeal, have you ever compared to people that might be worse off or better off than you in any way?] Yes, I do because one of the reasons I got involved with the cancer support and got on the committee is because No. 1, although I give out a lot of information, I gain a lot of information so it’s a learning process as well and I often compare, I volunteer at the hospital at the geriatric ward and I look at these people and I say, I’m so much better off than they are, you know, because most of them have some sort of dementia or whatever the case might be. I don’t want to be there. [17]

Well I can see at the lectures that some are worse off than I am. [So how does it make you feel when you hear about it?] Well I consider myself lucky. I guess, to be in the position like this, so far. [19]
I think I’ve come out easier than most people. I think, you know, the success has been better than some people, but you don’t really get that boasting sort thing.

For a small group, the [description of the person withheld] lady that was there today, she was mainly with the women’s group and just because there were only three of us there today, like we didn’t have it, but when I first went and listened to some of the problems that they had, I went, oh, man, my problems are minor, but a lot of the women there in the support group also have very poor problems of their own, health wise. A lot of your problems are because of our lifestyle [20wife] How can you say that? [20] I’m a firm believer of it. Your smoking [20wife] Just because I smoke a few cigars a day. [20] Your smoking and I was feeding you the wrong food. I was feeding you the wrong foods, because we didn’t know any better and I thought I was being a good wife by doing all this baking, and you know, that sort of thing, when really, I was killing my family but I know better now. I don’t do it. We have fruit. [20wife].

I have looked at individuals who are worse-off. The maintenance man of this building was 69. I didn’t have much to do with him. He had radiation before me. It was matter of months and he was gone. See, he was worse off when he was diagnosed, whereas I was diagnosed early. I was lucky. But everyone is different. [22]

Well, of course, having this problem, even though the surgery was successful, it affects, it’s sure to affect one’s life somewhere, eh, but then ah, other illness, other types of illness, like this by itself, just prostate problem, I suppose it’s not too bad, but in my case I have other problems like – unclear- so altogether like when you combine the thing, it is pretty bad. [But did it change your views about life, about the way you look at life, no?] Well, I had to accept there is bound to be some change, but then you know, it depends how you look at it. Like everybody else, I would like to look at it in a positive way, but it seems like, not just, indeed, by saying that you would like to look at it in a positive way, it comes easy, it is not easy but you keep on trying. Well, I know for sure there are people, there are worse cases even though there was surgery. Some surgery, there’s bound to be some that are worse than you and some surgeries are more successful, some are less successful, at least one of those things. [Have you ever compared yourself though, to those people?] Yah I do, just occasionally. [To people who are worse off or better off?] Especially the people that are worse off. [And how does it make you feel then?] I just feel that I’m a bit lucky. I’m lucky. [26]
Item: Upward Social Comparison (1/21).

Summary: When this individual sees others doing well, he has a feeling of encouragement and well-being [3].

Comment made by individual:

Well the support group is actually what’s helped most of anything. Well in the sense that I’ve seen and dealt with other fellows in the same situation and I see them surviving and doing well and it gives me that kind of encouragement and a feeling of well-being and that’s helped the most of anything. [3]

Items: Temporal Comparison (2/21).

Summary: One of these men believed that losing his eyesight was worse then having prostate cancer [8]. Based on his past experiences, another individual thought of himself as a survivor and able to handle difficulties.[9]

Comments made by individuals:

My life is my wife, my children and my grandchildren. Those are my priorities and I’m glad I’ve got what I’ve got now, you know. Like you say, It was worse when I lost the eyes, that was the hardest part for me. The prostate cancer was like a breeze. Oh, yah, I lost them [eyes] about five years ago. That was the hardest thing for me to deal with. I consider myself quite lucky to be around, you know, for where I am now, you know, but I like hitting things straight on and then from there continue on with what I have to do. [8]

Yah, yah, you know really, the ah, I have really a whole lot of faith in the urologist that I and I had, the care in the hospital was super and um, I’ve survived so many experiences in my life that you couldn’t ever convince me that I couldn’t handle any problem that came along. I would deal with it, I’m a survivor, I would do it. [9]
Category: No social comparison made on my part (3/21).

Summary: These men believed that they did not make social comparison for their self-enhancement. Specific comments made by individuals in this category were: I have compassion for those that are doing worst off, and I feel happy for those that are better than me [9]; I only look at my situation that it could have been avoided altogether if I had a good doctor [14]; it may be difficult for someone with a lower socioeconomic status to handle it. [25]

Comments made by individuals:

No nothing. All I have is compassion for anybody that’s worse off than me. I’m not, what do you call it? What’s the term? Jealous. Yah right, I’m not jealous of anybody that’s better off that I know. Um, it makes me happy that they are doing better. [9]

I tried to and I have found that thinking of people who can be worse off does not really happen, whether they are worse off or better off; doesn’t help me so I, yah, I spend a lot of many years? that doesn’t help. [So you only look at your situation?] Yah, I look at my situation and I see that it could have been avoided all together with the proper diet and if the doctor had, at least, sent me to a support group or told me where I could get information but she was ignorant or an incompetent and secondly, once the cancer had started—unclear—so that was, I still have a hard time digesting it because the whole thing was not necessary. The proper diet and the surgery could have been done much earlier with, maybe, less damage and with a sure outcome because if the cancer is very small then the outcome is very straightforward. The whole thing was so dam unnecessary, and at the time, I thought I don’t mind dying as long as people know that it doesn’t have to be that way. [14]

No, no. So far it doesn’t seem like a serious illness to me. Maybe I haven’t had many symptoms yet, but ah, it’s something, you know, I’m in the health field myself so I understood my body, but I can see someone who is of a lower income or educational background it can be pretty devastating, yah. If your understanding is good of how the body works and these things can happen so they’re accepted. [25]
Category: Comparison was made but everyone is unique and has difficulties at certain times (3/21).

Summary: These men believed that we all have our turn at bad times. A summary of the specific comments in this category were: everyone is hurting at one time or another [10]; we share the status of our PSA [15]; we are all part of the same group. [18]

Comments made by individuals:

[In regards to social comparison] In your mind you say, oh that poor guy or that lucky fellow. I guess I have, but everybody is unique, everybody is individual. I have to fight my battles, they have to fight their battles. I know last time there was a guy, there was a new fellow, you try to support him, you tell him, you know, it's going to be alright and the treatments are good and stuff like that, ah, what was the exact question? I have [compared myself with others] but not that I feel sorry for myself or feel happy about myself, no, no I can't say that. There are people that have tough times, there's also people that have struggles with their kids and different things and everybody is hurting one time or another and so I can't say I've every compared myself to others. There's two kinds of people in the world those that are hurting and those that will hurt. Everybody is going to get their turn and I can't say that I have compared myself to others very much, no. [10]

Ah, well I have friends who have been through this process, I've got a number of them so, you know, we trade war stories about how we are doing but ah, in terms of comparison, I don't know, I guess we share what the status of our PSA is primarily. That's about all. Well there are lots of people at this support group who are worse off than I am. Ah, in terms of people being better off, I don't know, I think that, so far, I've had quite good results. I couldn't have much better results than it has, at least, so far.[15]

[For you personally, have you ever compared yourself to people who might be worse off or better off than you in any way?] Oh yah, all the time. We just buried a guy, he looked fine, very nice fellow, he's part of our group here and doing a hell of a nice job, he's a prince of a guy. I don't know the background of any of these people, other than they've got prostate cancer. This fellow owned and operates [name of a business withheld]. He didn't have to come here, why wouldn't he go to his synagogue or his church, but he came here and found it very comforting to be part of our group. Another fellow, his name is [name of a person], a prince of a guy. The only thing I knew about this guy was that he was in the military, but he used to come to our meeting and he was in our steering committee and would always crack a few jokes and that kind of stuff. You had to
be careful about what you said because he would always pull something on you, it would be something that you had to pay attention to. I remember the first thing he did is, oh I'll volunteer for that, on July 3 it would be, except that July 3 was after the day that you wanted him to do something. So you had to listen carefully, he was always pulling some fast ones on us. I only found out at his funeral, he was a very high-ranking officer in the military and he worked in the diplomatic core all over the world. I didn’t know that and we didn’t have to know that and he didn’t share that with any of the guys. He came because he could be with a bunch of guys who weren’t asking him about any of his background, his pretenses, his status in life and all that kind of stuff, he was just one of the guys and that’s what he enjoyed being, just one of the guys, and I hope all the other people here feel the same way, I’m just one of the guys, I have a problem, I’m prepared to share my experience with everybody else. We have a medical doctor who comes here, a research doctor who worked in [name of city withheld], he comes, but he wasn’t here today. Engineers, I don’t know any researchers but I’m sure there were, all kinds of guys. [18]
Appendix G

Question: Please describe for me what your prostate support group has meant for you?

Category: Getting to know people / emotional aspects (7/24).

Summary: Men found it helpful to get to know other individuals at the support group. Specific aspects related to this category are: from an emotional aspect, support group has been good [1, 13, 20, 20wife]; there is always someone there to talk to or phone [4b]; I like the group, they do listen and you can ask them questions [8]; and I made lots of friendships at the support group. [16]

Comments made by individuals:

I think the prostate support has been crucial, you know in both the emotional, but more in really understanding prostate cancer, in what it is, in the whole spectrum of knowing what to expect, what to watch for. [1]

There’s always someone there to talk to, to phone, to talk to you, even though you don’t, you know that they are there. That’s the main thing. Once a month we meet altogether and we can share our experiences, good or bad and so there’s always someone there available, if it’s not [name of an individual] then it’s [name of an individual] or it’s me or it’s somebody else to go have coffee with if you want. [4b]

It’s a good group, I like the group. They do listen and you can always ask questions and they have Dr. [name of doctor left out to protect identity] come there, and he’s always there and when he’s there he’s talking to us at the support group there and we can ask questions and everything. I’ve made a few [friendships] there, I’ve got [name of individual protected] and [name of individual protected] both of them are guys I know and like [name of individual protected] and I go around quite a bit and there’s a few other guys, quite a few other friends I have. They have never changed, other than that. [8]

Well a lot of emotional support from other men that went through different types of treatment, okay. The support group will provide you with a lot of information about diseases about what to do about it, what will help you to cope with the different emotional, or psychological or physical or anything like that. As it was, how are you going to cope on your own and what do you do with it, and so, I
think the support group has a very important function. That’s why the Canadian Cancer Society organized and supports the support group because they feel that they have a role to play. [13]

Oh, lots [made lots of friends at the support group] , yah lots, mind you, my better friends are the best friends up there, or acquaintances, are the committee members, we meet here for our many planning meetings and working with the committee, but members at large too. [16]

The support group is there and they could do a lot more than they do. People come in, and I think the doctor sets them up not to listen to anybody and to make up their own minds. The support group has got a lot of information and books and stuff like that. If you go through it, we can tell people what’s going to happen, like they’re going to take you to the operating room and they’re going to put you under and when you come out they’ll sedate you. I had the operation and I was out in three days then I got an infection. They don’t know that, there was fear in the operation, people did anything to have the operation. I don’t think that’s the right way to go. If you’ve got to, and people do, you see them come in and they’ve read all the books and they know all about it, come on, I’ve been here for three years and heard all these lectures and doctors coming in to talk to us. There’s a pattern, and the pattern, this is what it is, the operation isn’t bad but two guys out of three that were on the CBC film got the operation so somebody was telling them. So the support group, we don’t tell anybody what to do, we’re not doctors. We try and make the stuff available to them, and say look, here’s an article, here’s another one, read that over, here’s another route you can go and here’s another route you can go, but, you know, the people that come in don’t seem to want to hear that. They know better than we do. When you’ve been through the process and everything and you come back in it all funnels back to the norm, it’s like the stock market it wants to come back to where it should be. The stock should be earning, it can be 20 or 30 times earning, but when you have a big drop, cancer treatment and the process of prostate cancer can be likened to that, it wants to come back into the norm but, he talked about it down there, he’s got a magic PSA rating it goes up and it goes down and it goes sideways and it goes, come on. It doesn’t do that. We’ve never seen it do that. We take some pills and we take some medicine and take some vitamin tablets and it temporarily fluctuates but if you take that stuff before you go and have the blood test, the PSA test, it’s going to affect it. It’s got to affect it, so you don’t get a true reading. Leave everything alone but when you go in it’s comparative. It’s not comparative. We get these people in all the time, and yet when they talk to people, there are people in there that have the disease, there are people in there that have radiation and stuff like that and they all come back thinking we should have just had it out, because that takes that lump of cancer out of them, and if some has gotten out, then you have to have radiation for that, but you are not fighting a continuous flow of cancer. I mean it stops, the disease stops, it stops the cancer [20] [Now wife speaks] I haven’t been to the support group for the whole time because I was looking after my mother and I would have like to have gone right at the beginning, I think it would have been helpful. I wanted him to go sooner than he did but he
was still in denial so he didn’t go as soon as he should have been. I think in a way, that this is something because more men are getting it at an early age, it’s almost something that we need to talk about. It’s not a thing that men will talk about, I think there’s more men talking about it, of course. Our group talks about it because there’s so many of them that have had it. Of course, breast cancer was something you didn’t talk about either, but now everybody does. Um, I think the support group is good because it lets you know that you are not the only one, that there’s usually 50 to 60 people there in the winter months, so you know that there are 50 or 60 other people in the same boat as you are [20 wife]

Category: Finding out more information to understand prostate cancer / reflective experiences (11/24).

Summary: These men believed that support group made them more reflective and they gained more wisdom from the guest speakers. Specific aspects from this category are: it has helped me in really understanding my cancer [1]; we have good guest speakers there [4a, 14]; support group provided me with technical support [6]; informational aspects and seeing how others are doing was good [7]; I am appreciative of the support group [9]; we get lots of information from doctor at the support group [11, 21]; they [support group facilitators] keep bringing interesting information [15]; they provided information to confirm what I had already read, and we got to exchange information with others. [26]

Comments made by individuals:

I think the prostate support has been crucial, you know in both the emotional, but more in really understanding prostate cancer, in what it is, in the whole spectrum of knowing what to expect, what to watch for. It can be depressing at times, I mean, you know, you come here and there are no cures, you know, but most of it is, it gives you, when I say depressing, I shouldn’t use that word, it should be, it makes you more reflective, okay are there things you can do, such as, alternate therapies like changes in diet where you start to know about antioxidants, are they the thing. It’s not that you start reaching for straws and taking way-out medical kinds of situations but it does let you know that, hey, your diet, for example, little things that in the past 40 years, the amount of nutrients and vitamins in vegetables
have decreased by about 70 percent and so without taking vitamins or therapies you cannot eat enough to feed the body what it would have got, say, just after World War II. Little things like that [1]

Talking about the columns, we have a lot of good guest speakers like the oncologist and urologist and people that are into alternative medicines and pharmacists that will come into our meetings and encourage us with wise words and support. I think that the support group is an all meaning thing, for the support of prostate cancer. [4a]

I think support groups are there for technical support. If one wants emotional support, they should look to family or friends. Maybe if a different kind of environment was created, like a small group discussion, then it may be possible. I spoke with the group leader [name left out for privacy], and he indicated that most people don’t feel comfortable discussing or talking about their experiences in front of others. But why wouldn’t they talk about it? I think they would that’s what they are there for. However, the opportunity is there during coffee break. I was approached by 2 individuals and I went to their home, and now they are both my good friends. I didn’t attend the support group in my area because it is a rather small group. I mean when you have exhausted talking about your experiences, what is there to talk about? I don’t go to the support group now because you see I wanted to reach a closure. Do I need to be reminded of the suffering? Do I need to be reminded of a low point in my life? No! At the same time, I don’t mind passing along information from my experiences, like I am doing with you. I want to reach closure but I also know that cancer can come back, then it would be nice to talk to others about it. I keep in touch but I don’t attend regularly. [6]

Yah, I’ve basically attended the support group on and off for three years. I also attended the advanced group because I was curious to find out how other people were coping who had intervention but they were not successful so they went to the advanced group, and of course, you’ve got to remember the knowledge especially from the consumer but even from the medical side of prostate cancer, there’s a lot of work done in just people talking about it. You go to the coffee shop and you hear somebody talking about it, where three years ago, nobody knew anything about it. I guess what I was going to say is that the group has been helpful, it’s been sort of a catalyst, it’s been more of a catalyst for me to do a lot of my own investigation into it, but no matter which meeting you come to, like even today, I mean I met you and that’s going to help me maybe focus more on the spirituality side of it, but every time I go to a meeting, I always get one nugget out of it that makes it worthwhile. I guess No.1 is that the meetings have given me more support than ever. People are getting, like, I’ve actually made a presentation, I haven’t presented it to anybody yet, but I made a presentation of what to do before you get a PSA test because when you get a PSA test it’s opening a full Pandora, you are basically giving the medical establishment almost carte blanche, you’re paying the $35 and it’s carte blanche for them to say, well your PSA is high so that means this, this, this and this but it doesn’t necessarily mean those things, you have choices. So what’s happening is people are getting involved in this whole
regime but they haven’t become educated enough in order to make valid choices. It’s sort of like buying a house and saying, oh, you want to buy a house, and you say, yes, and oh by the way you have to get a survey and you have to get insurance and you have to do this and you have to do that, and oh, by the way, that lawyer, if your neighbor’s house is sitting on your property, you may not be able to move it off your property and what are you going to do. You know there’s all these things that people don’t know about when they buy a house. The same way it’s their own body and people are getting involved in this whole prostate cancer thing and they don’t know enough to make a decision and so the people, the real estate agents, in effect, are making all the decisions but it’s my body and I see that’s happened. I see people in pain and agony and their solution is more and more drugs or hormones and then they’re worrying about losing their sexuality from taking female hormones. Female hormones, if you take those hormones and you’re not careful, you can generate in your body the same situation that causes breast cancer. It really doesn’t sound like a good idea for me and my body. So those are all kinds of things that people got to, they don’t know about. Coming to these meetings I realize there’s very little knowledge that the average person going up there has, so why would I want to go and commit myself? [7]

Well, I have to say that um, I have a lengthy background with support groups. For ten years I was involved with Alcoholics Anonymous and I, and that support group was what changed my lifestyle for a long time and where I’ve realized the other values in life and the rest of it and made me appreciate my wife and my family and the rest of it and it was a big thing in my life, and so, support groups, um, I’m very appreciative and very, yah, I have to say appreciative is the best word, of support groups and I belonged to a few associations, I belonged to an association, I was at clock collectors and I belonged to the rock and gem club, who are involved in rock hunting and lapidary and the rest of it and I enjoy, at times I don’t feel that I have enough time for the associations that I belong to but I feel a commitment to them, and ah, so I continue with them because of the appreciation that I have for the groups. I appreciate the library and I appreciate the sharing of the experiences with other people there. That’s what is to be appreciated most. Others that have shared their experiences and the rest of it, so you can all benefit by that. I think that’s great. [9]

Dr. [name withheld] was very good that way [in providing advice and education] and our support group is very good that way. It gives us lots of information, lots of things to choose from. [11]

Well it has meant mostly education. As I suggested I was part of the executive committee of that group that we changed the name on from support group to information group as part of the prostate information. That they should tell men they need support, they’ll say they didn’t need it because I’m a man and I don’t need help and I don’t need any support, and I’ve told people that I have prostate cancer, I’ve tried until I got to talk to these groups and I told them? they don’t support you at all, they give you information and I think there’s a need for the group to stress the fact that it is information. The information has been very
helpful. We’ve heard a lot of guest speakers who spoke about the evolution of the cancer and the amount of research done about so I know so that I’m not going to keep looking after this kind of problem and trying to fix it. It’s very well at the college, the treatment I received from the college, and I said, well nobody knows about this cancer, nobody is going to do anything about it and nobody wants to know, but now, I’ve been reassured that there is a whole research team who are going to work on it. So the support group for me has provided a lot of very good, very direct and clean and healthy information and that’s what I needed most. So I understand, I understand, now I know that I could have gone to the support group before I was even diagnosed with cancer, when I had tumors, I didn’t realize it would turn into cancer and I could have avoided this cancer all together by eating the right food and had my GP told me that you have tumors and they will likely develop into a cancer, but in the meantime, you can reduce the probability of cancer by being very careful, and having a proper diet. The kind of diet that they have in Asia for example, I could have avoided it all together, but she didn’t tell me, she probably doesn’t know, she never heard that nutrition. Nutrition is the B.C. Cancer Agency was of course dedicated for people with prostate cancer. Drinking tomato juice and green tea and all that good stuff and lots of fruits and vegetables. So now I’m on this kind of diet and I’ve said as I did before I haven’t had a cold in four years. So obviously it’s working and doing something for my immune system. So that’s what happened. So to answer your question is that from the information I probably got moral support. [14]

Um, I’ve been reasonably happy with it. It’s hard to run support groups, in fact, you have to keep bringing interesting information to it, so I don’t really have suggestions about improving it. [15]

[What do you think about the support group, the prostate support group, what are your feelings about it?] Oh, I think they’re good, it’s okay. [They’re good in what way, like, how are they helpful to you?] Well they still give out the information to confirm what you read about it. [Are you friends with anybody here too?] No, I know one Chinese guy before, but I don’t see him that often, he’s not here today. That’s about the only friend I have. [19]

I like the information I get here because the urologist also attends. I have only seen one or two other individuals from the Chinese culture here. I have no friendship here. [21]

Yah, I am a member, I joined, and I’ve been attending this group for meetings for the last two, more than three years now, although I don’t attend regularly. I do, but there are times when I’m away or on vacation or for some other reason. Occasionally it happens. Oh it’s great, it is very good to have such a support group where men can get a lot of useful information and exchange information and can even hear talks from a specialist from time to time which is very good and especially if you could attend meetings, I think it’s very good. [When you were diagnosed did you come to the support group right away, or you didn’t?] Um, no I didn’t know there was such a group then, I only learned about it shortly after my
surgery. [So you didn’t know beforehand about it otherwise you would have come to it if you had of known?] Oh yah, certainly I would have come, of course. I would have come even before the surgery, but then, as I said, I didn’t know there was this group, this support group, I only learned about it after my surgery. [26]

Category: Helps us in coping (3/24).

Summary: These individuals believed that learning from each other’s experiences helped them to cope better. Some key aspects that emerged in this category are:

it’s a good time to be able to get together and talk [4a]; it helps me in dealing with my problem [8]; people tell me how they went through it and where to go from here. [11]

Comments made by individuals:

Well, to me, it’s a good time to be able to get together and talk. We, sort of, split up into groups and for those that have to go for radiation, that group will get together, and the one’s that had surgery will get together. We, sort of, share with each other our thoughts and our feelings and how we cope with it and get through with it, and ah, I think that a support group is a very important fact in the overall healing too of getting back on your feet as well.[4a]

Well it meant to me, it meant a better understand of what’s available, what you can do, and ah, you’re not the only one that has the problem, and how to deal with the problem. That’s what I liked the support group for, and you help others who are in my same predicament. [8]

Basically to know there’s other people out there in the same boat as I am. I’m not an individual sitting out there trying to worry about things myself. It’s about having to learn new things and people telling me what they went through and go from there. Just sharing and the friendship of other people that have gone through it. Just the sharing. [11]
Category: Life-style changes (4/24).

Summary: Some individuals had changed their life-styles because of their experience with prostate cancer. Some aspects that emerged from the interviews in this category are: now I eat more vegetables and take supplements [1]; I have changed my diet a bit [3]; I have changed my diet to a certain degree [7]; and I changed it a bit, yes. I eat more tomatoes, more broccoli and beans and you know.

[8]

Comments made by individuals:

So you turn around and now you make sure you eat fresh vegetables and you know to supplement that. So what are the vitamins that really help fight cancer after you’ve got it? Okay, so those kinds of things come out of these meetings as well as getting to know people [1]

Diet-wise, I changed my diet a bit that’s one thing for sure. Ah, well, my priority right now is, have a good time. [3]

Other than changing my lifestyle and my diet to a certain degree [some changes were made in diet and life style] but I still, I mean, I know where I want to go with my diet but I’m not absolute. I know what my phys? is but I don’t worry about not eating. Within the meals that I control, I eat what I choose to. Prostate cancer itself, there’s no one cause. In my own personal, I’d say it’s a lot to do with one’s self-esteem and the environment you are living in and how you cope with the environment you are living in. The environment you are living in, being not just your physical environment or what you eat but your mental and emotional environment that indeed may be the environment you grew up in and that’s why people say it’s hereditary and maybe it is hereditary and maybe they can prove it’s hereditary and sell you on that one, but the fact of the matter is that most people grow up, the way you were brought up was the way your father was brought up and the way your father was brought up was the way his father was brought up and that’s how I honestly believe a lot of this hereditary stuff is, not necessarily a cellular issue, it’s an environmental issue and psychological issue within your family. [7]
I’m just saying that people do not, people are looking for a quick fix. We are brought up that way up in North America for the quick fix. After the war, the Second World War, everything was right, not a problem, drop a bomb. Not a problem the wars over. So it’s the same kind of thing that’s sort of applied to medicine, whereby, we’ve got a problem, cut the finger off right? When I was
six-years-old or seven-years-old my mother remarried, well then I started having
tummy aches and ah, sore throats, so I don’t even know if they did an x-ray, just
probably a physical exam and there goes my tonsils and there goes my appendix
and there goes my tonsils taken out. So probably the reason I had those childhood
diseases which are all very common in the late 40’s, early 50’s is because of what
was going on in my life. It was no different than having hay fever or asthma. I
mean most kids get asthma not because of some physical childhood condition, it’s
because of something that’s happen to them. I mean that’s not even a common
medical thing, but that’s the reality of it. Why did they grow out of it? The air
didn’t change, the air is getting dirtier, people don’t have asthma. Their bodies
have gotten over it, their environment has cleared up and they are able to, now,
not have asthma and the people that continue to have asthma because they are
carrying along with that. I used to get hay fever and I know it’s, somewhat,
physical but I’ve had hay fever worse this year than last year. Some years you
don’t even get hay fever in Vancouver but I’ve been having it this year because I
haven’t been getting enough sleep, I’m drinking more beer than I want to, and ah,
there’s a lot of stress and so I just know, that when I get rid of those things, my
hay fever will go away so that’s sort of where I’m coming from. Did I answer
your question? I went off on a little tyrant. I’m certain, you know, and that’s
right, and unfortunately the majority of the people you see here they were even
parents or even were in the war right? They’re of the mentality where Tommy
Douglas came along out of Saskatchewan and said we are going to have Medicare
and you go to the doctor and you’ll get fixed, but it doesn’t work that way. My
doctor tried not to, he tried not to give me a pill every time I wanted something for
my hay fever, you know, he said get more sleep, whatever, but, you know, I
wanted a quick fix. [7]

Oh, I changed it a bit, yes. I eat more tomatoes, more broccoli and beans and you
know. That I’ve changed too, I never hardly ever ate that stuff now I’m eating it
eh, in fact, every time we go shopping, I insist we buy it and that I have changed,
yes.[8]

Category: Helping others (9/24).

Summary: Some of these men believed that it was rewarding to help others by
taking a leadership role in a group. Specific examples that emerged in this
category are: it has given me a certain sense of satisfaction to help others,
especially those that are newly diagnosed [2, 17]; just helping others is the biggest
reward [3]; I get a deep sense of satisfaction by being able to share my
experiences with others [5, 15]; I have been supportive towards others, and I wish I had that kind of support too [11]; I am in charge of bringing guest speakers; you have to become a whole model [13]; I find it productive and satisfying to take a lead role [16]; and I try to instill a positive attitude. [18]

Comments made by individuals:

Well it’s given me a certain sense of satisfaction to help others, the research material I’ve been able to pull from medical journals and proceedings of certain medical societies, conferences, the papers presented there. I’ve tried to keep track of items that are coming from clinical trials and developments that will help, not only for myself, but for the other members of the support group. So this gives me the feeling of being some help and gives me some satisfaction, and in fact, it’s tomorrow morning that I go and be given the Governor General’s award for a caring Canadian for the type of work that I’ve been doing. [2]

Oh, well I think just the reward of helping people, I think is the biggest reward. To be able to talk to people, and ah, for instance, on their first trip into the support group they are always scared, terrified, and at the conclusion of the very first support, they go out feeling much calmer. So that’s a reward, helping. [3]

Very, very deep sense of satisfaction, being able to share my experiences with others and maybe help them in making the right decision which I always think is getting it out because then you are going to be here longer, but it is the most evasive surgery a man can have and a lot of people don’t want that. What’s good for one person, may not be good for the other, but I always say to myself, you know, getting it out is the best thing because if they can get it soon enough, but if it’s already metastasize then you are going to have a problem. [5]

Oh, of course [I have been supportive of other people]. When [name of a friend with prostate cancer] came in, he told us about that, we spent a lot of time together. He used to come over to our place and I used to go over there. Prior to his operation, we went through a lot of things. I kind of wish I had that support. I had that knowledge before I went through my operation. If there was some individual that came and spent extensive time with me because I was scared stiff. I was so scared. That was a radical operation and when you don’t know things, you are scared. I wasn’t in it at that time [in the prostate support group]. I wasn’t really introduced to it until after the operation because my period of time from when I was diagnosed to the operation was a matter of two or three months and the only reason why it was diagnosed was because I had testicular cancer before. I went through five years of stuff for that and they just thought that they’d do the check and unfortunately it came back positive. So in August, my son’s marriage was in September and I had the operation in October. They wanted it in
September, the operation, but I said I can’t, my son’s marriage. So I had three months there and I had other things I had to deal with. I had to put the prostate out of my mind. I knew there was a group [prostate support group], I just didn’t get involved until after the operation. [11]

Yah, because in my congregation [synagogue], for example, in the last 10 years, I have never hid that I have prostate cancer because I am an advocate of it, and ah, most people know and people have come to me when they did have prostate cancer, and I always was there to see if I could help them or give them some advice or a bit of support, give them a bit of material and so this plays a role always which is not actually involved with the support group but that’s an extension of my life in the community. Yah, I never hide it, in fact, I have tried to tell men when I see men are in a certain age group where they become a risk, to tell them, make sure you have a test for PSA and make sure you see a doctor and I want to make them aware about it, you know. [13]

Well you have to become the whole model. You have to see what you can contribute to the good or the well-being of this group or the welfare of this group, okay. In my group I have always been in charge of bringing a speaker to the group, and ah, I try to bring things that people will be interested in, people will want to know. So I try to bring variety and I’m very open. It may not be, necessarily, traditional medicine but alternative medicine and different things on food, on nutrition on lifestyle and so on and so, this is always a trial because it comes to a point where I cannot find a speaker for my group, okay. So sometimes I have to recycle some of them. So in the past year now, I have become a member of the foundation which is for the organization of all the groups and so your responsibility is more because it’s not just your own group but now you worry about the whole. Well, you think you are appreciated by some people. You feel that you get some satisfaction in doing certain things, you know. People recognize it, you know. For example, I can’t go across town to the shopping center without people recognizing me, who belong to those groups. Well, you are, you get that input from people that know that you do a real contribution to the group because some people come to the group and they sit there and they are ready to absorb things but they don’t do anything on their own. So you have to consider, you have these people that make that group viable.[13]

[What has the support group meant for you?] Um, well it’s provided me with more information, a better understanding, I think, I had basically made my decision so it probably hasn’t helped me, I understand some things about the disease and treatment that I didn’t understand then but I don’t know if any of that made any difference to me. I guess I wanted to participate so I could share with others things that I went through and how it had impacted me, how I came about, how I made my decisions and so on. I think that was the main motivation for me to go. To see if I could help other people to work through their problems. [15]
Yes, I like the people, they’re all really a good bunch and I find it productive and satisfying but then my health didn’t hold, it was too much, so I said I can’t do this it’s too much. [16]

Well it’s given me a lot of knowledge, a lot of insight, makes you feel like you are not alone and it guess it’s a pretty good feeling to help people that are newly diagnosed and are in the same boat that I was five years ago. I didn’t know what way to turn. So, I’ve gone through it, I know what it feels like so now I’m in a position to help other people that are in the same position that I was five years ago. [You say that you are also involved in the committee work and so on too right?] Um hmm. [So what do you find is the most rewarding aspect of doing the committee work?] So I guess what I’ve already said, is to try and help other people, give something back. [17]

[What would you say has helped you in dealing with cancer? Probably the support group. I joined the support group, I think it was about November 1992. The support group was actually started in June of 1992 by a nurse, a social worker actually at the cancer agency, and ah, a lady at the cancer society they joined together and said, you know, we’ve got to do something for these men, and ah, this is what we’d like to do and there was some encouragement that they had from the oncologists to do something to, sort of, give them an opportunity to blow off steam and that kind of stuff, and the social worker at the cancer agency was extremely good, very calming person and was able to, ah, bring people together, and initially, it started off by people just sharing their frustrations and talking about themselves and that kind of stuff and that sort of went on for quite a while, I guess, and I agreed in June of 1994 to facilitate the meetings and they started, or at that time, they were still having this discussion about people, having their frustrations and sharing their experiences and that kind of stuff, and we still do that, but we started moving away from that to getting speakers in to talk about the subjects. What is surgery, what is radiation, what kind of radiation there is so that everybody had an opportunity to look at what the treatment options were and what do pathologists do, what do physiotherapists do and all this kind of stuff. So we started that kind of regime. Prior to that, we didn’t have that opportunity, we just had the opportunity of sharing at our meetings. I have one, I’ll share with you one of the first meetings I was at that perturbed me quite a bit and we were meeting in a small room at the cancer agency, and ah, again, we just sort of went around the room and each person was talking about their particular situation, what treatment they chose and the results of the treatment and that kind of thing to that particular point in time and there were two people in the room that were on hormonal therapy, and ah, had some other treatment, I gather, but, sort of, the message sort of came out that they were at the end of their road and I was just feeling sort of devastated. I though, what the hell are these guys doing here, they shouldn’t be here talking about that kind of stuff, you know, they’re looking towards the end of life, and that kind of stuff, they should be some place else, and ah, I think it was a meeting later that I had the opportunity of riding up in the elevator with one of these guys, and he was a delightful person with a tremendous attitude of vitality and humor, and I said, just a minute now, there’s something wrong with me if I’m
thinking this guy should be someplace else. These guys have a lot to contribute, and that was a turning point for me, to be able to appreciate that no matter where you are in this spectrum of prostate cancer, there’s something you can always contribute, and I, sort of, agreed to share that kind of experience with other people. I try to instill, as much as I can, positive attitudes, realistically, like I did today, you know, I feel terribly unhappy when people say I’m cured, I feel uncomfortable about people who say that, I’d rather hear them say, that I’ve got things under control and I expect to have them under control for some time in the future, at least that’s my plan, but I know what to expect should things not go the way that I hoped they would. I prefer to hear that kind of thing from someone, than the person who says, I’m cured and I don’t have to worry about this anymore. To me, they have the wrong attitude and they are not facing reality because they have a huge problem if it doesn’t turn out the way that they anticipated. [So basically you took the leadership role of the group because you wanted to help others with some of these things, like looking at it positively and that sort of thing?] Yes, well the work I had been doing was coordination work anyway for the corporation I was working with, so this has allowed me to take the work that I had been doing and translate it into another field and make a useful contribution to those people who were having a very difficult time. [18]

**Item: I have not attended support groups (1/24).**

**Summary:** Prior to his treatment, this individual did not know that a support group existed. He was also not sure if he would have benefited by attending it; but, he is helping other individuals with prostate cancer now. [12]

**Comment made by the individual:**

I didn’t know about [prostate support group], and ah, probably, I suppose, I maybe could have helped others, in fact, right now, the person next to us, his brother is in [name of city withheld] and is going through this and there’s a bit of anguish over this so he talked to me about it and I phoned down to [name of city] and talked to this person and I found out from my neighbor that his brother is going to go through the operation, the surgery that I did. Now he had some concerns, both, sort of, sometimes you perceive something that is going to happen and it really
doesn’t and so just talking it out is ah, has a therapeutic affect. So, yah, I don’t mind doing that. As far as going to a group session, I didn’t do it, didn’t know that there was anything such as that that existed, and ah, I’m not sure whether I would have gone. I really didn’t feel I needed that, but the thing is, maybe I could help someone else like I did here, then that’s a different matter too and certainly I’m willing to do that. [12]

Item: Find it depressing to attend the support group (1/24).

Summary: For this individual, surgery has not worked, so he finds it depressing to get pessimistic information at the support group. [10]

Comment made by individual:

I started attending probably September, October of last year. So, I’ve attended, I’ve missed one or two here and there so I’ve probably gone five times and the information there is always very good. It doesn’t always apply to myself and I always leave very depressed because there’s always somebody, one of the medical people or so that says, you know, 30 percent of the guys they live six years. This treatment works for most people but not everybody, and I find myself, a lot of times, the except group that they say, you know except this group or except that group, you know I’m in that group, you know, I was younger so that makes it worse. It got away outside the prostate, that makes it worse. Then they have this scale, you know, 2.6, 7, 8; I was 2.7. I was a high-risk group. I did not react to radiation and they say, once you’re through that, they can’t radiate again so then it comes back, there’s really no cure. I walk out of there every time with some of that kind of input and that, I find that very depressing. So I don’t want to go because I know I’m going to come out of there depressed, but I go because you can put your head in the sand and say, you know, it will be fine, but that’s not right either. I should be educated about it, I should find out more about it and I want to support the group as well, but there’s good information, but I always find it very depressing. [10]
Appendix H

**Question:** What improvements, if any, do you think need to be made to the medical services and/or other support services that are provided for individuals with prostate cancer in your community?

**Category:** Provide free PSA testing and encourage PSA testing (8/23).

**Summary:** It was these men's opinion that PSA tests should be provided free of any charge at all since in the long run it saves government money. Specific aspects mentioned under this category are: PSA tests should be provided free for men just like mammograms are provided free for women with breast cancer [1, 5, 11]; all men should be given free PSA from age 50 [2]; they [the government] should pay for PSA tests [3, 13]; they should encourage men to take the PSA tests [4a]; they would save lots of money in the long run by encouraging PSA tests [4b].

**Comments made by individuals:**

PSA tests should be provided free for men just like mammograms are provided free for women with breast cancer. [1]

I think one, that all men should be given PSA tests free of charge from age 50 on. [2]

Yah, one way, they could start paying for the PSA test, that's for sure. [3]

Well I was diagnosed the same time [name of person] was in 95, and at that time, I think the stats were that one in eight men would be diagnosed with cancer in 95, but now almost 10 years later, the diagnosis is down to one in seven now. So it means that we're crawling up there like the ladies with breast cancer, and ah, I think more should be done on pushing men to have a PSA test done, for the simple reason that if they get it at these early stages, it's not going to cost the medical so much money. It's more of a preventative maintenance program and I think that men need to start to learn to listen to their body and when they feel that...
there is something not just right then they should get in there and get it checked out. [4a]

I’m not ready to say that it should be mandatory but very close to it that after a certain age, once a year, there’s going to be a test and it will save, millions of dollars in costs. [4b]

Well for one, start making PSA tests, giving them free to men because women’s mammograms are free, and ah, our same type thing, that should have been given to everybody. I know like the police, fire department, their companies all pay for each man when they come and once a year they send them all in and so I think it should be Province-wide, worldwide, whatever, you know, but ah, I think in the end it would save the government a lot of money by catching it early, you know, so. [5]

Medical services need to get their act together and make the PSA test part of the medical system. They have to. Men, and it’s common knowledge, every man if they live long enough get prostate cancer. Every woman will not get breast cancer and yet more emphasis is put on breast cancer for woman than there are on men with prostate cancer and we need to change that thinking, we need to do more for knowledge for men and their prostate. [11]

Well the only thing we want the Ministry of Health to do is to allow men to have a free PSA test, and so far, maybe because of the trend, it’s not accepted, okay. We see that every woman can go and have a mammogram free after a certain age and we want men to have the same access. [13]

Item: Educate doctors about the importance of PSA testing (1/23).

Summary: Doctors need to be better advocates for prostate cancer. Too many physicians are poorly informed about PSA and some don’t believe in it. [6]

Comment made by individual:

Too many physicians are poorly informed. Get the message out there that PSA is strong indicator of potential cancer. I was turned down twice from testing. I would have happily paid $35 dollars if that’s what the issue was. Some other physicians don’t believe in the PSA. When you are going to do the blood test, why not throw in the PSA anyway? Again, some doctors don’t believe in it. [6]
Category: We need to bring a change in men’s attitude (4/23).

Summary: Men need to go to their doctors on a regular basis from their 40’s onwards. Individuals from early on in their lives also need to change their diet and eat less of fast food. Men also need to learn about their prostate gland. Emphasis should be on the preventive efforts. Specific comments from this category are: we should start looking at preventive efforts and men should start seeing their doctors from their 30’s [1]; men figure the digital rectal exam to be degrading and that’s why they don’t go for a check up [5]; men are either not aware of prostate cancer or they don’t want to face it [8]; I didn’t know that there was a prostate gland and I didn’t know there was a support group for it. [17]

Comments made by individuals:

Oh, I think, exchanging the male attitude of getting to a doctor, particularly from their 30’s on. For me I think it’s the genetic thing, I don’t think it’s related to my diet, although more North American men get prostate cancer than Asian men but when Asian men move to North America and get involved with our fast-food industry, they have the same incidents of prostate cancer as the white guys. So, I mean, it’s hard to really pin that down but the biggest problem is the attitude of men that they, first of all, don’t know about their own sex organs basically, um, they don’t know about the prostate and proper prostate health and I think I’d sort of spend more time looking more into men’s health than they do into prostate cancer. I think that’s more crucial. I think in terms of where we should go as a society is, ah, start looking at preventative measures and I think that there is a lot in my own background that, yes, I am predisposed from my family history to prostate cancer but being from a typical Anglo-Saxon background where, when I was a boy eating a mashed potato-gravy sandwiches was a real treat or fried bread and those kinds of things and I think that we should start looking at our diet and looking at men’s health from the time they are boys onward. Because once you got it, just pray! [1]

There’s the thing with the men being too macho to even worry about things like that, you know, it’s funny how men look at it, you know, they ah, especially that DRI exam, or DRE they don’t want to get that done. It’s degrading, they figure, and ah, but ah, that’s about all I can think of. I enjoy helping other people. That’s
what the big guy put me here for, I guess. It wasn’t my time to go. So that’s all I can think of. [5]

That’s okay, but um, my thing is the more people that are aware of it, the better off we are and that’s the trouble, men don’t want to recognize it. To my view, if I knew what prostate cancer was about, I would have been tested a long time ago. I didn’t know. The trouble is people are not aware, men are not aware of it or they don’t want to face it, either one, and I think if you can get them in there early, you would see prostate a thing of the past probably, you know. Get it at the early stage and scientists and everything are improving all the time, because the old days, you used to die from it, now we are not. I think if we get the people early at it, get checked out early, there’s less chance. Right now it’s just sort of a hush, hush thing, open up, and that’s why I even say to, my son and my friends, when’s the last time you’ve had a prostate test, have you ever been tested for prostate? They don’t even know what I’m talking about, a lot of men don’t. This is our biggest problem. But that’s true though, men we’ve got to open up more not sort of hide in the back closet or anything. That’s my point of view anyhow, because I was sure ignorant, I didn’t know what was prostate cancer. My doctor never mentioned nothing to me. [8]

It was after my diagnoses. I didn’t even know what a prostate was until after I was diagnosed. I didn’t know what it was, never had heard the word. [And you didn’t know there was a support group beforehand either?] No, no. [And how did you find out about it then?] I don’t know, I don’t remember. [17]

**Items:** Cancer researchers should work collaboratively with each other and there should be more funds available for prostate cancer research and there should be more input from the survivors (2/23).

**Summary:** These men stated that cancer researchers should work together rather than to compete with each other. Specific comments from this category are: there needs to be more communication between the Cancer Agency and the research departments at the hospitals [3]; there is a big discrepancy between the amount of funding that is available for breast cancer versus the amount of funding available for prostate cancer. [13]
Comments made by individuals:

I would say one, of course, always, is more funding and the second would be more communication between the cancer agency and the research department at the Vancouver Hospital. A little more working together rather than butting heads which they are doing right now and ah, yah, that’s one of the things that would help. Sharing their knowledge a little more rather than competing with each other. [3]

Well, in a scientific point of view there is a lot of research being doing, a lot of studies being done and we don’t really have an input in that. We are, through the foundation not through the support group but through the foundation which is also a fundraising organization, we do support certain projects. We provide some money to some study, money to research, otherwise it would not be even starting. So that’s what we can do to improve, okay, but our main function is to help people, the men that are out there, they and their families find the support, find a place. Also, there is millions of dollars spent on breast cancer research and only $300,000 spent on prostate cancer. There’s a very big discrepancy between the two groups. [13]

Item: Be open to doing research about alternative therapies where drug companies do not have a conflict of interest (1/21).

Summary: Physicians need to have an open mind towards clinical trials that are going on throughout the world. Cancer researchers should also do more research on the alternative therapies. [2]

Comment made by individual:

I think that our system is a very slow cumbersome, heavy system that doesn’t take advantage properly of some of the developments around the world. People here are apparently being greatly restricted by what they think would be funded by the healthcare system. That’s one thing, and therefore, to try and bring something innovative or new that seems to have promise, it isn’t accepted and it won’t be used because it isn’t covered by the healthcare, and by the same token, these people that are experts and are specialists in this field are very much funded by the drug companies, so therefore, to try and bring something that’s potentially, well something which is coming from tests and trials being done elsewhere but is not in the area of drug products, I’m speaking now of complimentary things such as [Likopeon? --tomato paste product] and others, but to try and get it accepted here,
at least on a trial basis, is extremely difficult because the doctors here are doing research on those things and really only those things that are funded and in the interests of the drug companies and that's a shame. [2]

Item: Speed-up the process for clinical trials (1/23).

Summary: This person believed that treatments that have shown some promise in other places of the world, should be approved here without cumbersome procedures that take a long time. [2]

Comment made by individual:

I think they should be willing to investigate, as I said earlier, certain things that appear to be rather innovative and have good potential even if they aren’t all, shall we say, proven beyond doubt here locally. If it happens to be something which has been proven in France or Italy or Switzerland or the United States, I think they should be willing to take some of those results and move forward, if necessary, on their own investigations here and in that respect, also, I think that the procedures or the protocols are quite unnecessarily cumbersome. We’re speaking now, I can give you first hand experience of things that even to get a fairly simple clinical trial through the ethics board can take months and months and months just to have a person review a piece of paper and what they require for the clinical trial to be, ah, perceived as being satisfactory and suitable for publication and so on is a clinical trial is very expensive and very cumbersome and very time consuming and it’s my thought that there are men there that are dying who would be quite happy to have some shortened path or even they would be willing to take certain products that had potential proven elsewhere. They would be willing to take those products without a lot of clinical trials being done right here because my men, many of them, don’t have other options. When they get to the point where it metastasizes they don’t have anything left accept chemotherapy and that’s not been proven very successful for prostate cancer patients. [2]
Category: Focus on treatments that stop metastasis. Meet the needs of advanced patients and find new kinds of treatments that don’t have a negative effect on sexuality (3/23).

Summary: There needs to be an urgency to stop the metastasis, and this urgency should be present in the research that the cancer researchers carry out. Specific aspects presented in this category are: it is very urgent to reduce the spread of cancer through body but yet cancer laboratories hire Ph.D.’s with a long-term approach; in fact, there should be a better process in place for patients with an advanced disease [2]; they should improve on the techniques of operation for prostate cancer so that sex related nerves can be spared during surgery. [11, 12]

Comments made by individuals:

I think that, ah, the urgency of coming up with some means of reducing the tendency of the prostate cancer to spread through the body or metastasize that it’s a very urgent and important matter, and yet, I can’t instill into the people in the system here that same sense of urgency. They are quite prepared to hire PhD’s that have a long-term approach and they hope that their research in five years or ten years might have some beneficial effects, but they really don’t have the same sense of urgency that I think there should be. [2]

I think that there could be a little better process than what presently exists for information for people at a more advanced stage because I’m doing a lot of this work, but quite frankly, the number of days I have left will be limited, and ah, there isn’t any real source for these men at advanced stages to get information. They go into their specialist, yes, but quite often that specialist is a very overworked person who hasn’t actually had a chance to review the literature from foreign medical publications and so on. [2]

Before [one has been diagnosed with cancer] they need to get out into the malls, whatever, and inform the male public, 40 and over, I would say. People say 50, but I say 40 years and on. Inform them that this is a very important thing in a man’s life and to deal with it. You don’t put medical problems away and say it will go away. They don’t go away. After the fact, keep those that have the prostate problems, keep them informed of new techniques and new information that’s out there so that they are not scrambling around in the dark looking for things that may help them and if there’s anything that’s out there, other than this
Viagra which I get a terrible headache, I think there needs to be new emphasis put on the sexual problem. That is a big problem in the 60’s, maybe not so much when they are, 80 but I would say 60’s. They need some more work in that area to overcome things. Maybe the techniques of the operation. I’m not a medical person but you go in there, and I know there’s some areas that are cut to get the prostate out so that they have to join it together and as embarrassing as it is, you end up with a shorter penis. It just kind of pulls it in. Somehow to overcome those difficulties in those areas. [11]

Well I think in the present day, it’s fine, but you know, we are making such advances all the time in our technology and I think that at some time, ah, they’ll probably be able to do the operation without destroying as many of the nerves as you have there so that you can maintain your sexual function in the post-operative time. You know, we’ve made such tremendous strives in our medical procedures and just our basic knowledge, and so, I’m sure that this will happen that you will see some advances and maybe that’s what I would wish for or hope for. Outside of that, um, I can’t think of anything. [12]

Items: Provide accurate information about treatment side-effects (2/23).

Summary: These individuals claimed that men are not provided with accurate information to the degree of side-effects they will have in regards to their prostate cancer treatments. Key aspects presented in this category are: medical statistics about treatment side-effects are not accurate and they are misleading [2]; I was not given enough information about treatment related side-effects prior to my operation. [10]

Comments made by individuals:

I’m sure and don’t be fooled by some of the statistics you see that our medical system give as to the percentage of people that are going to be sexually active afterwards or the number of people that are going to be incontinent afterwards, they have their statistics and they call it a successful prostatectomy, for example, even though a person like myself has had to wear pads for incontinence now for seven years and yet I was considered to be quite successful in that respect. So that what, for me, is a real inconvenience, it isn’t even recognized as being serious at all, they considered it quite successful. In the same way the percentage of men that are able to function adequately sexually, their approach is, oh well, a lot of these men are older and wouldn’t be able to function anyway. So the percentages that you get if you take a survey, like you are doing of the patients, you are going
to get a different percentage than is given by those people who are advising men what therapies they should use. [2]

No that’s one thing I really feel bad about. I really feel I was not given enough information before the operation, because I did not realize that after this operation my sexual life was totally gone. I wasn’t prepared for that and there’s no way to get it back so it’s finished and that was kind of tough to come to terms with that. Did they prepare me, no, I don’t think they did. Before the operation they prepared me very well. In the hospital they told me exactly how many tubes I would have and what bags I would have and that preparation was really good, but as far as the preparation for incontinence, no. The preparation for sexual activity, no. The preparation for lack of energy and everything, no I don’t think I was totally prepared and I think they did not tell me because then maybe I’d change my mind or maybe I’d get depressed ahead of time or I don’t know what, but no I was not fully informed about any of that kind of stuff. They always kept painting a very nice picture, oh, you’ll be just fine, you know, just a little operation and you’ll be just fine, but they never told me about all the side-effects I could have. I went through the internet a lot but there is so much information out there and so much of it depended on age and how far it spread and it’s so hard to pinpoint what you are going to experience and how far, I did read up on it a bit, but I found it quite depressing too. Sometimes you just hope for the best, because no matter how much you read, it’s not going to change anything, you still have cancer and it still has to be treated, and sure, you can go and try drink a lot of carrots or drink a lot of tomato juice or something like that but you still have cancer, and I just chose to listen to the people that had the most experience and the most knowledge which were the doctors and the surgeons and I went with their advice. You know, people suggest that I go to Mexico and get different medications in Mexico and different things like that. I think that’s kind of silly because these people here, they do most of the research, they have all the experience and that’s why I went with their recommendations. [10]

Items: Provide more support and funds for support groups (2/23).

Summary: Support group facilitators would like to do a lot but they are limited by the amount of time it takes, and sometimes they lack appropriate funds to do all the things they wish to accomplish. Specific comments made in this category are: there should be funds for support groups and for advanced support group so that these groups can write information to disseminate to their group members [2];
would be helpful if support groups were supplied with current reference materials, books, tapes etc. [16]

Comments made by individuals:

Well in the sense of information I think there could be funds given for some group whether it be the advanced prostate cancer group to have, for instance, regular newsletters to disseminate this information. I don’t do it because it would take quite a bit, as you know, to prepare the newsletter to make copies, to mail it out to people, but if there were funds to do that, that would be one thing. [2]

Help with funding and also assist in supplying us with very current reference materials, books, tapes and potentially productive speeches. I mean they are scrambling for funds themselves but if you take money out of the equation, like we have, the board gave us $1000 to operate our library so we can’t just go to Chapters and buy the books. What we want is to go for some research at the Center of Excellence, the Cancer Clinic, or whatever, and see if we can’t get an intelligent assessment of what we should purchase to operate our library. We won’t burn the library books we’ve got right now, we’ll send them back to the board, and ah, as the groups across the Province, if they come into being or are relatively new, they will supply some of this reference material to them. So it stays in the cycle. [16]

Items: Give more recognition to the support groups (2/23).

Summary: These people stated that the support groups should be recognized by the urologists and other medical professionals. Also the support groups wanted to receive backup support such as to having a place to meet. Specific comments from this category are: some of the urologists seem to think that the support groups are not important [4a]; the support groups would like the medical community to make sure the patient has the information in his hands before he walks out the door. [18]

Comments made by individuals:

It would be nice if we got some recognition. I know that the, some of the urologists here don’t seem to think that we’re that important, yet other urologists do, they support us highly, but, you know, I would like to see everybody get on the bandwagon and become a unified group where we could have real caring and sharing and ah, you know, there’s always support that we need for back up for a
meeting to be able to have a meeting place and to hold our meetings at and if they would come along side in some supportive way financially as well. We’re not asking for a great big pile of money, but I think, really, what I’m trying to say is that what we’re looking for really is recognition. [4a]

Yes, a lot. We would like the medical community to see the value of support groups and make sure the information is in the hands of the patient when he walks out the door. Getting that to happen is very difficult. Giving the patient a list of materials that he can read, that give him the opportunity to see what other medical people are saying about his particular conditions. I say this for two reasons, at one point in time the doctors were the total source and only source of medical diagnoses and recommended treatment. Any soul today can go to a computer and get any information they want from any place in the world. Any doctor that thinks that he can provide the sole solution to that patient’s problem is not in the twenty-first century. So he can provide himself and his patient with a lot of value by giving that patient the information that the patient can choose to do something with or not. If the patient feels comfortable with this doctor, then fine, they’ll get along well and the patient will accept the recommendations of that particular doctor and proceed. I think we just heard here today, it’s not what treatment you do that is the best treatment, it’s whatever best treatment will work for you, that you can live with. That’s the best treatment. The other ones don’t matter, they are good treatments too, but it’s the treatment that works for you or that you can live with is the right treatment for you. So getting that information in the hands of the patient is, from my point of view, from a medical perspective, really important to let them know that there’s more than one way to skin a cat and you need to examine those before you make your final decision. I’m quite prepared to help you out and I’ll give you some information as to how you can do that and all that kind of stuff but to walk out of the door with nothing in his hand, I think is a mistake by the medical community. [But what would you say to those—that there might be other magazines sitting around there in the doctor’s offices] Well, let me recite to you a little scene that’s in a video by Mr. Cousins, Norman is his first name. That’s in a video that’s called Belief Becomes Biology, Norman Cousins, is the guy’s name and he describes a scene in a hospital. The scene in the hospital is the patient is lying in bed and has just gone through a number of tests, and the first scene is the doctor standing at the open door where the patient is and says to the patient, hi, I’m doctor so and so and I’ve just looked at your particular reports and I’m sorry to tell you that you have cancer. Then he says, well, I’d like you to think about this other scene. The same office, or same bed, same patient, same doctor, but this doctor does it a little different. He comes in closes the door and brings the chair up beside your bed, takes your hand and says I’ve got some bad news for you. I want you to know that we are going to do everything possible to help you out. Those medical tests that we had indicate that you have cancer. Which situation is going to make you, as a patient, feel better, and b) how much time difference there is between the two scenes. Zero time difference but the impact on the patient is enormous. That’s what the medical community has to learn is that they can impact a disease tremendously by the way they act. So that’s what the medical community has got to learn. Some of the doctors are pretty good
at it and some of the doctors are terrible. We hear all kinds of stories. Imagine getting you diagnosis on your answering service at your home. I had one patient arrive at the Vancouver agency, sent over from Victoria to ride there and back, and I said, what are you here for, and she said, I don’t know, my doctor just sent me over here. She had to make arrangements to look after her children while she came over here, and she had advanced case cancer. The doctor didn’t tell her. Just sent here for somebody else to tell her. That is just terrible. You see, if you think about it another way, hey the doctors are all human beings the same as everybody else, they have a time constraint. Coping with this whole issue is not easy, it’s extremely difficult, and ah, they are afraid to have somebody come and tell them, you know, we can help you out, we’d like to help you out, here’s what we can do for you. You know, I’ve made that offer available to you, all the associations say, can we have a liaison person talk to, we never got a reply. All we wanted to do, as I see, is a role, is to say, look, I’m not talking to you as a patient, I’m talking to you as a representative of the patient and here’s what the patients are telling me about you, not you personally, but, you people as a group, you have one impression of what they are saying about you, I can tell you there’s a very different one. They don’t want to hear that and I’ve heard some of the stories coming back, oh, yah, his incontinence level is this kind of things, so a lot of the guys I’m talking to are having a hell of a time with that. Erectile dysfunction, I haven’t got one person in the group that I’m talking to that has regained any erections. Who are you talking about that says it’s 50 percent, well who are you talking to? Yah, they don’t have all the answers in the world, nobody has. Recognize that that’s the possibility or at least that that’s reality and accept assistance wherever you can get it. If someone can provide something that will help other people, take advantage of it. Don’t say that you are God, because you are not, no one is. We are making small imroads that way and we get, more brochures are available, some doctors are more receptive. There’s an urologist in [name of municipality], Dr.[name of urologist withheld], you know him, and he’s very good. There are some of the doctors here that are very good, getting information out, the prostate clinic is very good, they refer people, Dr. [name of doctor withheld] helps out providing information and that’s really, really, really good. It’s helped out a lot of people, and there’s more work being done in that area that’s helping. [18]
Item: Need transportation to access clinics (1/23).

Summary: It was difficult for this man to go to clinics without transportation. [4b]

Comments made by individuals:

One of the things that people find problems with, older people, it’s an old man disease, of course, is to find transportation to go to the hospital and it’s very, very difficult right now for older people to find transportation to go to the clinics. Chilliwack is well-organized, Abbotsford is not organized at all in this sense. My wife and I are doing that kind of work now but as far as I know there’s nothing in Abbotsford. [4b]

Category: A few Suggestions for improving the support groups (3/23).

Summary: Individuals should be encouraged to share their personal experiences related to prostate cancer in the support groups. There should be some one-on-one discussions as well. A summary of the specific comments is as follows: inviting everyone to share their experiences would make these meetings more beneficial [9]; our group should open-up more to the members [10]; one-to-one situations where men could discuss how they dealt with their prostate cancer would be nice. [11]

Comments made by individuals:

I thought the other day on that same line, you know, in AA what we did was we bared our souls. Everybody got a chance to get up and speak, really ah, I don’t know if that wouldn’t be a better contribution to the whole membership, to those attending and the rest of it, but you know, like I said, I, the comradery and sharing our experiences and the rest of it was the most appreciated thing. I think perhaps inviting people to share their experience and the rest of it, might be a way to make these meetings and the rest of it more beneficial to everybody. Yes invite anybody that wanted to get up and share their experience and whatever helped them to handle the experience in their own way would be beneficial to everybody. I believe that. Yes, for a person to be, for anybody in the audience, whether it’s the spouse or the friend that was supporting the male through this, or, I mean, I’m
sure that there are people there with sisters that have had breast cancer and have had mastectomies and the rest of it that are there and sharing the whole experience of what got them through coping with the cancer and the rest of it. It's going to obviously be beneficial to everybody. So I would say that asking anybody in attendance to share their experience and their, whatever got them through, however they managed to handle the whole experience. Some of these people have young families, you know, they're in their forties or fifties and have young families. That's got to be really traumatic. With me, my family, I'm a grandparent and it's all beyond me. It's beyond them, kind of thing. I really feel that sharing, getting up, it's a hard thing getting up and baring your soul in front of a lot of people, but once you break that bond, or break the bonds that keep you from this, it's not that difficult to do. You can do it and sharing their experiences, and the rest of it, is the most, the best way to support everybody else and there isn't anything about our life and our experiences, and the rest of it, that we should feel in any way inhibited about sharing with anybody else because, I mean, we're all made of the same thing. We all have the same inhibitions and we all have the same natures and everything else, you know. [9]

I haven't become involved. I find the group in [name of municipality withheld], and this is strictly my own personal feelings, I find the group in [name of municipality withheld] is run by a bunch of guys that have cancer and basically that's all they do is run this group. It's a little bit political in there. The guys that are in control, want to keep control. One of the guys I said I'd like to help out in Malls and information meetings and the other guy says, no we've got it under control, you know, like he didn't want any other people involved. So, I think it's a little too much the baby of a few individuals. I'd like to see that change a little bit. For it to be a little more open minded, but other than that. [10]

I have one suggestion, I would like to see more time spent individually discussing alternatives how each member dealt with their individual situations. We don't do enough of that in our group. We bring in specialists, we bring in the doctor, but there's very little one-on-one. I'd like to see that. I'm dealing with my particular type of, my operation. I don't know if my situation would relate the same to ?, because he did the penal radiation and he's on the medication stuff, hormone medication. I can't relate to that because it's not something I'm doing so I would like to see how its working. [11]

Items: Provide more medical and educational “tips” to help individuals going through with treatments for prostate cancer (2/23).

Summary: These people ask for more “tips” as to what the medical treatment procedures for prostate cancer will be. They would like specific suggestions for taking care of incontinence, impotence and pain [6]. Support group members
believe that a lot of the information about prostate cancer and about support
groups is not being given out by the doctors. [17]

Comments made by individuals:

Well, I touched a little bit on my kind of recommendations or observations in my little summary report. There are a few things that aren’t so much the medical system but rather the information that is available. I thought I really read extensively and um, there were still things that I only picked up through friends, like the tip with the stool softener because it’s initially very painful. I mean just on the other side of the bowel is the operating side so obviously things happened there and initially it’s very painful to go and have a bowel movement and it was a tip from my buddy and then I confirmed it with the physician and the nurses and they said, oh, by all means, yah do that, it will make life easier, but I hadn’t read it anywhere. No to me that’s a tip that should be given ahead of time. It should be one of the things, you know, I know our support group, [name of group leader not provided because of privacy] he is kind of the leader for B.C. or one of the leaders and they are working on a brochure. I’ve no idea what that brochure will look like at the end, but to me, it would be nice to have a handout like, “Our Voice” the special issue, to me, is a wonderful publication because it gives you the types of cancers, the treatment options, the likely treatment options to choose from and all that. The next step would be, well if you’re going for surgery, you will go through such and such, and um, one of the items, somewhere it should say, make sure you take when you start eating again, which is only about a week after the operation, take stool softeners because it will make life so much more painless and bearable, that’s one. The other one that impressed me so much, my, and I always had trouble with this word, anesthetist I have really trouble with that word, he was a wonderful person and I told him, I’m a chicken when it comes to pain because I have not really had to experience pain in my life. So I’m really afraid of suffering that pain and he said, look don’t worry about a thing. Well, that’s easily said, I do worry about it but at the end, I had a wonderful experience, and again, I compare myself to me friend who did not have this treatment, I had the epidermal inserted in the back and he explained to me that that was um, not an alternative to being put under but it was pain control and he would do both. I wanted to be under, I don’t want to be aware of the doctors talking and hearing scissors and tools or God knows what, you know, just put me out and I don’t know what’s going on, but in the literature that I read, it talked about the epidermal as one of the options and the way I read it, it was more an option instead of being put under and not as the pain control option, and my experience was so positive, it stayed in for four days and after four days, he said, look, you can now ask the nurses to put something into your IV drip if you have pain, pain control on demand and when you go home you get Tylenol. Well I never experienced pain. I didn’t have to ask for anything and I got my Tylenol and never took a single one. Now, if that message can be louder up front, I think it will take a lot of anxiety away from a patient and then I compared notes with my friend and what he went through and
especially with Tylenol you get really plugged up, well he didn’t have the epidermal and I don’t know exactly how the discussion went but I know his anesthetist touched on it, he had heard about it, but he didn’t push it, whereabouts, my doctor really pushed, it. He said, don’t you worry about it, that’s what I’m going to do, not, kind of, this is one of the options, that’s what I’m going to do for you and you will like it and you will not suffer and that’s exactly how it happened. Why doesn’t every one of them, kind of, push it when it is proven to be so successful and the literature dealing with the prostate cancer surgery, the ?, there was very little along those lines. It was just mentioned that sometimes an epidermal is administered without a lot of details, not making the point that I think is very important. I mean I would push it to anybody and say that’s the only way to go. That was one factor, um, the whole bag affair is something that, well the nurses talked to me about it and they explained it in the hospital, they did a good job but there was relatively little, it has been mentioned in the books a, kind of, that you get your day bag and your night bag and all that, but there is very little description in those books as to, yah, and what it means is the side where it comes out, you have to have that hose go down to the side of the bed and you can’t turn around. See, this is the kind of details that again, maybe, it is designed that you talk with others. I picked it up from the chap at the support group who told me that, yah your sleep is not going to be very good because you are connected to this hose and you still have the drains and you can’t turn around and you can’t do this and you have to make sure the bag is always lower and otherwise there is a bit of a vacuum affect and it causes pain inside the bladder and spasms and all that. Well, it shouldn’t be a horror story but I found, despite all my effort to read, there was too little along those, what I call the practical side. There was too little in the literature, it was as if, oh well, to me it was a pretty nasty thought of having a catheter installed and then actually the one in the penis was blocked off because I was draining through another catheter and that’s the one that, you know, I had to watch so I wouldn’t kink the hose or lie on it or pull it or, you know, put stress between the bag and my body and those kinds of things, again, what probably comes through in my comments is, I’m an engineer. I like to know every little step and every little detail and to me that was something that, well, I struggled with for, it came out after two weeks already. Some people only, my buddy only had it finally out after five weeks because he had complications, it had to stay in. So I was fortunate, I only had to struggle with it for two weeks, but your sleep during those two weeks is of low quality because you tell your body, don’t turn, don’t turn, you know, don’t do anything, so um, you know, you are up and um, the other thing I found is I didn’t bother with a day bag, um, it’s supposed to allow you to walk around and hide it under the long pants. If somebody has it for many weeks, he will have to eventually get out and deal with it, but for me it was just the two weeks so I just stayed at home and didn’t go anywhere and I didn’t switch back and forth because it was easier to cope with, with a night bag, emptying and handling it, you know. I clipped it to my housecoat and put it on the inside of the housecoat with the safety pins and all that. So there are different approaches and maybe everybody has to eventually, kind of, make their own decisions, but for people like me who like to know, I found that was another fact of where there was relatively little in the literature to describe, you know, what’s coming up. Beyond
that, well, I found the nurses very informative and competent, my urologist, was excellent, and it’s important, you know, that you trust him. Some people go for a second opinion, basically, because they either don’t have a rapport or they don’t trust them. I haven’t faced a situation like that so, you know, you end up with your urologist just because your GP is recommending somebody, you know, he says, you go there and get some tests done, and eventually the tests confirm it and that’s your surgeon, right, um, that’s how it happens. I haven’t had any problem with it, not actually, I cannot think of any major issues that needs changed. There is a major awareness campaign on the go, and I mean you can only, they say, you can only lead the horse to the trough, but you can’t make it drink. There is a lot of information for people who want to familiarize themselves, it’s not a one-stop, you know, it’s a combination of magazines and associations and books and internet and person contact, you know, its, I had a six-month warning of what’s coming because I had to go onto hormone treatment. So the six months while I went through my hormone treatment getting ready for the eventual surgery, there was a lot of time to do a lot of research and ask a lot of questions. Now some people get diagnosed and they have to be operated on, kind of, within three weeks, four weeks, because of the urgency of their case, they may not quite have that time, and ah, I could see that they don’t quite have either the mental or physical time to do all the research that I did but um, you know, right now I would probably take tidbits from each of the books, some of the internet sites, some of the personal comments I got plus the magazine “Our Voice” and create a pamphlet out of it. No I think Val’s group is working on something like that, I don’t know what will end up in it but um, that’s always, I think, a chance to have a better publication but then that’s my way of looking at it. Maybe somebody else, there’s different priorities but how do you please everybody, it’s not possible, you know. Fortunately there’s a lot of information out there because so many men, you know, such a high percentage of men get it, so there’s a lot of experience by the medical profession with this cancer and a lot of information is out there so. Now, I um, I mean the Abbotsford Hospital is nothing to write home about, it’s an old timer and they’re working on re-building it. It was interesting for me to get into a somewhat out-dated facility, um, but the care I had, I thought was excellent, you know, the nurses knew what they were doing and they were definitely dedicated. [6]

[So, do you wish to share any other thing that you consider to be important?] Well, there’s a lot of information that is not given by the doctors, an awful lot of information. It’s almost too numerous to mention, just to give you an idea briefly, I’ve been on hormones about four out of five years, although there has been a few things the doctors have told me to look out for, there has been a lot of things that they haven’t told me to look out for. [Like what?] Well, one of them was bone loss, alright, I was on hormones almost three years before the subject came up and it was actually Dr. [name of doctor] brought it up at one of the meetings that when you are on hormones, there’s a good chance that you’ve got bone loss. So I had a bone density, and sure enough, my bones are not as healthy as they should be so I’ve been on Fossilmax which, by the way, the government doesn’t pay for, even though it’s cancer, sort of, related. Um, there’s all kinds of
things, very simple things, it’s simply, not much, and I only found out a year ago after four years, I asked because the skin on my penis, actually, I couldn’t pull it back as far, why is that? Well, I found out that when you are on hormones the secretion in there dries up so eventually the skin comes forward and I can’t get the skin back anymore and then I had to get special cream so it wouldn’t get any worse. This was never told to me by a doctor. All these types of things that there should be some sort of an education thing. I think that came up at the meeting today that there should be one central place where you can get all this information, the pros, the cons and all this type of thing. A lot of this stuff that I found out is on the Internet, by researching the Internet but no doctor has every told me that. I’ll give you another example, which I found very interesting and also very disturbing, a couple of years ago there was a seminar over here at the Sheraton Hotel up on whatever street it’s on, on forth or whatever it is, and there was a bunch of doctors from the cancer clinic up there, one of them being Dr. ?, being the head of the cancer clinic and in his speech, he said that every once in a while we get a patient that comes in and all of a sudden the cancer is gone. We don’t understand, why is it gone? So I asked the question, all these people who have the cancer that’s just gone, has there been any discussion with them to find out what they did, to find out a common thread that maybe there’s a common thread here somewhere, whether it be vitamins whether it’s acupuncture or whatever and the answer was no. That disturbed me, because if there is people out there that the cancer has suddenly cured for some reason or other, why not ask a whole bunch of questions as you are and say what have you done for yourself and ask every individual the same question, maybe there’s a common link in there somewhere that we can all use and nobody asks the questions. That disturbs me. [So you would like to see more active research into some of these things?] Yah. [And more knowledge being passed out?] Exactly, like how do you research something that you don’t even know about. So if somebody says you get a dozen patients and one of the things they are doing is similar, then you have something to research that particular, similar topic. You say, let’s do some research here. But if you don’t know about it, how the hell are you going to research it? [Um hmm.] Anyway it’s just a thought. [17]

Category: Put more emphasis on prevention (4/23).

Summary: There needs to be more emphasis on preventing prostate cancer by stressing the “whole person” approach, where there is emphasis on one’s environment. Specific comments are: medical system is great for chasing symptoms but it doesn’t make people healthy [7]; young individuals should eat
lots of broccoli, tomatoes, beans and other healthy food [8]; and eat healthy foods.

[10, 13]

Comments made by individuals:

There is a medical system and for the majority of systems it’s probably, the medical system is great for chasing symptoms, it doesn’t necessarily make people healthy. It’s like people who are talking to you are people who have invested, the GP’s shouldn’t be able to talk about this, they don’t have enough knowledge, they pass it on to the urologist. The urologist, generally speaking, is in the cutting business, but they pass you on to the radiologist and he’s in the radiation business. The GP’s don’t have enough information and experience and understanding and if you get this cancer, and that’s the trouble they call it cancer, they call it prostate cancer and everybody gets all excited. It’s just another symptom of unhealthiness and the medical system doesn’t work that way. [7]

My advice to give them [young people], eat a lot of broccoli, a lot of stuff that’s cancer fighting like broccoli, tomatoes and beans and ah, when you get to that age, when you get to the age of 40 start going in for a check up. [8]

Yah, don’t smoke, don’t drink, their health education. I do think, you know. I’ve been out of it for so long but I do sense now, see my family is from Holland and we have Dutch values. My wife is from Holland and sure we were both only four years old when we immigrated, we met later here. She was from [name of city withheld]. And I’m from [name of city withheld], and we happened to meet when she was teaching out this way and we both happened to be from Holland but we have traditional Dutch meals, potatoes, meat, vegetables. I do think that the average Canadian family, eats a lot fast food, drinks a lot of pop, they probably don’t get their share of vegetables. They eat a lot of pastas, just fast foods, and I would really encourage them to get good meals, you know, as far as health education goes, don’t smoke, don’t drink, just your whole healthful living, but my outlook on that has not changed because of my prostate cancer, because I really don’t know what caused my prostate cancer, I don’t know. I, sometimes, in the back of my mind have thought, in my business we did a lot of work for dairy farms and build a lot of machinery but we also did a lot of welding of galvanized pipe which is coated pipe to stop it from rusting. I spent many, many, many hours welding stall dividers and gates for dairy farms and I think, I often wondered if the galvanized fumes was a part of it. I’ve asked the doctors and they’ll say, oh no, no, that’s not part of it, but there’s so much they don’t know. So I don’t know how that is, you know I haven’t got lung cancer because of it, not yet anyway, but I often wonder if that hasn’t been the contributing factor. Other than that, I just don’t know, I have no idea, it comes right out of the blue, but as far as advice to young fellows, eat healthy, live healthy, get an education but in relation to my prostate cancer I have no advice. [10]
Well teenagers have a long way to have prostate cancer, but we know, like we say to people, well don’t smoke because you’ll have lung cancer. We know that certain foods affect more prostate cancer in the future, for example, we know that red meat and we like to have a barbeque and we like to have, but we know that there is a connection between red meat and prostate cancer. What can we do, okay? So, we live in a society, especially in B.C., where a lot of people live a healthy lifestyle, because of the way that people do a little more exercise, more walking, more going to the mountain, going to the sea, going to the beach and so on, and also, we live in a Province where people eat a little more healthier diets than people probably in the East, okay. So, in fact, in B.C. surviving prostate cancer is much greater than any other Province. Also, we have very good people in the medical field here. Many of them which are better known, in fact, outside of the country than in the country itself. [13]

Item: Post-operative companionship with social-workers or outreach workers would be nice.(1/23).

Summary: The following individual stated that some men may need the guidance and support of a social worker or an outreach worker after their surgery or radiation. [12]

Comment made by individual:

Yah, I’m not sure but it seems to me that there is a provision right now for this [professional companionship during and after treatment]. I didn’t, I think somebody came to see me in the hospital and talked to me after in my post-operative time. They were a social worker and we were talking about this and we had good conversations. I can’t remember that much about, I don’t remember her name now, but there was no real follow up because, ah, I don’t think that it, it wasn’t needed, and for people who do require this, I think it’s wonderful that that is available. [12]
Item: Encourage young children to have more respect for individuals with illness (1/23).

Summary: Children should be more respectful of their elders especially when they are experiencing trauma in their lives. [9]

Comment made by individual:

As far as the young people are concerned my advice would be to live life to the fullest and be respectful of their elders. I really don’t think that there’s a whole lot of respect today, totally disrespectful society in general and I think um, I’m not looking for sympathy or pity or anything else, but be understanding of people that have had this experience, and I really don’t, like my grandchildren and the rest of it, their attitude towards me hasn’t changed one darn bit and that’s alright by me. I don’t, I’m not looking for sympathy or anything else. [9]

Category: Have one medical doctor who had specialization in all the treatments that helps with the decision making process. Presently, there may be some bias in passing out information or in the kinds of treatments that are recommended (4/23).

Summary: In spite of doctors’ best intentions, sometimes there is bias when the information comes from one specialist. Specific comments in this category are: I would have liked to have known more about the different kinds of treatments [15]; each speciality of doctor has his/her own bias, and a lot has to do with the mindset of the doctor [20, 20 wife]; “if you are the surgeon and think surgery is good, or the radiation doctor and think radiation is good, so there is a bit of bias there.” [26]

Comments made by individuals:

[Observation: This issue was brought up in different support group meetings for a discussion by two different individuals than the ones presented below]

Well, I’m fairly satisfied with it. I think that if I were going through the process again, I would like to have known more about procedures like Brachia therapy which I certainly knew about it and was aware of it but I wasn’t, I didn’t know as much about it as I think I should have at the time. My guess is it wouldn’t have changed the treatment but I would have known more information. So whether I
should have insisted that my urologist refers me to a radiologist or somebody like that. No, my GP referred me to an urologist, the urologist said, he gave me a book to read and a whole bunch of stuff to look at, and he said, you know, we have these three options or four options whatever they were. He said, I think the surgery is the way for you to go, given your symptoms and so on. He also said, he was a surgeon, and therefore, has some bias so I should be aware of these things, that he was biased about that. So, I think I would have liked to have known more about brachia therapy before I took a final decision but I don’t think it would have changed my decision. [15]

Well even when you read all the material, look at it closely, you still don’t know enough about it. Once the doctor writes about their specialty and another one will write about their specialty. The person that performs the operation and has cut everything out, he will tell you this is best, where the other fellow that’s going to give you radiation talks about it being the best way. My experience, so far, is the operation is the only way to go, because then you can have radiation after the operation. If you have radiation first, you can’t have an operation. I don’t understand why the radiation blocks any other treatment. We saw that in that CBC film too. [So, what approach do you feel doctors should take then?] Well, I think the only approach is for the doctor to sit you down and tell you all the aspects of it up front, I don’t think they’re up front enough. [20] I think that there should be an independent person that talks to you [20wife] To be able to analyze it and come up with a friend who could run this by you. You’re not the doctor, you don’t have the background, you’ve hardly seen it, you don’t even know what prostate cancer is. Oh, I’ve got a prostate, I’ve got cancer, and ah, when they first tell you, in that first meeting, I have prostate cancer, now what in the Christ am I going to do. I don’t remember what he said, maybe you do. [20] I don’t remember everything because it was a shock, but [another husband and wife’s name] when they went, they went together. The wife should always be there, but she was madly writing everything down, and I guess I should have done the same thing, because you think about one thing and then you miss the 10th thing he said [20wife] [Do you feel you had enough time to decide?] Well we did it very quickly. We made our decision very quickly at the point of being in the doctor’s office and telling what we were going to do, but we had about three years with [name of a person], Our Friend [20] And then my cousin coming in, in a year and a half, and seeing what they went through. It with talking to them that ah, of course, coming from my background, I had my mind made up what was going to be done [20wife] That tape, it was a good tape to demonstrate the same, the one fellow who just had radiation, he got cured. [20] Yah, but he hasn’t gone five years. [20wife] But the other fellow [in the video shown at the support group], later on who was the smart ass, he screwed himself, so that he can’t have any treatment. So it’s something you don’t—unclear—, I don’t think you can do anything but just cut it out, and then the radiation, I don’t think there’s enough information and I’ve been at it for three years now, and lot’s of people come in and I’ve talked to them and I don’t think there’s any other way to do it. I think the doctors should say this is the way to go, bang. It’s not up to me to make up my, what the hell do I know about it, you know, what do I know, but if you’re a
radiologist and you have a patient referred to you, are you going to tell him he should go have an operation? [20] There’s a fellow, his doctor got sick and there was no follow up and he went until his PSA was 18 and then at his age they decided that radiation was the way to go. So he went through that, and we just saw him this summer and he said, that his PSA was up to, now, 10 or something was it? [20wife] Um hmm.[20] He’s 80 years old but they didn’t want to operate on him at 78, but you see there too is the problem with the doctor.[20wife] [So, he couldn’t go to some other doctor?] Well, when you live in the [name of a small town in B.C. withheld] you are having to go to another city, he’s in a small town. So he got recommended to go to a doctor in Castlegar, he was in New Denver, so he had to go to Castlegar, but there was no follow up, nobody from the doctor’s office contacted him to say the doctor is not going to be available for three months, you better go find somebody else. To me, the doctor’s office should have been finding somebody else to take him. [So besides this, deciding on the treatment and dealing with the doctors, were there any other things that you found stressful?] The strike with the nurses, that was stressful.[What did that do?] Well not knowing whether you are going to have the operation because of the nurses’ strike.[20]

I think my suggestion is, you go to your doctor, your doctor tells you, your doctor is the one that usually makes the appointment for you about the radiation or whether you go to a surgeon, so I think a lot has to do with the mindset of your doctor, where he’s coming from, we’ve never discussed that with your doctor, have you? Why he sent you to [name of the urologist] and not to a radiologist, but I think we need to have a person out there that is knowledgeable in all the aspects and can talk to you so that they’re not going to be just pushing their schooling. [20 wife]. We tried to set up, as you know there’s an office in the old wing of the Willow at the hospital and that office is about the size of these two rooms. In one of the rooms, the smaller room, it’s full of tapes and books and information, a computer that we gave them. I think it should be compulsory that the doctors give the patient, the new patient, the handouts. I tried to put it together and I couldn’t get anywhere. The master group oversees all of these, which I’m not in, and has put a package together. We’ve got the best package in the world but you’ve got to get it that last three feet, from the doctor to the patient, and the doctors will not cooperate because we’ve tried it.[20] [Why wouldn’t they cooperate?] I don’t know, I guess they don’t want their patients to easily find out what’s going on. They might get educated but those packages are all put together with information supplied to the doctor. We just want to supply the best information available and the best information has to be judged by the doctors. So we are presently putting that together, but I want those patients to be aware of this little office and then the initial plan three years ago was for somebody, like myself, to go down and volunteer to be there, right, and sit there and the patient would come in and we would help him get the information out and run through the experience and take that fear aware. Dam, they were good at the hospital, I can’t say enough for them, they were just, and the other thing is when you’ve got cancer, your treatment is set up for a certain date, that isn’t going to happen come hell or high water because they’re having all these strikes and people are being put off and the list is getting
longer and longer. So that’s what I would like to see happen. How to organize that. We’ve done support groups and got this information put together, but now we have to get it in there, and I think that one of us should be there so when the person comes in with his wife in that little room, we’re there and not a doctor but part of the support group and then those people should come to the support group but I didn’t know the support group existed except through [name of a person withheld] [20]. Nobody here ever said anything to us about the support group and when you had to go in to get your first injection of the hormone, I was standing downstairs and there was a bulletin board there.[20 wife] The patient is diagnosed, the doctor tells him, at that point in time, the patient is blown, he’s, I know a person, who thought, oh, Christ, how much time have I got left and what the hell is going to happen. The doctor really hasn’t got the time to sit there and talk to them, and quite frankly, they’ve got no interest in talking to you. All they want to do is get, if you go in his office, you see the lineup of people and they’ve got people going through there every five or ten minutes just like a machine. I think if they come out of that office and know about the other office, and we got them over there and knowing that there was somebody there, like, there’s a nurse there, she’s a nursing doctor, and she’s really good, I didn’t know that was there and the only time I’ve ever been in the place is when I’ve been doing something for them, you know. The system breaks down, the support group, I think that the guy that runs the support group, a friend, we were in there today and I think he’s getting tired -unclear- you can just see the look on his face. He didn’t have to, he never sent that message because he was caught in the middle. When they come in, people have to understand the support group is only there to help. We don’t get paid for it, we don’t make any money at all and I spend, I guess, eight hours a month doing this. I used to phone.[20]By sending out your announcements on the email, means you’re not going to lose this contact that you had with that group that you phoned.[20 wife] It didn’t really work.[20] Well you had some that worked.[20wife] No, it was like I was trying to sell them something. We were only asking them for a buck or two to pay for the food and the drink.[20] Maybe there’s somebody you should go and see that’s impartial to all the things.[20wife] Not to tell them what to do, but someone who’s got the background and say, okay,[20] These are the things that can be done and then that person can tell you to go to that center where all the tapes and the books and everything are. It should be, you need to know that that’s there and go and use, it and I don’t think we used it enough, but I had my mind made up because I just kept thinking, what would my father say to do. My father was a [in a health related profession] and I know that his idea would have been, especially when we had found out he had aggressive cancer, it would be, go and get the thing cut out, because then if they didn’t get it all, he could do the radiation.[20wife] Talking about cancer, the problem is we can’t get any of the doctors to give information pamphlets out and a lot of it dealing with prostate cancer or lung cancer or everything else. [20] I know, but I pick them up and look at the ones that are pertaining to me at the doctor’s office the other day, I noticed the one that said post-polio symptoms so I went over and picked it up.[20wife]You know what should be done, is you know how they’ve got those racks, you know, in the motel, they’v got a very nice rack about, yah, big, it fits on the wall and it’s got about 50 pamphlets, they are all the
Was it advertising other motels? [20 wife] Yes, it was put out by the company. What we need to do is have health racks in doctors’ offices, so somebody goes around and replenishes them, because it’s all hit and miss. How are you going to get volunteers to do that? [20 wife].

I have not thought of that but ah, but because there are several methods of dealing with this prostate cancer, if you are the surgeon and think surgery is good, or the radiation doctor and think radiation is good, so there is a bit of bias there, so I suppose you need to make up your own final decision and from the patient themselves. The doctor can tell you what he thinks but usually you are getting a bias opinion. [26]

Category: Expert speakers from the South Asian and Chinese community should give more talks to these groups (2/23).

Summary: Even before individuals get diagnosed with prostate cancer, they should have some familiarity with it. Specific examples are: expert speakers from the Chinese community should give talks to Chinese men about prostate cancer [21]; the medical community could have a South Asian Health Fair because there are a lot of illnesses and conditions that are specific to South Asians. [25]

Comments made by individuals:

In terms of suggestions for improving the system. Well, you should be able to go to different specialists without a referral. This way you are better informed and have more choice. Expert speakers from the Chinese community should give talks to Chinese men about Prostate cancer. [21]

It's probably a good idea to get people to talk about it same as they do with diabetes and high blood pressure and, I think there is not enough awareness. [So more awareness?] Um hmm, um hmm. [Do you have any other suggestions for bringing this awareness?] No, how can you do that, maybe through, I’m sure all groups have there own health schemes and rehab. We have health fairs every year and there’s always somebody from prostate who talks. So those kinds of things. They could have a South Asian health fair, because there are a lot of illnesses and conditions that are specific to South Asians. So this way they could have a forum. Have you tried any alternative treatment or anything?] No, no. Diet, yes I found out more about what things are important in my diet. [Did you drink or smoke ever?] No, no. [25]
Appendix I

Question: What do you see as some of the challenges in running a support group?

Item: Trying to meet the needs of the individual members: especially those with advanced cancer (1/6).

Summary: One needs to keep on top of the information about prostate cancer and the clinical trials. The support group leader also has to present this information to meet the individual needs of the men attending the prostate support group. [2]

Comment made by individual:

Trying to determine what would be of the most value and what the people attending would like to have, because needs is a very great deal and that was the reason for starting my group which is an advanced group. Unlike all the other groups which try to cover the complete spectrum, I felt that the needs of people with advanced prostate cancer were not being met adequately by the other regular support groups so I started this special group for advanced patients and I try to, as I say, bring information on the latest clinical trials etc. Now, even within this grouping of advanced prostate cancer patients there are different needs, there are some people who are already focused on palliative care etc. and there’s other people that are still fighting to find the best chemotherapy drug and so on. So I try to find out what the needs are and satisfy them [2].

Category: Motivating individuals to volunteer at the support group (4/6).

Summary: Motivating support group members to take an active part in the activities of the group is a challenge. It’s a challenge to get group individuals motivated to help out in the group. [3, 4a, 16, 17]

Comments made by individuals:

Getting volunteers is one of the big challenges, trying to get the other guys motivated to help out a bit. That’s one of the challenges. [3]
Maybe it might be a good thing if there was more advertisement for volunteers to do this [provide transportation]. I know that in our peer group meetings, we have, sometimes, a little bit of difficulty getting the people that are coming out to the meetings to take an active part in volunteer work, and we have a small committee that has started here in [name of municipality] and we have a chair, a chairman, a vice-chairman, a treasurer and there’s other offices that are hoping to be able to facilitate the needs in that area but it’s just really hard to get people to volunteer time. [4a]

Um, that’s a good question, nothing substantial but, I think ? but the committee is much more manageable in terms of planning but there is just numerous tasks that have to be done, and ah, that we’ve been trying to shift or get help from the members at large, not that they join the committee, we don’t expect that. Like for instance, when we have a guest speaker, we would phone everybody on our contact list. The committee members would all take five or six pages and call them and just to remind them that we have a guest speaker. So, that is difficult, I mean, it was difficult because it took a lot of time. I still, although I’m not driven, I’m still in business for myself and I want to carve out some time for myself. Others on the committee drive patients to the Fraser Valley Cancer Clinic and on Fridays they deliver bread to the food banks, stuff like that, so we do quite a bit. [Where do you get the bread from?] You get it from a supplier, outside of the prostate group. He’s just that type of person and so he assists that organization. So we are trying to expand that to share these tasks that they can do, and ah, like a simple task, like at the end of the meeting, putting all the chairs back in position. Committee members are doing that, because the support group will get up and leave, and we need to clean up the table and stuff like that, so we’ve included a team of three or four guys to be responsible for the clean up, and we ah, so we are trying to identify areas where the members at large who didn’t want to help us, although, when you join a support group, you’re a volunteer, and ah, you really don’t have to do anything you’re just a volunteer. So, we are trying to work on that and just to share the load, because if you don’t watch it, you can –unclear—which I was in overload when I was a board member as well always in the key role and I was the one who put together the food for the Concept and I got the suppliers. So, that’s the biggest problem. Getting new members is not a problem. As I say we’ve got notices about our group in many of the doctor’s office and we get over half a dozen, five or six new members every meeting and they find out about it through the blue card program and I’ll make calls at random asking any of them to talk about it, about the group.[What’s the blue card program?] The blue card is a card that we made up, I don’t know if we’ve got any or not. Like it’s a card that we put together that talks very briefly about the support group, and ah. [So it’s an information pamphlet?] I’ll give you one. We’ve got names on here of people to contact. [And this is put in doctor’s offices?] Doctor’s offices. It’s got our name and number. Have you ever read the pamphlet on the Do it for Dad run at our major foundation? [Oh, yah I’ve seen that]. I can’t say it’s an inconvenience because I like going to the meeting, and ah, I like seeing the guys again, and ah, it’s usually a lot of fun. [Are there any other words that you feel are important from being a committee member?] No, I don’t have any other words. Just that I
know that, I’m not sure any of the members appreciate it, and ah, I guess the last problem is a huge problem, is that on a regular basis, is getting funds for the support group. Our budget is now over $3000. Most of it is in the support pamphlets, they need to be updated and stuff like that unclear and new members, but we’ve got it on disk and so one member does the upgrade. At the end of the year, we spent over $3000 on it. We pull in about $100 to $125 a meeting with the raffle so we have to make up the different. Ask (Drisanika – spelling) who has been kind enough for the last four years, I guess, they send us a grant of about $1300 and we get some donations at large from the members and then I’m responsible for fund raising and also getting the prizes for the raffle. So, on a regular basis, I’m trying to develop programs, solicitations for gathering funds for us.[16]

Well, one of the challenges is, as I was trying to get the point across today, is we need some volunteers to help us out. We have about five members on the committee, one of them as you can see, she’s lost a leg, may lose another leg. Myself, my cancer has metastasized, another person, he has another type of cancer now on top of prostate cancer. So we really, if you took a look at our group, we only have a couple of members that you can actually call health and it is very, very difficult to get people out their chairs to help us run this group and take on some tasks. So it gets to a point where it’s very taxing and there’s been times when I’ve actually felt like I should be dying because it’s taxing, but each time I think of that, I say, no not yet, I still need to continue for a while longer. [17]

Category: Finding the speakers, finding the time, and getting individuals to come the support group on a regular basis (2/6).

Summary: It takes time to find the appropriate speakers to meet the needs of the support group members. A summary of the comments presented in this category is: one has to bring in different speakers to keep the group members motivated [3]; it is challenging for me as a group leader because I also work full time [3]; getting individuals to attend the support group on a regular basis is also a challenge. [5]
Comments made by individuals:

Of course, getting the speakers. Trying to keep the support group motivated by bringing in different speakers is one of the challenges.[3]

The other challenge is just the time, because I do work full-time and I’ve got other activities that I take part in. So, that’s a little bit of a challenge but I don’t mind it. [3]

Getting the guys to come back [is a challenge]. You have to have diversity and a variety of speakers, a lot of new knowledge and a CPS and Canadian Prostate Cancer Network. They send me new stuff almost every month, and ah, the guys come down here quite often, you know, they miss a couple of few weeks but they’ll come for another one to get all the new knowledge etc., and ah, we had a thing up at the showcase here at our, I don’t know what you would call it, where we have our swimming and all that up here, we had a showcase where all the different community services, and that, well we were up there. We had our own booth and all the guys volunteered to help look after it for two or three hours each day. We had it for two days, or two and a half days actually and they all volunteered. Some of the guys were too sick to come down but, ah, they were all happy to help out. So I think the prostate group really helps in that way, togetherness, you know. Gives them a sense of wellbeing and being able to help somebody else. Like when I told them about your papers to send out, oh yah, I’ll help, yah. That’s a good attitude, you know, and there’s a lot of people that don’t come that I know have prostate cancer, and they say, we just don’t need your help, it’s fine. I said, well, if you ever do, give me a call, we’re here every third [name of day]. Tell them what time etc. [5]
Appendix J

Positive aspects of the current medical and support system for treatment of prostate cancer

Item: Satisfaction with the amount of information about prostate cancer that is out there in the doctors' offices and on the internet (2/18).

Summary: There is lots of information available about prostate cancer in the doctors’ offices and on the internet. [19]

Comments made by individuals:

I think there’s plenty of information now. Even when you go into your family doctor’s office you’ll see the signs on the wall, you know, information about the prostate. The Web has got more on it and I would think that urologists have to be careful because the patient goes in with a wealth of knowledge, not necessarily put into proper context but with a wealth of knowledge. I think we’ve come a long way. I think the hardest thing is the cost of the medical program and of course we start to become quite selfish but I’d love to see a test for breast cancer like a man has for prostate cancer. A woman doesn’t have a blood test that can tell whether that’s developing. It’s hard to know. [1]

I don’t know if any other improvements could be made better than what they put out in the literature and books and all that, what they say. I don’t know what else they could do better until they discover something new or something that cures it. That’s about the only thing. [19]


Summary: The Prostate Cancer Information Centre is very helpful for individuals at the early stages of their diagnoses. A summary of specific comments is: it is good that there is a Prostate Cancer Information Centre [2]; since 1995, there has been lots of improvements in the province of British Columbia by opening new cancer centres [4b]; it is good that there is a nurse to give out patient information at the Prostate Cancer Centre. [13]
Comments made by individuals:

Well, I think that recently there has been a good deal that has been done by way of helping at the early stage of diagnosis and the prostate cancer information center which has been set up. [2]

Since 1995 which was my time for prostate cancer, there’s been a lot of improvements here in the Province. We have the “What Now” center in Surrey and there’s a center in Kelowna and they are talking about a center here in the Valley once they build this hospital. So there’s a lot of cancer centers propping up all over the Province. I don’t know where else, but since 95 there’s been good progress in treating cancer and prostate cancer, but I think there’s a long way to go for some urologists to be aware. They don’t seem to be aware of how much of a problem this prostate cancer is in B.C. Prostate cancer in B.C. is epidemic, at epidemic level for some reason, it is more so than any other Province in Canada. [4b]

So we have been doing a lot of work. Dr.[name of person withheld], sees people when they come to the prostate center, gives them information, gives them assistance. [13]

Item: Happiness about the role of the Canadian Cancer Society (1/18).

Summary: Cancer society has taken an active role in providing funds for cancer research and in initiating public forums to provide information about prostate cancer. [3]

Comments made by individuals:

The Cancer Society for instance, phoned me up just last week and asked me to help them put on a prostate cancer forum in September. I put one on about four years ago and they asked me to help out and get some speakers lined up and they are going to pay for the advertising and stuff like that. So they’ve taken on a role to help out. Well what we did last time was, ah, we had a hall rented and we advertised the prostate seminar and we brought in Dr. Art Hister as the MC and I brought in a urologist, an oncologist and a radiologist and these sat up as a panel in the front and each one of them gave a talk and then it was open to questions and answers. [3]
Category: Praise about the cancer related publications and organizations: “Our Voice” magazine, “CPCN” (Canadian Prostate Cancer Network), and Prostate Foundation (4/18).

Summary: A summary of the specific comments in this category are: “Our Voice” is excellent, especially the sharing of the personal stories in it [6, 15 bought some books listed at the back of “Our Voice” [9]; the Prostate Foundation and the Canadian Prostate Canadian Network are the national organizations that are supporting educational and research activities for prostate cancer . [13]

Comments made by individuals:

Our Voice is excellent. I like the sharing of the personal stories, and what worked and didn’t work [6]

Yes Our Voice and I thought, I want to go further with this, I want to know better about the options and the rest of it so I bought, I think in all, I bought four books on it and these books were listed in the back of Our Voice and I, so I read through the synopses on these books and the rest of it and I thought, I think I would like that one and that one and that one, you know, these books were suggested and um, Yamaguchi, I read that book, and um, in the book he said, I mean you go through the introduction and through the book and you get the whole view of the prostate and all, and you know, and it would take you through, you know, the incision and the rest of it and at a point in the book, he said, if you radiate the prostate and this area you turn it into a clay ball. It’s dead matter, it’s like this clay ball matter that’s going to stay with you forever and whether in this beam radiation or how you radiate it, if they got it all is questionable and if after you had it radiated you still had cancer, then according to Yamaguchi, they can’t operate on you because you can’t get this dead matter to knit or to do anything, where are you at? You are dealing with this injured dead matter and the rest of it and it no longer has circulation or anything, it won’t knit, you’re S.O.L. so, I’m mean, that sold me. I read the rest of it and I read everything else that I could on it but that stuck in my memory and I thought, you know, if, eventually, eventually, you are going to damage the prostate and the nerve, and if you are not careful, a whole lot of other stuff with this radiation and, if you have a radical proctectomy, if there is something remaining there, you can shoot it with the gun or you can put a seed in there and radiate it or you can do something with it, but you can’t if you go the other route. So, I mean I’m so, and when it boils down to it, I mean, it’s better, it’s better, to me than I anticipated. [9]
Well, our problem in the past has been that ah, to make sure that the doctor, when they have someone detected with prostate cancer that he will be referred to a group like our group, because the doctor doesn’t have the facility to give advice and counseling and so on. He doesn’t have the time to do that, they are on their own to do that, okay, and so for many years, doctors didn’t even check the prostate. So we have created an awareness and so on, now the foundation was a help with the Worker’s Compensation. We’ve got the grant to develop the kit so every time someone will be detected with prostate cancer, when he would go to the urologist, when he would get the urology report, the pathology report, he also will get a kit and the kit will include the book on prostate cancer, it will give the information about the different groups, it will give all kinds of information, where they can get a test and so on. So this is one of the things that the foundation is doing. Oh, yes, it will be provided to pathologists and the pathologist will send to any urologist the report when it is positive then it will include this sort of kit. Okay, the foundation was created, it was, at the start, it was for all the different groups that we have, okay, and the problem was they wanted to be able to raise money for different projects to support and in order to do that, they had to create a foundation that was tax free and would be able to issue a receipt for people that gave a donation and the main donation, we use it for Burnaby Lake and we have people that have different groups and people that come and participate in it. Also we get, for example, a grant of $20,000 from WCB, we also got a grant, not long ago, from QLT. QLT is one of the major biotechnology companies in Vancouver and they do some research on products. Their main product right now is a product called Visodine, which is a product for people that have problems with their eyes, with vision, and ah, we get about $7,000 from them, and we have some people some times, if somebody dies from prostate cancer and they want to make a donation, we get the donation. We have been doing the whole thing and from this money we support the different groups and with this money we also support, we provide SID money for different research. In fact right now, besides user resource, a student from UBC that is the research project, and he has also come and interviewed people and so on. So, we encourage anything that will help in the long run. When you reach the age of around 50 make sure you have a PSA test. You see, in the past if we know that somebody has a history of prostate cancer in the family, like father or grandfather or brother, they should start to get tested at age 40 but in the past they didn’t have a record so we didn’t know. I knew my grandfather had prostate cancer but my dad died young so I didn’t know if was going to get it, but um, as we keep a better record, medical record, people will be able to check it better. If I talk too much that’s what happens. So do you have any more questions? We have been working lately with the center for integrated healing, are you familiar with that and we have, the foundation we gave given them some grants to do some initial research and because we give them the grant some pharmaceutical company will also give them a grant but without our grant they would not get anything. So we provided money for that kind of thing.

[13]
There is in Canada an organization called CPCN, Cancer of Prostate Canadian Network [for helping individuals with prostate cancer. We also bring our presentation to the government, okay. On the local level, we [Prostate Foundation] make sure for the local people, we are there for whatever they want, we are there, and we offer, you know, if we know somebody is in the hospital, some people will visit them. If somebody wants to phone, we have some people that will answer the phone, if somebody wants help or wants information that we’ve got or things like that, we always offer that kind of job. [13]

[Personal note: Through one of the support groups, I also found out that the Prostate Foundation donated $1000 to buy resources for its library, that is available on a table, when the support group meets]

Yah, I guess it’s Our Voice, anyway it has addresses and contact numbers for all of the support groups in the area. So I think it was through that publication which I got in the doctor’s office, he gave it to me that I found out nd at what time did you get involved in the prostate support group, was it before your treatment?] No, at the time of the medical. [And how did you find out about it?] Um, I think that my urologists mentioned it and there was this publication, quarterly publication t how to get in touch with them. [And you’ve been attending regularly?] Fairly regularly. [15]

Category: Happiness about the way treatment services were / are provided by doctors, nurses and other professionals (7/18).

Summary: Overall, these people were happy with the way they were provided with their prostate cancer treatments. Summary comments in this category are: I have no complains about the way things are done[10]; I just had an excellent rapport with the medical staff [12]; I couldn’t ask for better treatment, the doctors were fantastic [17]; it was the finest experience, it was 99 percent perfect [20]; I think the doctors and specialists are doing a fine job [26].
Comments made by individuals:

The way things are done, I really have no complaints. I was diagnosed, it was suspected, I had a biopsy within six weeks, I had a cat-scan within days. I went into the doctor’s office and we decided to have the operation. Eleven days later I was in the hospital having the operation. The service has been excellent, follow up treatments, I needed a bone scan, blood tests and all of that, I got it all within a couple of weeks. I’ve no complaints. You hear all these stories about long waits and all that stuff, I don’t know if that’s political or what it is but I certainly have not experienced any of that. I have no complaints about that. What I would encourage the medical profession to do is maybe share some of the possible side-effects, what could go wrong. Like, after my operation I came out of the hospital with a catheter. I had it in for 10 days and then when he pulled it out, I thought, he’ll take it out and I’m back to normal, and he says two-thirds of the guys have trouble controlling their bladder. Well that was over a year ago and I’m still wearing a pad, I still have trouble controlling my bladder. I wasn’t prepared for that kind of thing. I wasn’t prepared for the loss of sexual activity that quick. You know, it just totally finished, all of a sudden, boom, gone. I wasn’t prepared for that and that was never talked about either. A few things like that, but for the follow up, I think the systems pretty good considering the short-comings that they have to deal with and the lack of funding and everything, I have no complaints. No, I think it’s good. [10]

Oh yes, oh yes, I just had excellent care, you know, during my pre-operation, operation, my recovery in the hospital and also afterwards when the health nurse came in for a number of days. I had excellent care and very caring people, you know. It wasn’t something was, oh, this is my job I have to do it, they really cared, and also, when I was in and out of the ambulatory daycare and the day surgery people, they again were just excellent. I was actually going in there so often that they became good friends. I think we did, sort of, touch on the subject by, and you probably from the way that I have been speaking, refer to the kind of quality, and I really mean that, quality care and assistance that is given, that is given to you. I had just excellent rapport with my doctor, excellent rapport with the people at the cancer clinic in Surrey, I thought they were very, very good and thorough, and you know, and when I was going in for all of these pre-operative procedures, scans and whatever, I was really treated with as much dignity as you could and it was caring. [12]

I think I was well treated, ah, I couldn’t ask for better treatment, the doctors have been fantastic. You know, I hear a lot of systems that the healthcare is in bad shape and maybe it is, I don’t know, because I haven’t had to use it other than cancer. I can say the cancer arm is in fantastic shape. They are tremendous. [17]

What I was going to say before, that in Vancouver, you know how we always have to wait and bugger around, when I went through my cancer operation, from
the time I walked into the Vancouver General Hospital until I came out, I don’t have any criticism about the hospital. It was the finest experience, it went 99 percent perfect, it was unbelievable [20] There was just that one nurse[20wife] [You mean talking at the nursing station?] Well you said they told the same story over four times. [20wife] Every person that came in, they told the same story. [20]

I am happy with the services I have received. The Cancer Clinic in Vancouver is a good place. I didn’t need to travel so I stayed there for a month in 1990. [22]

Um, well, *I think what the doctors are, the specialists are doing, they are all doing a good job. So, I’m not in a position to suggest anything better than that. They are all doing a good job except that they in the line of duty, this I can understand it’s acceptable, I mean something reasonable.* [26]

**Category:** Happiness that a social worker or urologist sits in our meetings. The BC Cancer Agency and the Ministry of Health should make sure that doctors also participate in all of the support groups (4/18).

**Summary:** Men that made comments in this category were happy that a social worker or an urologist sits in their support group. They also wanted to see this kind of medical professional support for all the support groups throughout Canada. Summary comments for this category are: we have a person who represents the BC Cancer Agency that and he sits in our group and we are happy about that [13]; from last several years, the only time our urologist has missed our support group meetings is when his daughters were graduating [16]; other support groups should be facilitated to have the presence of medical professionals [17]; there should be more medical manpower to help support groups in all areas. [18]
Comments made by individuals:

We do have some people from the B.C. Cancer Agency that sit on our group and we have a couple of people, we have a person who represents the agency, and ah, he's a social worker and deals with a lot of people, and they do have representation. We have, like a steering committee which is like our executive of the group and so we have people who sit there. So they are aware, and ah, they bring the information that they have on their side, they get from us feedback. [13]

Our support group has over 330 members, that is unique. I think [another city's name] has about 45. That's the normal size between 30 and 40. The big thing that we have going for us is Dr.[name of doctor]'s support and willingness to attend our meeting to field questions, and ah, he's just a phenomenal person, and ah, he's only, I mean the support group started in somebody's garage, [name of person withheld] garage, I think it was [name of person withheld] ?. So it started out with two or three guys but Dr. [name of doctor] since it's conception, but when it got, I'm sure it wasn't as the meeting was still getting started, but I would say in a relatively short period of time, he, at least for the last 10 plus years, and probably he's only missed two meetings and they were because both of his daughters were graduating from medical school in the United States so he took leave to attend both those graduations. He knows how well he's thought of. That makes the [our] group unique, nobody else has that, and as a result, we are draining people out of [name of another municipality] and yet there's a support group in [name of another municipality] but they come here because they've heard of Dr. [name of doctor] and they keep coming. [16]

I think one of the things, we are very fortunate here, we have Dr. [name of doctor] that comes every month and that's one of the reasons that we are the largest support group in B.C., if we lost [name of doctor], we fall flat on our rear-ends because we don't have the knowledge that he has so, yes, we get it together and run a meeting but when it comes to technical support, or whatever, we have Dr.[name of doctor] , so I think either the B.C. Cancer Agency or the doctors or whatever, if they could get somebody like a Dr. [name of doctor] and help other support groups around the Provinces, it would be fantastic, a lot more men would be helped in that way. It's only the men here at our group that has a Dr. [name of doctor] that helps them. Every single one. Nobody else in B.C. has that luxury and if we can get that luxury into other prostate groups, it would help a lot of me. [17]

The medical centers are very centrally located, so providing assistance makes it extremely difficult for them unless they pour a lot of money into it, and ah, yah, they would have to pour a lot more money into it than they are currently pouring into it, and that. Perhaps we should address some of that and, to some degree, I would support that kind of thing. Pouring more money into manpower so they have more people to, like [name of social worker] here is from the cancer agency, he was here today. He comes to all of the meetings as a representative from the
cancer agency and to sort of help out. He's also a social worker so the social
needs of people are addressed in his particular department and they have an
extensive department there. Although, unfortunately, it's only in Vancouver.
What happens to the person who is in Fort St. John, how does he get that kind of
help? So there would need to be a lot more money poured into it in terms of
manpower. [So some of these professionals could attend the meetings?] Yah,
either attend the meetings or be available. Who's going to travel from Fort St.
John to Vancouver to have a discussion with a social worker about a social issue
with his family about his condition? It's not going to happen so he just has to rely
on someone else in his community to be sharing those experiences with and some
people have extreme difficulty in sharing those kinds of things. So at these kinds
of meetings some of those kinds of things come out. The way we structured the
meetings is about dishing out information first. The meeting is not about personal
outpouring, but rather, you are here to learn something, but in the process people
outpour their frustrations about what they are feeling and about how they ought to
be treated. Other people hear him and say, just a minute now, did you think about
this and did you think about that. In that particular context we are hearing that
particular person's frustration and it's very unlikely that men in our community
can do that. Well, they don't do that, to start with, without going to a meeting to
learn something new. Well, I'm going to this meeting only to hear about
something and we've had a lot of men come here and say, do you have to say
anything. As soon as the word support is used, men have a tendency to shy away
from the meeting and we had some discussions about whether we should change
our name in order to avoid that kind of situation. So, to answer your question,
they do a very good job, there's probably a bit more they could do, but the most
useful exercise is to have men sharing with themselves. Having other professional
people input tends to put those professional people on a bit of an uncomfortable
basis because they don't have the disease. It's the other people who have the
disease and it's people who have the disease sharing their experience with other
people that have the disease that really counts. I have mentioned to too many men
that I have the opportunity to talk to on the telephone, come and see the eyes of
those people who have already been there and that seems to work for most of the
people that I've experienced. They come and they say, oh, I'm not the only one, it
happened to you, oh how did you deal with it? Oh, I did this. Maybe I ought to
try that and it's through that experience the persons are healed. Well my doctor
didn't tell me anything about that. I didn't hear anything about that. Another one,
is a guy came in, my doctor didn't tell me anything. Did you ask him any
questions? No, he was supposed to tell me. So go back and ask him some
questions, he'll give you some answers. Those are the kinds of things that come
forward. So I think the outpouring of support would be in the organizing of
groups to come together and share amongst themselves, seems to me to be the
most useful. [What do you mean organizing the groups together?] Well, going into
a community and holding a public meeting, see how many people might be
interested in coming to that particular meeting and then taking people who are at
that meeting, and say, well, we'd like to have another meeting next month, and
we'd like to do it in this area, and ah, the subject matter we are going to talk about
is this. How many of you people are interested? We have a dozen people who are
interested, good! We’ll see you then, kind of things. How you support that kind of thing with manpower, I’m not exactly sure, but you need some kind of health unit, an interventionist, a person who is adept at public relations that kind of stuff to get people to come out, that kind of thing. Who might engender, the organizing of people coming together? The tendency is to allow that person to be, the controlling person responsible for organizing a meeting, the person has to manipulate it in such a way as this is your meeting guys and you can do it, and then say, who wants to do this and who wants to do that and then you leave them with the responsibilities and they set it up and they can run it, and then you say, oh, I’ll come back and help you out and here’s what I’ll do for you and that kind of thing, but get those people to organize themselves and then the network starts working really well. [18]

Item: Happiness that the support groups help to collect research funds for cancer and that they are self-supporting (1/18).

Summary: “Do it for Dad run” collected close to $80,000 dollars in donations for cancer research. [13]

Comment made by individual:

Yah, in fact, our group, the regular group, we are self-supporting, we do little things to raise a bit of money. When we have coffee and drinks and so on, we have a little basket where people give a donation and we do a raffle every month. So, again, we earn a little bit of money and some of the money we do, at the end of the year in December, we have a lunch for all the members and we call it a celebration of life, okay, and we also make a donation every year to the Cancer Agency and to the research of prostate cancer. Yah, so we are not taking out money but we want to be able to contribute and give it away. [13]
Appendix K

Advice provided by the survivors for other individuals with prostate cancer

Item: Take responsibility (1/6).

Summary: Be in charge of your own treatment plan. [2]

Comment made by individual:

I would encourage anybody diagnosed with prostate cancer to take responsibility for learning what's necessary to make a sensible choice as to what's necessary to the therapy and to continue to be responsible because an overworked specialist with 10 minutes to spend is not really sufficient. Each individual has to take control of his own situation. [2]

Item: Take a positive attitude, and be happy with the consequences of whatever treatment you choose (3/6).

Summary: Once you have made a decision about the kind of treatment you want, you should not look back. Have a positive attitude.

Comment made by individual:

Have a positive attitude. Make a decision and accept all the consequences and carry on. You only draw yourself down into a hole if you don't move in that direction. Life is only what you make it, if you choose to make it difficult for yourself, it will be very difficult, if you choose to get everything you can out of it, choose to see all the good things there are, you will have fun and you'll enjoy, there's much to enjoy and much to relish in if you want to. Do it. [18]

Now, on the positive side, it hasn't been all bad. It's been a life's experience that, in some cases, has been very good. I've become quite well known in the medical fraternity, in the cancer agency, cancer society and the prostate center, and I've made some excellent friends out of it, close friends. So, it's not all bad. There's positive aspects as well as the negative. [3]

It's embarrassing, but I think men have to get beyond that point to realize the situation there, if they have to wear pants, so what. You don't tell the world about that and it's not that noticeable. I just say, don't be ashamed of it. You have incontinence, you deal with it. Look positive on life. Attitude is a very big thing.
If you have a positive attitude, you can make things easier for yourself and you can overcome situations. A positive attitude. [11]

Category: Get your PSA done routinely (3/6).

Summary: One way to detect prostate cancer early is to get routine PSA tests.

Specific comments in this category are: get your PSA and DRE done [3]; it’s almost criminal that men are dying a horrible death because of not having just one test [4b]; men. get your prostate checked. [5]

Comments made by individuals:

Get your PSA and DRE done that’s for sure. [3].

Myself, I would feel a lot better if there was more emphasis on asking men over 50 and more years old to go and get a PSA test because we’ve been through that and we know that we are just a spec of dust, just a spec. We are only a spec and there’s thousands and tens of thousands of men who do have prostate cancer and they’ve never had a PSA test and their doctor is not pushing it and so on and so forth. It’s really, it’s almost criminal, really, that men are dying a horrible death because of not having just one little test. [4b]

Yah, what we are trying to do with the group is make prostate cancer, people more aware of prostate cancer especially the men, and ah, go into these different areas and having a booth there. You get a lot of men stopping that would normally not even think about their prostate, and ah, my question to all of them is, no matter what, even if there’s women around, I’ll say, have you had your prostate checked yet and they get a little embarrassed sometimes or they’ll come right out and say, I get mine done every, you know, and I try to push this into the community as a whole. Get your prostate checked. I had a talk with the Rotary Club here, and ah, first thing I said before I introduced myself is, ladies get your mammograms, gentlemen get your prostate checked. The first thing I think of is, men get your prostate checked. [5]
Appendix L

How priorities in life have changed for these men

Item: Trying to keep busy (1/10).

Summary: I try to keep busy and not think about it. [3]

Comment made by individual:

Golf, tennis, travel, yah, I’m having fun and I don’t spend a lot of time worrying about it, and that’s the truth, although, it’s there, I’m not saying I’m that carefree, I’m not. It still hangs over your head, but I’ve never been in depression, not even close. [3]

Category: I have more appreciation for life and others (3/10).

Summary: Prostate cancer has not stopped these people from doing the activities and things in life that they wanted to do. Specific comments related to this category are: I better appreciate things now [9]; I have become more closer to people [14]; I am more charity minded, and I want to give something back to the support group. [16]

Comments made by individuals:

Yes, truly. Learn a deeper appreciation, a better appreciation for things. I think that my daughter got married, she’s close to 40, 37 years old and she got married. I mean, that’s got a lump in my throat, I’m so happy, I’m so happy for her. She’s, you know, she’s found some fulfillment and the rest of it, and being a parent with three surviving and healthy siblings, with the grandchildren and the rest of it, what could be better, what could be better, and I mean, prostate cancer is nothing, it’s nothing, you know really. I mean I can do everything with these people that I did before. You know, I can get out and backpack and hike and fish and do whatever and it’s not going to affect me one dam bit. I’m going to be out there having fun with them and I’m not going to let it bother me, and like I said, my wife is my biggest support. I have more appreciation for her every day. When I see others at the support group, at the meetings and the rest of it, and I have friends that I golf with and the rest of it, that are having a poorer experience with it than I am. I
really have a lot of sympathy for them but um, and I'd do anything to support them, to help them in any way, you know, so. [9]

[Going through the ordeal, did this change your religious or spiritual views in any way, if it did?] Not religious. I was brought up as catholic and I’ve been very active in the church. It hasn’t affected my religious belief but it has a dramatic impact on the outlook that I have on life and on the way I live. That has been the, in fact, it’s been a very rewarding experience. I’ve become much closer to people. It’s entirely changed my approach, I used to be very hard, very aggressive, partly, I guess, because of my business background. I’ve been senior management, executive positions and now I talk to people in the streets, and when I get the groceries, I converse and I talk to people on the bus and I never used to do that and now I’ve discovered real people and I look at the birds and I look at the clouds and the sky do some sailing quite often and I try to enjoy everyday as it comes instead of planning 20 years ahead. I enjoy people and I enjoy living and that’s very rewarding. I really appreciate that aspect and it’s given me a shock, on the other hand, I think ah, I’m glad I’ve had that experience. I would recommend it to anybody, it’s very positive. [14]

Eventually you meet so many potential life-taking situations, I had two valves replaced and had Lymphoma three times, so I’m already starting to get an appreciation that life is precious and that’s something that seems to grow as I get older, because really through my adult life, the only hobby I had was business and ah it’s still my hobby but I know now I have some balance. I look at trees in wonderment and the sky etc. I can do those things, like stop and smell the roses, and ah, I work at a much slower pace. I’ve gone out on my own and it’s a much more relaxed pace, much more manageable. I can take control of my time. I’m in a position to retire and I don’t want to and I don’t intend to and from that perspective, ah, it’s different. Also, I’m much more, I call it charity minded in terms of prostate cancer, being active, giving something back. [16]

Items: More appreciation for others with traumatic experiences in their lives (2/10).

Summary: Now, these individuals appreciated more about what others had to go through in their lives while coping with a traumatic event. Summary comments are as follows: I have gained a little more appreciation for those that have gone before me [9]; I am more talkative about other people’s problems now.[15]
Comments made by individuals:

I think maybe I gained a little more understanding and appreciation for those that have gone before, and um, I have a sister-in-law that’s doing really well. She had a radical, both breast removed. They found a malignant tumor in one and she made the decision and had both breasts removed, and I think it’s got to be 15 years and she’s doing well, and I, you know I, you know your reaction in the first place is disbelief, I mean, how could a person do this. Yet you have this female, this image thing with females, and the rest of it, how could she have that and like her husband and their relations and how they deal with this, it’s a big part of this whole sex act and the rest of it, you know. I respect her more today than I ever did. [9]

[The last question is do you feel has it changed your priorities or outlook in life, going through this experience in any way?] I don’t know, maybe a little bit. You know, I’ve slowed down and am trying to enjoy life a little more, not be quite as worried about the little things and try to be a little more talkative about people’s problems. [15]

Items: I spend more quality time with my family (2/10).

Summary: Now these men with prostate cancer took time to slow down, and enjoy some time with their families: I take more time for my family now realizing that later may never come [10]; I take a special effort to snuggle up to my wife now. [14]

Comments made by individuals:

No, I don’t think so [in regards to whether or not if cancer has affected family relationships]. We were always a pretty close family. We are still a close family. I do think maybe, myself, I will maybe take a little more time than I did before. I had my own business before and I was always busy, and ah, and I always thought the business comes first and I’ll have time for this later, time for the family later, we’ll do this later, we’ll do that later. I realize now that later might not be that far away so the situation was right, that in 95 I sold the business so I’ve taken on different activities, but I do feel, like I’m involved with the seniors group. My term is up next year in May. I’m not going to get involved that deep again. I think I’ll want to focus more on taking quality family time, but I do take time now, more, for the family. Our relationship is still good but I feel personally, myself, that I take more time and more quality time. Like I used to go to some of
these things but in the back of your mind, you are still working on this or working on that or quick make a phone call here or make a phone call there. Now I leave the phone at home and I’m there. So in that regard, it’s changed but my relationship with my family was always good and still is good and they’ve been very supportive. They’re very supportive, but we’re not going to talk about it all of the time. We may not talk about it for months, but last week I went to the cancer clinic for test results and they’ll ask me, how did it go, but it’s not that we talk about it a lot. [10]

[Ah, has it affected your relationship with family in any way, kids?] There was a lot of stress before but it has helped in my relationship with my wife. I always had good relations with my children but with my wife, it hasn’t always been good, although I think that she supports me. I’ve changed my approach to life and I make a special effort now to snuggle up to her and avoid complicating our life, because she has, all of a sudden, become very precious to me. [14]

Category: I have always valued life and I try to get along with others (3/10).

Summary: These people stated that they had lived a good life. Some of the comments were: life has always been precious to me [11]; it certainly is very vivid of a time of appreciating everything that I have, but I have always appreciated everything that I had [18]; I have done what I wanted to do in this world so should I go now, I am not afraid. [19]

Comments made by individuals:

No, I don’t think so. We are still pretty well doing the same. Life has always been precious to me. If I was taken, you know, I’ve had a good life, and I think of all the other people out there who have gone through a lot of crap. So, no, my priorities have not changed. I’ve always been a family man, we’ve always done things together as a family and that was one of the reasons why I was very surprised that I got it. I just didn’t think that I lived the life that would warrant such a thing but, I thought as respectable people, we could handle it. It happens so, and I guess because of my family and my church life, I was able to deal with it, but I felt it anyway. [11]

[Besides what you just mentioned, has it changed your life, your philosophy of life or whatever in any way?] No, I don’t really think so. It certainly is very vivid of a time of appreciating everything that I had, but I’ve always appreciated everything that I had so in that context, it probably made things more vivid than they were before. Those kinds of things. Interestingly enough, I didn’t realize it
but a lot of people indicated to me that I have a very positive attitude and I don’t understand that because I don’t see, myself in that context at all and the first time it happened to me I was in an elevator, and it was an employee, another employee in the office with me and they complained to me about my positive attitude and I said what the hell are you talking about, I’m just an ordinary guy, and, but I thought about it a little bit and I tend to look at other opportunities for situations that maybe other people don’t look at, not everybody, but some other people may look at things in a negative way and they’ll say, what are the other possibilities of this. That’s a negative situation but are there any positives that you can take out of this that might be beneficial to you, because everything that we do in life, there are negatives and positives and can we see the positives or are we stay on the negatives. I suppose I’ve done those kinds of things and didn’t know I was doing it, but it wasn’t really a conscious thing, my point of view is, just something I just did and ah, I don’t do anything now differently in that context. I try to be who I am. I certainly don’t want to be a fake. In other words, I don’t tell people, oh, you’ll be alright, knowing very well that it’s not going to be alright. Like there’s a guy here today, his name, is [name of person withheld], he was just talking to me. He was telling me his PSA is rising, it tripled over a period of three months. I just asked him, are you seeing your doctor? I didn’t tell him he’s got a serious problem, but what I said, I recommended he see his doctor and not leave it for a whole lot of time. I know he has problems, but I don’t know all of the details, you see, but I think if he goes to a doctor, he may find out those kinds of details because he’ll ask him many more questions, he’ll do some more tests and so and so forth to see where he is at. [Wouldn’t his doctor know because who would prescribe him the PSA?] Well, I don’t know because he spends a lot of time in the US, so you can go into an laboratory in the US and get a test without, necessarily, getting a doctor’s prescription. Here in Canada the only way you can get a test is you have to have a doctor’s requisition, so that may not be the case in the US. So, I didn’t ask him that particular question, but he says he has that information. Well, he may have a lot of other information and some of the things that he’s telling me are not really right and that kind of stuff. So, we have to look at it, you know, the fellow we were looking at was riding his bicycle and the next day he goes and gets a PSA test, and he says, why in the hell is this two points higher than it was the last time I had my test, you know, that kind of stuff. When you don’t know that kind of stuff until you start asking a whole lot of questions and start taking measurements at regular intervals to find out what’s really happening, but the important point, at least I think, in the whole exercise is, hey, I think it’s time you go see your doctor because I’m not sure that whatever you have is good news. So that’s the kind of thing that I think that’s helpful. There was supposed to be another guy here today, who is depressive, he’s got a very depressive state, in fact, he attempted to commit suicide a couple of times, and he is having difficulty getting out of the state of depression, so I invite him to come. I don’t think he did, so, what can I do, but ah, what I was after, in his case, is to look in the eyes of those people that are here. How do they feel? Do they look depressed? Are they depressed? Then you should ask yourself, why should I be depressed? These guys seem to be carrying on, why can’t I, and I think that would pull a guy out, or at least I think it would, I’m not sure, I don’t know
enough about psychology to, in that context, to see if it would, but it seems to me that depression is an extremely difficult state of mind, but I think the most value in a depressive state is to see that other people can carry on with your kind of situation and be relatively happy about what is going on and happy to be around for tomorrow too. So there may be other ways of dealing with it, but I think that’s one of most effective ways. [18]

Well, I guess, I just have to take things philosophically. I’m at an age, I have enjoyed myself, my life, I have done what I wanted to in the world and if I should go, I’m not afraid of it. I’m prepared. The only think like everybody else, is you don’t want to have heavy pains or suffer heavy pains before you go, that’s all. I guess, you don’t know when the day is going to come so you try to live each day at a time to the best and enjoy it the best you can. [19]

Yes, I have changed life. I take it as it comes. I like to get along with people. [22]

Item: I have an attitude of helping others even during my work (1/10).

Summary: This person even helped other individuals at his work.

Comment made by individual:

Yah, when you are hit by something like cancer, because I think a lot of people, they don’t just say prostate cancer, the first word that comes to mind is cancer, you know. Cancer that means it can be devastating to a lot of people. Some people they go to the doctor and they say, you have prostate cancer. They don’t hear the word prostate, they hear the word cancer, and they are shocked, you know, and so you say, me, I’m going to fight it and I’m going to survive it and I am going to overcome it, and that, again, is your attitude, you have to have a positive attitude, well this life is work but it is also to enjoy. You have to have time for your family, your friends, your church, your community and so on. You can’t say, I’m just here just to make business. When I see a client, it’s not just to make business, I’m doing the job because I believe I’m doing something important for him and his family so the pay cheque is different. I want to say that we do have people in this office that they will do the business, they don’t care what it is, but you can not do it yourself if you do a job that is important for other people. [13]
Appendix M

Question: If having cancer has changed your relationship with family members, how has your relationship with family members changed?

Item: After cancer, as a family, we have been brought closer together (2/7).

Summary: A summary of the comments under this category are: I think prostate cancer has brought us closer together [5]; now, I spend more quality time with my family. [10]

Comments made by individuals:

No change whatsoever, if anything, closer. We are a very close-knit family. We get together, probably, maybe, once or twice a week and ah, have breakfast together and whatever. Talk about things that are happening and our grandchildren come over once a week, type thing, and there’s four of them so they take up a lot of the week and they come over and stay with grandma and grandpa.

No, I think it’s brought us closer together. [5]

No, I don’t think so [in regards to whether or not if cancer has affected family relationships]. We were always a pretty close family. We are still a close family. I do think maybe, myself, I will maybe take a little more time than I did before. I had my own business before and I was always busy, and ah, and I always thought the business comes first and I’ll have time for this later, time for the family later, we’ll do this later, we’ll do that later. I realize now that later might not be that far away so the situation was right, that in 95 I sold the business so I’ve taken on different activities, but I do feel, like I’m involved with the seniors group. My term is up next year in May. I’m not going to get involved that deep again. I think I’ll want to focus more on taking quality family time, but I do take time now, more, for the family. Our relationship is still good but I feel personally, myself, that I take more time and more quality time. Like I used to go to some of these things but in the back of your mind, you are still working on this or working on that or quick make a phone call here or make a phone call there. Now I leave the phone at home and I’m there. So in that regard, it’s changed but my relationship with my family was always good and still is good and they’ve been very supportive. They’re very supportive, but we’re not going to talk about it all of the time. We may not talk about it for months, but last week I went to the cancer clinic for test results and they’ll ask me, how did it go, but it’s not that we talk about it a lot. [10]
Category: No change happened in the family (3/7).

Summary: These individuals stated that their families had stayed intact, and in fact nothing had changed in their families: nothing has changed in our family. [8,15, 22]

Comments made by individuals:

As my wife says, nothing has changed in our family. [8]

[Did it affect your family relationships in any way going through this experience?] No, I don’t think so. No, no, I don’t think it had much impact on my family life at all. [15]

I had no change in the relations of my family or friends. Some of my friends have gone (passed away) and I miss them. [22]

Item: Children were afraid that dad may die (1/7).

Summary: A diagnosis of cancer is scary, and my children were worried that their dad may die. [11]

Comment made by individual:

Initially, a little bit. The kids, the children, you know, they, cancers scary and they think they are going to lose a parent and there’s a lot of hovering and wanting to do things for you, but once, like I say, two years now, two plus, and things just kind of got back into the norm. We all think dad’s going to be around for awhile so we’re doing everything normal. I would think not to much has changed in our lifestyle and what we do for each other. The youngest [children] is 32 and the oldest is 40. [11]
Items: I want my family to be educated about it (2/7).

Summary: These people believed that they wanted their families to be educated about prostate cancer because they did not want their families to suffer: I am making sure my family members don’t end up on the short end of the stick [11]; I want to make sure that my sons will be aware of the dangers of prostate cancer.

[13]

Comments made by individuals:

It’s kind of a negative thing but the beneficial part of it for my family is there, there’s not that much information out there, in trying to keep them ahead of it so they don’t end up on the short end of the stick, shall we say. I would say that’s the best that I got from it. I survived and I am surviving and I’m keeping my family, children, brothers, uncles informed of it and ah, I just give information. [11]

Well, I just want to make sure that my children, especially my two sons, will be aware of the dangers of prostate cancer that they will make sure to check into it and so on. Ah, you want to make sure that you are going to survive and be around for awhile. You want to make sure that you keep in contact with your doctor and get tests and so on, because you want to have your family around and you want to see your family see you and growing. [13]
Appendix N

Suggestions for improving the system

Item: They should keep you longer in the hospital (1/2).

Summary: An individual gets better care in the hospital.

Comment made by individual:

Yes, they send you home right away after the operation. I think they should keep you there for one or two days for an observation. The kind of care you get at the hospital is not the same at home. For example, at home you have to carry all that system (catheter?) with you. [23]

Items: Provide more education about prostate cancer in Punjabi (2/2).

Summary: These people believed that there needs to be some discussion about prostate cancer in Punjabi language: the medical community should have discussions about this at the Punjabi Senior Centers [23]; the medical professionals should have question and answer sessions about prostate cancer in Punjabi [24].

Comments made by individuals:

They should have discussions about this in Punjabi at the senior centres, where individuals can talk about what has helped them- although I have never attended senior centres. For example, about ejaculation difficulties, the doctor didn’t tell me until I inquired about it after the treatment. [23]

What may help is if there were questions and answers in senior centres in Punjabi language. I have a language problem. [24]
Items: I did not attend a support group (2/2).

Summary: These individuals had very little information about the role of the support groups: I don’t think the support groups can help me [23]; no, I have never attended, where does this group meet? [24]

Comments made by individuals:

No, I never have. There is no time for them. I don’t think they can help me much. I have seen their pamphlets though at the doctor’s office. They collect donations there. Is there any remedy there also, do they tell about treatments too? [Sometimes the have a urologist there and sometimes they have a herbalist that provides information as well].

No, I have never attended. I have gotten an Indian aurovedic medicine (chandarparbhaveti) but I have not used it yet. [Have you read information in Punjabi about it?] Yes, I have and I have read them. [23]

No, I have never attended any support group. Where do they meet? [24]
Appendix O

A summary of the written comments provided by the individuals

These comments were provided at the end section of the questionnaire that contained the psychological scales.

Please note: Each comment may include only some aspects from each category. The number besides each category is a code number that was assigned to each individual, and this code number is different from the qualitative data. For example, two individuals with #1 are not the same individual in qualitative and quantitative data. Each individual’s comment was also put in the category where the person himself had put their comment, and no editorial changes were made to any of the comments. Since each comment contains so many aspects, I thought it would be useless to divide each comment into many different categories. Therefore, the emphasis was not on how many comments were made in each category, instead, it was on the summary of the comments individuals had made. Moreover, all the comments have been included in this appendix so that individuals with prostate cancer or other individuals may benefit from the stories shared by these individuals. Also, this provides opportunity for other researchers to come up with their own conclusions as to what this data may indicate and to confirm or question this study’s conclusions. In the following comments, nine individuals (numbers 16, 29, 47, 48, 68, 70, 75, 78, and 83) did not provide any comments.
Question: If having cancer has changed your view of the world, priorities in life, or life in general (either in a positive or negative way), please describe how your view of the world, priorities in life, or life in general has changed...

Summary: These individuals answered the above question as follows: Each day is a gift and because of my experience with prostate cancer, now I have: greater appreciation for life; greater appreciation for health; greater appreciation for relationships, lesser significance for material things; greater compassion for people dealing with life issues, and strengthened faith in God. I help out at the support group. Proper diet is important for me. I have researched more about prostate cancer. I look at my whole environment (mental, physical and emotional) now. People should live their lives with less concern for material things. I still feel lucky compared to people who have more serious illnesses such as blindness, and MS. Also, I realize my own mortality more now.

Comments made by individuals:

#1 I have changed my outlook on life! I see myself trying to help others with cancer. First by accepting the role as Prostate Support Group Facilitator in [name of city] BC for the Canadian Cancer Society. Things just seemed to fall into place. The present president in 2000 retired back east to [name of place] and asked me to take over the position. I have been enjoying both jobs for 2 years now. Helping others is very rewarding. I volunteered my wife for the job of office manager and she said yes. We had made a good team for 36 years.

#2 Being diagnosed with cancer is a wake-up call. Life can be very routine and taken for granted. After surgery and recovery, it is easy to fall back into the same routine and to some degree I did. However, I do have a greater appreciation for health. Each day is a gift. I have a greater appreciation for my relationships—especially kids and the grand kids. Dealing with cancer (any threat) pulls a family together as they deal with it—giving added strength. Material things have taken on a lesser significance. I have gained a greater compassion for people dealing with life issues and try to offer encouragement and hope. I believe I have become better and stronger person because of it. It has strengthened my conviction that I am not always in control of what happens to me— that there is not always a defineable
reason for things that happen. It has also strengthened my faith in God. I also leaned to value our medical profession.

#3 Cancer has made me appreciate life more and enjoy the beautiful things of this world and the company of family and friends. I try to help other people who have diagnosed with cancer to realize that there is light at the end of the tunnel + keep a positive attitude.

#4 I now appreciate more fully the dedication and caring provided by the BC Cancer Clinic. I also am more aware of my family concerns about my health and their support during treatment etc.

#5 I don’t think cancer has changed my view of the world. God has all things in his hands- including my life. Having cancer has reinforced in my mind to make the most of each day. It also has caused me to take some more time for family- such as visit our children, build relationship with my grandchildren etc. It has forced me to realize I may not live to be a very old man. I may only have 5-8 years left. I want to have my family remember me as a dad who cared- not as someone who was always too occupied with things to spend time with them. Things that used to be important are not so any longer.

#6 Having tried retirement before without success, I now decided to definitely retire and spend some of my savings on the things+ toys I like.

#7 It hasn’t changed my view in anyway. Life is about making choices, often unknowingly, that effect our future. Life isn’t fair as far as consequences are concerned but I live in a world of serendipity and don’t get upset very easily. Usually out of the most upsetting of situations positive growth results.

#8 My life is in God’s hands and I trust him to do what is right for me.

#9 I’m very optimistic about the future in general. I’ve lost a very small part of my anatomy, which has made a big change in my sex life. Nothing is forever and I’ve accepted that. I count my blessings daily and feel very blessed. Good and forgiving wife, three children of which I am utterly proud and four grandchildren (hale and hearty) who are a pleasure to us daily. How could life be better?

#10 Good physical health is more important. Proper diet is important. Enjoy life- holiday, golf, worry less. Concern about inability to perform a normal sex life- pump works but does not tally take the place of a normal sexual relationship.
#11 Life is short- can be even shorter. We must make the most of it- the best of it.

#12 My life style has not changed. I am volunteering much of my time with Man to Man Prostate Cancer Support Group. Our mailing list is over [?] I get a great deal of satisfaction from helping others cope with Prostate Cancer.

#13 Lucky that the prostate cancer was found early and treated with Brachy therapy. Second major problem in 2 years. Had an emergency Colostomy in August 2000 had a bag for 5 months [word?], lucky to be alive. Appreciate family & friends all the more view of the world remains the same as before. Always thought priorities in life were ok. As I get better will take up my exercise program more often. Expect to lose 10 pounds in the next 6 months.

#14 Each day I wake up, I feel that I should try to make the most of it. Normally I have a very positive attitude. The fact that I have cancer, have been treated, but my PSA is rising does concern me. I keep hoping that perhaps the trail medication, Atrosenten [?] will slow and stabilize my PSA at a certain level. There doesn’t seem to be any sideeffect so I may be on the placebo. I dread the day when I will have to start hormone therapy. I am disappointed in my family doctor, who I’ve been seeing for an annual medical close to twenty years, checked me regularly for the past ten years (DRE) and did not suggest that I have my PSA checked. I only learned about the PSA test after listening to talks by Allan Rock and Preston Manning and their experiences with prostate cancer. My next visit to my doctor, I asked to have my PSA checked.

#15 Cancer diagnosis and treatment is an industry no different than the “weight loss” business. Standard medical practice attempts to identify and eradicate symptoms while ignoring the patient’s environment which likely continues to compromise their immune system – the precursor to disease. My cancer diagnosis was likely unnecessary, premature, supported by limited knowledge and alternatives by the cancer community, caused me severe difficulties with my spouse, family, friends, employer and indirectly resulted in my losing my job. I trust myself more now. I look after my needs more than I did previously. I am healthier than I was previously.

#17 My life has become centered in a major way, on treatments/ therapies for prostate cancer. For 8 years, I have conducted research (many hours each week) using medical journals, conference proceedings, clinical trial reports, etc. so that I could bring current information to the members to the members of the support group I started and still chair. I’ve attempted to get clinical trials started in [name of city withheld] to prove or disapprove the efficacy of certain complimentary/alternative therapies. I have had some success but, also, much disappointment with our medical system ( or should I say “cancer industry”). My support is, I believe, the only one for advanced prostate cancer patients; thus the questions, requests for obituaries that come my way certainly have altered my view of life patterns and priorities. People should live their lives with less material concerns.
#18 I think that more men should open up to prostate cancer and be aware at age of 40 years demand check up and talk about it. Then we would have less chances of it.

#19 I realize I am just as vulnerable as anyone else to disease- I'm not infallible- only God is therefore it has increased my faith in God and how fragile the human body and life really is. My experience has given me the desire to help others in a similar situation by being involved in a Prostate Cancer Support Group. My priorities in life has not changed: #1 God, #2 family, # friends and others.

#22 Any change was mostly brief. I feel that I am cured! I've gone over 3 years with no sign of recurrence (undetectable PSA). There is perhaps a bit of residual feeling that I should do things I want and enjoy now, rather than waiting, but then again, I'm at an age where I should feel that anyway (I'm looking forward to retirement soon). I feel lucky to have been detected at a time when it was totally curable. I try to encourage the guys I meet at the support group that it can be that way for them too.

#24 Having had prostate cancer and having successful surgery was a very difficult time for me. But after 12 years things are long ago back to normal for me. At present (age 75), I realize that I may not have many years left and the closer I can live to the Lord the better. I have never lived for money or material wealth but the Lord has allowed me to have a share of both. Recently a good friend of mine died of prostate cancer and this has caused me to be even more thankful for the good health I now enjoy. The events happening on the world scene are indeed shocking to say the least which causes me to realize that only spiritual things are really worth while.

#25 I am more aware of the importance of time and the use of it. I appreciate more the need for close ties to family and friends. I feel a desire to volunteer and help others in similar conditions. It has also reconfirmed in me the connection to my religious beliefs.

#26 I have always have been a very positive person. Never have I felt that my life was over because of prostate cancer. I never felt sick in any way & subsequent to surgery I felt great. I look forward to many years of health and happiness.

#28 At the onset of the disease, or very soon after, I realized that Canadian male residents (or the great majority of such men) feel ashamed of their disease and they will not readily disclose the facts to their fellow citizens. The result is that the public is not aware that prostate cancer is as common in Canada as breast cancer. The end result is fewer dollars for prostate cancer research.
# 30 The things that got me to come terms with my cancer were having my wife and oldest daughter who is a RN sitting in my hospital room explaining what the doctor and nurses said and realizing that the only way to cope was to take each day and event as just another day and another event, and just keep going. I like one liners- Good health and good habits are the slowest way to die, and –None of us will get out of this life alive. It’s one day at a time.

#31 I have learned that you can not expect the medical system or procedure to fix you up. You need to take charge of the situation, and you need to do more than what the doctor does. Treatment is ok but uncomplete if you want to feel better you need to change your lifestyle, our diet is the primary healing medium.

#32 Expect that anything can happen and deal with it.

#33 I have really learned to live for today, to enjoy the moment and make the best of life.

#37 Family life has become more important than work life. Time with family is very important. I take time to smell the roses no matter how small they may be. I tell my wife, “I love her” more often. I encourage men to get their PSA checked once they reach 40.

#39 I was treated just over 8 years ago. It now appears that I am having a recurrence but that has not yet been confirmed at this time. I am a little unhappy about having to deal with the cancer again. From year 2 to ? after treatment, I was very positive about the outcome. My life came close to what it was prior to the original diagnosis. I was 59 eyars old when treated. Now at almost 67, I’ve blamed some of my feelings as aging as much as dealing with cancer. Our sex life has changed. Only occasionally do we have sex without assistance. Overall I felt life was good since being treated, but that has changed somewhat since my PSA has been increasing.

#40 Treatment has left me with bothersome side effects i.e. loss bowel control, tiredness (anemia). Have got involved with Prostate Cancer Institute and the Prostaid Calgary support group.

#43 I lost my wife of 69 years at the same time as I discovered I had prostate cancer after fifteen months I am now starting to adjust better to my own life and am coping better. I have a long standing friend who has now become a part of my daily life.

#45 I realize that no matter how well I try to take care of myself ie diet, exercise, religion, that there will be things and situations that I cannot control. I still feel lucky compared to people who have more serious illnesses re blindness, MS. I realize my own mortality more. I can really have a positive impact on those around me who complain of minor problems.
#46 Don’t think that bad things can’t happen to you. No one is exempt. Anybody can get cancer. Not being able to get a complete erection has taken from my manhood & ruined my sex life. I envy those people who can still have a sex life and have not been interfered with by having to have their prostate removed or treated because of prostate cancer.

#49 Health has become a major factor/priority where it had none before - not work, money, things. b) though my aims are similar to before, the time in which to achieve them has shortened. c) Cleaning house of side interests (committees, political associations, community events), d) Putting one’s things in order is now a priority, e) Wills, P. of A’s, funeral arrangements (pre-paid) are considered, f) Payments for non-covered drugs/treatment is a worry-major, g) Transfer of duties and responsibilities is being documented, h) Financial security of “surviving” partner is a concern.

#50 I have known that I had diabetes II since I was 24 years old and therefore I had to discover myself over the years and when I was diagnosed with Prostate Cancer, I vowed to take whatever action was necessary to reduce my problem. It was a shock, initially, but then my sisters died of cancer, one with breast cancer and the other bowel cancer. The one thing that really upset me was the urologist calling me into his office alone and giving me the news. My wife sat outside in the waiting area. He said that I have prostate cancer and I asked, “You mean it’s malignant?” “Yes it is and I was asked to find it and I did. I want you to see {urologist’s name) and he will set up the date and time of your operation.” “Thanks doctor.” And I left his office, told my wife as we walked out of the waiting area. My wife has been 100% supporting my situation. Our children are spread right across Canada and can only ask how I am doing. We have changed our diet slightly but we never did eat or drink in excess. It has been years since we chomed into a big steak at The Keg or anywhere else. Nothing has changed as far as world views are concerned. We have to live with what goes on in the world, ie Gulf War, Iraqui war this year, Israel and Palestine conflicts etc. My wife and I have been writing extensively to keep our minds active along with doing oil or acrylic painting for the last nine years. This has been pure pleasure during my retirement of 13 years. I keep active within our apartment complex by serving as president of the Men’s Club, work in the workshop and of course walk my dog three times a day. It took a while for me to get back to my endurance level but I am there now. The one thing that has really hit me and that is not working more than one and a half hours physically in the workshop. I spend a good deal of time on the computer but get up several times to keep my body functioning. I managed to write a novel of 132 pages. At night I am completely exhausted and for most of the time sleep right through the night. My objective is to live life to the fullest, help where I can until someone calls me to greater good or down to the abyss. You know what I mean?
Due to the fact that in my case, Prostate cancer can only happen to a man—as such we (men) don’t get involved with verbalizing our inner feelings. It find it is so hard to garner support, sympathy or any understanding for inner feelings of denial, anger, grieved while at the same time playing the role of STRONG MALE IMAGE. With living my life with having been more caring and giving. More caring for my own well being (health). Its disappointing to receive this [...] so early in life. I’ve always wanted to see and do throughout life however its more important to enjoy Now.

Changes in food consumption, lifestyles, and coping with stress related situations. In each of these areas attempts are being made to help the body cope with cancer and the related factors of cancer inducement.

I never gave much thought to death or mortality. My family enjoyed long, full lives. Death and serious illness happened to others and not to my family—parents and grand parents into mid eighties. Now the prospect of not living until retirement at 65 is very annoying but I accept that death comes to us all, sooner or later. My goal at the moment is to delay the inevitable and enjoy the time left. I no longer allow the work to consume me (difficult to do but trying). I want to make more time for myself and for my wife. My employees and coworkers have been very supportive and the owners of the company have been exceptionally supportive. My life and outlook is more positive than I expected.

Makes you think about being mortal.

Only thing is that if I feel like it is worth doing I do it now. Otherwise, I don’t do it. I operate as if there is no tomorrow.

I tend to want to get things done, just in case!

Gave me an opportunity to come to terms with life and how “precious it is.” Appreciate things more and realize that we are not in this world but only in this world. Gives me limited time to do the things that need doing from my perspective.
My experience has not so much changed my attitudes and priorities as it has reinforced and focused them. Because I was diagnosed 6 years after formal retirement from work, I had already begun to arrange priorities around family, health, work (at a lessively pace) and hobbies. I had already thought about death in a deliberatively positive way - as a kind of Buddhist extinction of self and selfishness through disappearance into the ultimate Principle. Cancer has made me more patient, more willing (since its recurrence) to think it as a management problem, and since I'm a goal-oriented person, given me a goal to help deal with the uncertainty of ageing and of cancer's progress. I'm aiming through treatment to manage and control my cancer until I'm 85. After that, from what I understand, cancer growth is very slow and one usually dies of something else. That was the case of my mother who died with cancer but died of old age at 92.

I am having marital problems at the same time. These have been ongoing for some time. These are the cause of more of my anxiety than the cancer. I have resolved to do something about it but things are still tumultuous at home. These problems affected my answers to your survey. I am spending more time with my children/grandchildren and aunts/uncles than before. I think that is the good effect of having cancer. I expect that my wife & I will separate and this will be a big change in my life style (probably lower) but I expect I will be happier. I do not blame anyone for my cancer, bad-luck, good-luck - it was found early - good treatment by my doctors.

It is very important to live in the moment because that is all we human beings have. Enjoy our family while we can.

I have certainly changed my priorities in life. Where I once spent all of my time working, I now take time for the little things. I would once work all day, come home; change; go golfing or to hockey; then home to bed. Now I spend more time with my wife and family.

Because my prostate cancer diagnosis followed so closely my need to have quadruple bypass surgery, my priorities in life have changed dramatically. I know that I could have died from either diagnosis and appreciate life much more now than before. My wife and family was important to me before - it has become even more important to me - more important than anything else in life!

Cancer has changed my way of life and work was my life and now I have taken a slower path.
I have three survivor health challenges: 1) Prostate cancer (had surgery May 17, 2000) 2) Diffuse Triple Vessel Disease (heart condition and surgery isn’t an option to due to the potential blockages 3) Myeloproliferative Disorder- bone marrow disorder. It take Interferon for this disorder and it is working positively. I changed my life style in 1995 after a heart attack (diet, exercise, meditation, etc.). This process has helped me cope with the other challenges that came along subsequently. I enjoy life more now than prior to my life challenges, examples: family (mainly grandchildren); church; free masonary (fraternal organization), neighbor and friends (golf, exercise etc.).

I think following having prostate cancer—one appreciates each day more. One’s priorities change somewhat, “what one thought was important prior to surgery is less now.” Life in general has changed somewhat i.e. sex life. Although I wasn’t that active it is a huge change in one’s life style and relationship with your spouse. She has to sacrifice an important part of her life as well. I know there are items available to assist one in this area but both parties must be patient.

Doing things we would have normally not done- like traveling and spending more money! Trying to do as many things as possible while still able: “New attitude about life and how good it is! We appreciate everything more! A real attitude adjustment to the positive.

I have often felt I was a fatalist, therefore my view of the world has not been altered because of Prostate Cancer. I am certainly doing things more deliberately because of my situation, but not to change my life, but to be aware of the melody. All in all, I am pleased with my procedure, and I am quite content with life.

I had lived in Ottawa for 43 years. I was feeling bored and in a rut. After cancer diagnosis and treatment, I decided to move to Vancouver. I sold my condo, my car, and most of my possessions. I moved to a small rental apartment in downtown Vancouver with the aim to live as stress free a life as is possible. I am very happy here. I travel extensively (as I did previously) and never give my cancer a thought. Other aspects of aging (deteriorating eyesight and hearing for instance) are of much more concern.

My sex life has changed due to impotence and incontinence as the result of having radical prostatectomy. Although this is not the best situation to be in, it could be worse- I am still alive.

Every aspect of life, either negative or positive in sickness or health, I accept it out of the hand of my Lord and Saviour, and I know that he is the great healer.
My view has not changed:

#20 I don’t feel my view of the world has changed because of my bout with cancer. I am a professing Christian and my faith has and continues to sustain me. I am very much the same as pre-cancer/ post-cancer.

#23 Always have been a positive thinking.

#27 My view of the world has not changed because of the cancer, except I wish my doctor had taken the trouble to order PSA tests for me. Initial one was 31.4 gleason 8/10. I was very disturbed when first diagnosed since I was so ignorant of the disease, but since getting information on it, and receiving treatment, my PSA is very minimal now. I have excellent doctor treating me, and I put my trust in them, knowing that if prostate cancer doesn’t get me something else will. I am enjoying life to the ultimate. I seldom think about prostate cancer. I am too busy enjoying too many activities in my life and am hopeful I shall be able to enjoy them for years to come.

#34 Life hasn’t changed much except our sex life.

#35 Just stayed about the same. Just no sex.

#36 View of the world has not changed. I now have new focus because of my cancer:
   a) learn as much as possible about it. B) Adopt healthy eating habits. C) Take supplement and complementary treatments.
   b) D) Counsel others in their prostate cancer treatment options.

#38 No, it has not changed my life in any way.

#41 I don’t feel that having cancer has changed my priorities or view of life. I have had other health problems before I had cancer, which made me face my own mortality, and I have always been somewhat contemplative and have always valued life highly.

#44 Has not changed.

#60 Having cancer has not changed my outlook towards society in general, family relationsh and my relationships with friends. Both my wife and I accepted the issue of having cancer as something one dealt with realistically and did all the right things (we felt) to deal with it. Our priorities did not change other than to adhere to a more modified diet. We’ve always followed a recommended healthy diet, and now follow a diet appropriate for cancer survivors. This is my 12 th year in remisision. Life in general has not changed.

#67 Not greatly.
#77 I think I have come to understand how “mortal” I am. I have always loved my family and friends- if possible, I love them even more now. I feel very lucky in my life.

#80 Nothing has changed. Life goes on and so do I.

#82 Very little if any.
Question: If you were to give advice to another person who was diagnosed with prostate cancer, please describe what advice you would give...

Summary: These men stated that one should seek out information, and others. A summary of their comments is as follows: There is hope, have faith in God. Be prepared to live with the side-effects. Seek out support at a support group. Take one day at a time. Don’t look back at your decisions. There are worst things in life than prostate cancer. Ask about side-effects of various treatments. Quit smoking and alcohol and eat properly a balanced diet. Discuss openly with your spouse. Be happy with the choice of treatment that you have made.

Comments made by individuals:

#1 Get as much information as possible. E.g. internet!, books, videos, meetings re prostate support, one on one support. Make your decision with your spouse or girlfriend.

#2 Diagnosis is not a death sentence. Prostate cancer is treatable. Get all the information you can. Don’t be afraid to ask questions. Seek out others who have gone through this process. Don’t be fearful. There is hope. Overcome fear with faith in God and in your doctor. Be positive. Seek out the best treatment option for you. Share with others- don’t try to cope alone.

# 3 Don’t feel like it is the end of your world. Lots of people feel like this when first diagnosed with prostate cancer. Support groups really help people get through the initial shock of being diagnosed with prostate cancer.
#4 Get all the information you can on the stage of the cancer and possible treatments. Use the cancer library the city library and any books or articles friends can recommend. Contact anyone you can who has had prostate cancer and discuss their treatments and results. Listen to any professional advice and take notes. Make notes of any questions you have and don’t be afraid to ask them. Discuss with your spouse and family and make your own decision on what course of treatment to follow. All treatments have side effects so be sure you are well prepared to live with the side effects of the chosen treatment. Keep as positive an outlook as possible.

#5 Stay positive! Get lots of information. Be sure you feel at ease with your doctor. Make sure you trust and believe them. Go to a support so you find out how others are being treated; how they are coping etc. Take one day at a time. Do not blame yourself or your doctor if things don’t work out as you expected. Make informed decisions, and don’t look back. Go to God in prayer. God is the great physician. He can guide the medical staff, he can cure you if he wants to. Learn to accept God’s will for your life. Read in the Bible all the great things God for us. Each new day is a gift from God. Perhaps God is using your cancer to help you see or experience a certain thing you would have missed otherwise.

#6 Fortunately this cancer has a very high success rate of cure. Go thru the treatment and expect that is the end of it. Most men die with this cancer but not from it. Go to support groups and listen to others who have been there. There are worst things in life than prostate cancer. Heads up, in a couple of months you will be your old self.

#7 Learn all about it, don’t become an ostridge. Join a PSA group. Get on a healthy life-style.

#8 Become as well informed as possible about prostate cancer. Read the literature. Go on internet to find the latest in research. Join a support group in your area. Prepare a list of questions you want your oncologist to answer. Ask about side-effects of various treatments.

#9 Please seriously read and study all available material before making your decision.

#10 If you drink alcohol or smoke tobacco or other substances- quit or do in moderation. Eat properly a balanced diet. Take diet supplements. Build immune system. Get opinion of more than one doctor as to path you should take to cure. Listen to what path others have taken- be strong- take your own course. Doctors specialize- do not accept that there method is the best- make your own choice after careful review of what other doctors say.
#11 Get as well informed as you can be from doctors, from reading, from support groups- so that you can make the best decision about your treatment.

#12 Education about all therapies is very important. Join a support group- try to attend all meetings and sessions. Be sure you have someone (wife) attend all doctor appointments. List your questions on paper before attending the doctor’s office.

#13 Educate yourself to all the options and side effects. Join a man to man support group. Awareness is important. Talk to people. Do not keep this to yourself. Take someone with you when you see a doctor. Get a second opinion or a third if necessary. After you make the decision do not second guess yourself. Keep your family informed. Follow the doctor’s advice.

#14 I would not give them any advice. However, I would tell them of my decision to have surgery and how to this day, I don’t regret the decision, even though I am not cured of cancer. I would suggest that they commence an exercise program, continue with Kegal exercises and eat a healthy diet. I am still hoping to lose 10 to 15 pounds. Lost about 15 pounds since the time of my diagnosis of cancer.

#15 Even in the most serious cases intervention by traditional practices will likely only produce short-term (less than 10 years) suppression of the symptoms. Your cancer will go into permanent remission as you improve your health. Cutting out or irradiating your cancer without improving your environment (metal, physical, nutritional) will allow the cancer to return or exhibit elsewhere. I see this across all cancers. Patients are being encouraged to make life-affecting decisions without adequate understanding nor time to contemplate what is best for themselves- not the medical system their family or employer.

#17 Seek as much information as you need to make your own decisions as to the best treatment option for you as an individual with certain needs, priorities, health considerations, etc. Take responsibility as the person that “calls the shots.” Live your life in a way that makes good use of the time you have.

#18 Go for check up 40 and up.

#19 Determine your options- Do research- by internet or other means- join support group to hear other experiences and professional info. Involve spouse and family in your decision. Make contact with Canadian Cancer Society- for books and information on subjects. Be positive and change eating and exercise habits. Be informed. There are more survivors than not.
#20 I would urge him to research the prostate-cancer subject as thoroughly as possible there is a lot of information on the subject). The doctor (urologist) is the expert and you should be very frank, candid and inquisitive in gaining the best understanding possible! Discuss openly with your spouse & close family members your feelings and seek their feelings. Make things as transparent as possible. A belief in God is the greatest comfort!

#21 Think positive. Look for the good things. There is a very good chance that you will come through this ok. Find a good support group. Keep active. Do not stop living, there are many good times ahead. With time, all things get better.

#22 You have some time to make a decision on what to do about it. Do your research, get other opinions, etc. Assess it according to your particular situation with respect to lifestyle etc. Make a decision and then stick with it- don’t second guess. Tell your brothers and sons about it- your friends too. Tell them to get tested.

#24 Yes, and I do. If you are over 40 be sure to have your yearly check-ups. PSA is a wonderful tool to pick up early signs of cancer. That’s how my cancer was found in a yearly check-up. Check-ups likely saved my life. Don’t play with gimmick treatments. Stay with the regular recognized treatments- either radiation or surgery.

#25 Inform yourself well of all aspects of the disease. Get the best medical advice available. Join a support group. Explore all available options for treatment, including alternative/ supplementary approaches. Review / change diet and lifestyle (low fat, exercise etc.). Don’t panic, the majority of men diagnosed will die of other causes.

#26 I would state these facts:  
  a) There is sex after treatment.  
  b) You probably won’t die of this disease.  
  c) Embrace a health life-style (exercise and lose weight).  
  d) If you smoke, quit.  
  e) Be positive, enjoy life.

#27 Get all the information that you can, join a support group.

#28 Do not panic – a cure is possible. Without a cure, life can be extended. You decide the mode of treatment not your medical advisor.

#31 I would tell the person to take the treatment recommended after your own treatment confirms that decision. Then decide to get better, defeat cancer by a date, e.g. I year from now, I will be cancer free. Then cut out all sugar, all manufactured food, all meats, all soft drinks all alcohol. Eat loads of fruits and vegetables everyday take supplements and believe you just beat cancer.
#32 Have it removed by surgery.

#33 You won’t die tomorrow. Seek the best treatment option for you, go for it and be happy with your choice. Don’t later think, “I should have…”

#34 Be treated as soon as possible and join a support group and then you know you’re not alone.

#35 Find a good doctor and put your trust in him.

#36 Explore all options for treatment personally and do not rely on your physician to guide through the decision making process.

#37 Get as much information as possible on various options available to treat prostate cancer. Join a support group and do not be afraid to ask questions. Choose the option that feels right to you. Talk it over with your spouse- she is your greatest supporter. Keep the faith.

#38 Go to a good doctor/ specialist. Avoid all alternative medicines.

#39 Research the modalities of treatment. Talk to as many people as possible who have dealt with prostate cancer to get input. Be as confident as possible with the doctor you choose for treatment. Stay as positive as possible. Prostate cancer doesn’t mean that life is over.

#40 Learn as much as you can about the disease and the options open to you for treatment. Get involved with a local support group. Make a decision on treatment.

#41 Try to have contact with other men who have experienced prostate cancer.

#42 Gather as much information as you can on the subject and treatment, then decide what course of treatment is best for your situation.

#43 Keep your chin up, things can get better “Today is the day that I worried about yesterday- and all is well.” Find out all you can about alternative treatments.

#44 I would and have advised any of my acquaintences to get lot of information before committing to any procedure. The result of my radical surgery was complete incontinence where I had to eventually have a cutt (cuff?) installed. This is still less than perfect but I live with it.

#45 Do as much research as possible. Tell your friends and family as soon as possible. Challenge your doctors to think hard about your treatment options. Be as optimistic as possible. Include your spouse in all decisions.
#46 Decide what treatment you want and have the treatment. Don’t put it off. The earlier a treatment the more likely a cure.

#49 Read sufficient info to make a decision re treatment. Treat doctors as navigators but CAPTAIN your ship. Seek out various remedies. When treatment decided, do not second guess it. Form a support group. Attend regularly. Keep a positive attitude throughout.

#50 My advice to people who are diagnosed with prostate cancer is to deal with it ASAP and get the necessary treatment whether it be prostatectomy, radiation or Brachytherapy, get it done. The unknown is worse than not doing anything about it.

#51 Join a support group such as Man to Man or wellspring.

#52 Because this disease affords us up to five options to for a plan of attack its imperative to get as much information quickly as to one’s awareness. In my case, I was only given information piece meal as was relayed to me by each doctor’s speciality. Even at that, I doubt long term facts are not yet available as to the percentage of hazards along the way.

#54 Get into a good physical condition prior to having surgery. Establish a sound faith and belief focus. Maintain a health lifestyle.

#55 Depends on the age of the person. Gather as much info. as you can and make an informed decision about your treatment. If all goes well with my upcoming surgery, I hope I can recommend this treatment.

#56 Think positive. Take control of your situation and treatment. Do not allow yourself to be rushed into alternative decision. There always is hope. Look to living with PC- Do not focus on a cure. Become as knowledgable about PC as possible. Ask questions, build a network for support. Look at complimentary and alternative therapy. Do what seems reasonable and affordable. Gives you a feeling of control. Keep your doctor fully appraised of your alternative efforts. Buy a lotto ticket- who knows you might get lucky. Do not deny yourself some quality of life- eat and drink what you like but in moderation.

#57 Find out about all possible treatment options. Make your own decisions on treatment after doing your own research. Do not rely entirely on only one medical professional.

#58 Weigh all your option make a decision and don’t look back or second guess your decision.

#59 There can be a good productive life style after prostate cancer treatment. However, treatment should not be delayed.
#60 Be a member of a cancer support group and seek as much information involving your own cancer as possible. Communicate with others who have been diagnosed and exchange details with one another. Seek emotional support if none has been forthcoming. Get professional help in this regard if difficulties arise. This is perhaps a difficult time in marital relations where stress is evident. Keep active—do not dwell on perceived consequences. Exercise regularly and work at it. Have a good diet as recommended by health professionals for people diagnosed with cancer.

#61 Don’t panic—join a support group and learn the best path to take—also bear in mind this cancer is slow growing. Everyone is different.

#62 Research information on your condition and connect to a support group whenever possible. Spirituality could be of great assistance in handling matters of this nature.

#63 I’d suggest 3 things: 1) A positive attitude 2) Information 3) Naturalness when talking about cancer to others. It’s imperative to accept your cancer as a natural and inevitable part of the process of aging. Of course this easier to do if it happens in your 70’s and not in your 50’s, try to stay on an even keel: don’t rashly think you’ve beaten cancer, it will come back and don’t dwell on treatment choices you’ve made that might not have been the best. 2) Inform yourself—really listen to those who have been there, formulate good questions to ask your doctors, make informed treatment choices. 3) Speak naturally to loved ones and others about your cancer. Help them to get over their terror and taboos. Joke about it when you can.

#64 I trust my GP very much— I talked to him about my choices ie surgery vs radiation—also talked to another doctor friend. Both asked what my choice/leaning was then agreed that they would have it removed. I did the “Net” thing but it is too big & overwhelmed me with info. The brother of a friend was diagnosed recently. I told him of my experience but made no recommendation. Only told him why I made my decision. My surgeon stated that if I had surgery I could still have radiation later if needed but if radicated- no option for surgery later.

#65 They can recover in time if they stay positive and get involved with the support group survivors.
#66 If I were to give advice to someone else. The first and foremost thing would be to get yourself to a support group or talk to someone who has experienced it. I certainly wish I had someone, although the day I was diagnosed, we had a man come to our house and tell us everything he went through, from the hospital stay, to the incontinence problems, to even the sex. We (my wife and I) were very thankful to this man, whom we both knew, but not very well. Don’t keep this diagnosis to yourself, talk to someone, find out your options. And if you go to a support group or talk to someone, bring your spouse with you, as this cancer is definitely a couple thing. If you have any brothers, make sure they get tested also, as prostate cancer is hereditary. My identical twin brother had his PSA done when I was diagnosed, and his reading was fine, but because he was an identical twin and has the same DNA, a biopsy was done, and lo and behold, he had the cancer worse than I, so he also had his prostate out. You should also ask your doctor at an early age, as I was only 45.

#67 Have a positive attitude.

#69 To try not to worry too much about it as it is a slow moving cancer and there are many different treatments for it.

#71 It is not the end of life. If they will come to our support group meetings they will see men who have had treatment for prostate cancer, 10+ years ago.

#72 Get as much info as possible from doctors and men in a support group who have been where you are going, so that you can make an “informed” decision when the time is urgent. Also, once you have made that decision- no matter what that is- consider it the best decision “for you” and do not ever second-guess yourself about that decision.

#73 Make sure you understand results. Do not rush your decision. Get someone else’s opinion. Seek support via a support group. Keep positive.

#74 Get good medical advice prior to making a decision regarding the route to follow. Get second or third opinion if you feel those are appropriate. Allow the family to share in the decision making (spouse, children and grandchildren) in most cases they want to be involved. Change lifestyle if appropriate re diet, exercise etc. My church has helped me a lot.

#76 Study and learn all the treatment options before having any treatment.

#77 Think positively about the outcome and try to think beyond the treatment/surgery/radiation to life on the other side of the procedure.

#79 Go slow. Don’t jump into decision too soon.
#80 Take your time to check out all the options. Attend support group before making a decision.

#81 I would strongly recommend they seek medical attention immediately. Maybe a second opinion would not be a bad idea- but don’t let it go unattended.

#82 Join a support group. Read all about alternative options. Learn as much about disease and prostate itself.

#84 Join a support group and get knowledge and understanding! Knowledge is power- the enemy is the unknown. Being positive is the answer! There is great support out there the cancer clinic and the resource centre. Support groups change your view to the positive- meeting people that are living proof of life after cancer! And you are not on your own with this disease. Support groups support /create prostate cancer awareness.

#86 If diagnosed early enough, it is not a death sentence. There are far worse concerns. Although it is a psychological and physical burden, one can live a full life as a prostate cancer survivor.

#87 I would join a support group to learn about the various treatments available and talk with individual members who have experienced these treatments to help me decide which one is best for me. Surgeons and radiologists have a tendency to their line of expertise. Do not worry, there is a good chance for a complete cure if diagnosed early. Get the best medical practitioner that you can.

#88 I would give the advice to think very carefully if your doctor advises to have an operation or radical prostatectomy or you will go through such a big operation since that changed my life very drastically.
Question: Please provide any other comments that you feel are important from your own experiences with prostate cancer.

Summary: Men with prostate cancer stated that: God, family and friends are important for coping; you should accept your condition; do things for others and stay positive; busy yourself with things you feel are important and have a lasting value; make your life count; pick up on practical tips; and be thankful there are treatments for prostate cancer. Further, cancer researchers should put more emphasis on finding treatments that will help present day prostate cancer patients.

Comments made by individuals:

#1 Ask your doctor if you have any questions. Whatever you decide make sure all your doubts questions are allayed.

#2 In talking with another cancer patient, I asked her how she managed to cope with her illness. Her answer had a profound impact on me, and has helped me a lot after I was diagnosed with prostate cancer. Her answer was simple and yet so powerful. She said, “My faith, my family and my friends have helped me as I dealt with cancer. These were my greatest resources as I struggled the physical and emotional aspects of my treatment. We don’t realize how powerful they are until we face a challenge in our life.

#3 Having a believe in God is an important thing for me. A positive attitude really helps the man and his family + friends.

#5 Do not think you are tougher than others and will sail through this at record time. Accept your condition and accept you are human and will take time to heal. Expect to be healed. Trust God to guide the medical people to help you. Accept God’s will. You may not live long- so use each day in a positive way. Do things for others. Make your life count. Do not feel bad if you are not always positive. Realize its normal to want to be cancer free. Also realize that now you have cancer and it is now reality. Learn to accept it and use the years you have left being the best you know how. Busy yourself with things you feel are important and of lasting value.
#6 None of the literature I read detailed the practical tips I received from friends. Get and use a stool softner as soon as you eat again. Rent a commode for your toilet (Red Cross!) to ease the bowel movements. Don’t bend or life for a few weeks. Purchase the “depend” product initially which covers you like an underpant. Liners may suffice later. Avoid use of Tylenol 3 causes constipation. Ask your anesthetist for an epidermal. I had such for 4 days in the hospital and needed no other painkiller after what so ever! Get an oversize “PJ” where you can slit the leg where your catheter bag is connected. Free yourself of all responsibilities for 2 weeks after coming home from surgery.

#9 My older brother has undergone Beam Radiation treatment combined with Hormone therapy. My younger brother has undergone Brachytherapy and complains constantly about sideeffects, though many are not related to the therapy, I am sure. For myself a statement made in one of the publications by a practicing urologist which described the radiation treatment as a lump of clay, eliminating my chances of surgery to repair an unsuccessful treatment, led me to my decision for a radical prostatectomy. To this date, I am confident of my decision.

#10 To beat cancer is your challenge – no one else’s. Be positive- believe you can beat it.

#11 It is important to detect prostate cancer early. It is important to start PSA screening at age 50 or earlier. It is wrong for the BC Cancer Agency to discourage men from screened and to fail to support or recommend PSA screening for men. Compared to cancer screening in women- mammograms and PAP smears, it seems men get nothing- this is sexist.

#13 Have a positive attitude. Be thankful there are treatments for prostate cancer. The Man to Man support group was important to me.

#14 Maintain a positive attitude.

#15 Highlighted the irrelevance of the healthcare system for those who need it the most. Current prostate cancer research is primarily focused on science, not patient’s health and quality of life.
#17 We must have more advocacy for improvements in our medical system. With some exceptions, it is an inefficient, slow-moving, inflexible system with wasteful practices. The treatment and care of cancer patients has become a “cancer industry” with many people having a comfortable, well-paid, secure job for life. There is empire building, and personal agendas, of the type found in most bureaucratic structures; “cover your ass” syndrome is there as well as the need for peer acceptance and the desire for acclaim re published papers. No real sense of urgency to have practical results from research that will help present-day prostate cancer patients. I see no need for greater funding, just a better use of the monies that are there.

#19 See your doctor annually and ensure you have a DRE and a PSA test. Be aware of family history and statistics on the subject. Check yourself on a regular basis for any lumps and changes in your body- and react immediately. The sooner found the better chances of survival. Be open to talk to others about your situation and especially your doctor to know what options are available and what side effects you can expect from your choice. Be aware that incontinence and erectile dysfunction are almost guaranteed up till now. Involve your spouse in your decision so that it will be more easily accepted with consequences. Join a support group to keep informed- know how others are coping and what you may expect. Have someone to contact in difficult situations and to know what is available in the community to help you.

#20 I had a very good doctor (GP) and urologist and they kept me well informed and there was not much room for doubt. The cancer-clinic (Surrey) was very professional and caring and if I had chosen some other treatment (not the radical surgery), I would have felt very confident dealing with the people there.

#21 Time with my God. Keep active. A good and supportive partner. Take time to rest, do not over do things.

#24 Prostate cancer is no longer a rare disease. The idea is to get early treatment- then likely not much to worry about.

#26 I was very pleasantly surprised to receive such care from the medical profession, my doctor, surgeon and all those at the cancer centre were very accommodating, very sincere and caring. I certainly appreciated their help.

#28 Obtain the pertinent facts. Utilize complementary aids: selenium, lycopene, vitamin E etc. Adopt a vegetarian diet if possible.

#31 Believe and mentally see yourself healed. b) Focus on health and wellbeing. c) Meditate and work on being in a relaxed state. d) Don’t think of cancer, think of health only.

#32 I wish I had looked at more alternatives.
#33 Helping another man cope with learning that he has cancer is one of the greatest joys of life.

#35 Don’t blame anyone for your problems. Just get on with your life.

#36 There is no such thing as a cure. Cancer can return, regardless of the initial prognosis.

#37 I had an extremely strong spiritual component in my life. This was a big help as I was able to pray to God at any time. I was very grateful for the openness and honesty of my urologist- he answered all our questions and took time to make sure I was comfortable with my choice of radical prostatectomy. I am very appreciative of the support, love and listening skills of my spouse. I should have made better use of them. I am happy with my therapy choice although I find the erectile dysfunction problem very annoying. It is hard to wait for an erection to occur.

#39 Belonging to a support group has been helpful. You learn a lot about treatment modalities you hear about the ups and downs of others. A feeling of comfort in knowing that you are not alone and if you have a recurrence there are still many options for dealing with the situation.

#40 Be wary of alternative medicine propaganda.

#42 Tell family and friends to be checked / tested. My younger brother’s tests showed that he had prostate cancer that was further advanced than mine.

#44 With two brothers having had Prostate cancer I was not prepared for the diagnosis. I took it in stride and thought (hoped) there would be no complications. The resulting urinary problems (complete incontinence) and impotence were a surprise they didn’t correct themselves. On second thought, I would likely consider either Brachytherapy or cryosurgery. Meanwhile I manage with 1 or 2 pads per day depending on my activity.

#45 We must work harder to find the non-surgical, non-chemical treatments for success. I believe that we must find the more natural therapies possible. If Asian men have the lowest rates of cancer, their lifestyle must be healthier. I must accept that our current, hard paced lifestyle is hurting us too. Men need to be much more talkative and open about what is happening about their cancer. I would say that I am thrilled with my choice of treatment. I am cured of my cancer and am able to physically resume my life. My experience with the Rockyview Hospital was excellent, great staff, caring people, good coverage of medical support.
#46 Make sure you have a doctor that you can trust. I had to go to a second urologist because I lost faith in the first as I found I couldn’t converse with him. I had to have a second operation because the first doctor didn’t join the ureter properly to the bladder & my right kidney wasn’t draining properly. If it hadn’t been for my second doctor, I might have lost my kidney.

#49 “It aint over, till the fat lady sings.” “Do not go gentle into that dark night... Rage, Rage against the darkening of the light.”

#52 It may be due to the dreaded “C” word but intimacy is so important even in these times. These may be just too big to expect even a reduced amount during the mental turmoil one goes through. Intimacy- closeness of spouse, sons, a daughter, sisters and brothers- all so important so one doesn’t feel too alone in this world.

#53 An early diagnosis is very important by getting a PSA test.

#54 I have two very caring doctors and very good nurses.

#55 Use a doctor whom you feel good about. You must have confidence in your doctor.

#56 I do not dwell on the past- no health & you cannot undo what has been done, especially a radical prost. I am fortunate that my sideeffects of the operation were minimal and short lasting. When my PSA did not go to zero and started rising rightaway, I realized the operation failed and I went on hormone therapy. The side effect of H.T. (hot flashes, and impotence ) are annoying. But better to live with them than not.

#57 Dislike the attitude that prostate cancer is an old men’s disease and therefore is not important. Need more treatment options that are available in the USA but not here in Canada- proton radiation facility, latest imaging technology.

#58 Be sure you contact a support group. Some will be better than others. But you will always find some support and information.

#59 Early diagnosis is very important.

#62 Surprised that there is not enough work done for doctors to be more definitive re: treatment. Unfair to ask the patient to determine his/her own treatment plan. However, realize that doctors don’t know for sure unless its an extreme situation and immediate treatment is warranted.
#63 In the treatment of prostate cancer, the state of art is still pretty primitive. But effective treatment is possible if caught early and treated rationally. There are some promising new directions in treatment research and some may become available fairly soon. Informing yourself and making treatment decisions as rationally as you can is important. So is sharing your problems and anxieties with loved ones and friends.

#64 I feel fortunate that it was found early and having it removed by surgery made me feel like it is probably gone. I will continue to closely follow Dr. advice for PSA tests etc. It is time for me to get my life in order & have time to do that. I needed my chain jerked! I really appreciate how my GP took care of me in finding it and getting me a fast referral. I have had great care by everyone in the clinics, hospital and Dr. offices. I have always had respect for these people and it has grown.

#65 We can recover with the support that is available to all of us.

#66 I found out that life’s too short to sweat the small stuff. I have also found out that my wife and I are stronger than we thought and our relationship is stronger.

#67 Early testing provides confidence that it may not become terminal.

#69 I always felt positive about it. I always have believed that I would be able to beat it.

#73 Family support, group support.

# 77 Support groups are wonderful. I am enjoying all the new people I’ve met through my volunteer work a the support group meetings.

#81 My biopsy was 4 “snaps” on the left and the same amount on the left. One showed early cancer. Once I knew for sure, I was very uneasy until the day I had my surgery. Following surgery I followed my Drs. Orders- “right to the letter” and made out fine. Did all the exercises + rest “the whole nine yards” this I realize helped me greatly.

# 86 Listen to, and respect, your doctor but seek other advice as well, regarding treatments. The internet (although information overload is a problem there), books and prostate cancer support groups are valuable sources of information.