

Perceived social support and depression in men with prostate cancer as compared to
women with breast cancer.

CAREY DAWN MINTZ

A Thesis Submitted to the
Faculty of Graduate Studies
In Partial Fulfillment for the Degree of

DOCTOR OF PHILOSOPHY

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ABSTRACT

Although prostate cancer is the most commonly diagnosed cancer in men and the second leading cause of male cancer death (Herman, 1992), there is only a very limited of literature available on either the psychological issues faced by men with prostate cancer, or regarding possible psychotherapeutic interventions for this population (Feldman, 1993; Sestini & Pakenham, 2000). While there has been some speculation about the similarities of experience between women with breast cancer and men with prostate cancer (Kiss & Meryn, 2001), very little research has been conducted to actually investigate whether or not these similarities exist. Therefore, this research project sought to address this gap in the literature by assessing the rates of depression among men diagnosed with prostate cancer, their social support needs, and how they compared to a sample of women with breast cancer in terms of both the prevalence of depression, and the relationship between perceived social support (PSS-Fr and PSS-Fa) and depression (CES-D). Sixty-nine women and sixty-six men participated in this study. In this sample, 25.8% of the men with prostate cancer reported symptoms of clinical depression which is consistent with common epidemiological findings for the incidence of depression in the general cancer population (Grassi, et. al., 1997; McDaniels, et. al., 1995; Mermelstein & Lesko, 1992). However, despite demonstrating significantly lower levels of perceived social support than did the women with breast cancer, the men with prostate cancer did not demonstrate significantly higher levels of depression. In addition, no relationship was found between perceived social support and depression for men with prostate cancer. Thus, while the relationship between perceived social support and depression is a robust finding in the breast cancer literature, no relationship between perceived social support and depression was found in this project's sample of men with prostate cancer.

Despite the fact that prostate cancer is the most commonly diagnosed cancer in men, and is the second leading cause of male cancer deaths (Herman, 1992), there is only a very limited literature available on either the psychosocial issues faced by men with prostate cancer, or the possible psychotherapeutic needs of this population (Feldman, 1993; Sestini & Pakenham, 2000). Instead, the majority of the psychosocial oncology research has focused on women with breast cancer and to a significantly lesser degree, men and women diagnosed with other forms of cancer such as lung cancer, colo-rectal cancer, and malignant melanoma. Despite this, there has been a persistent assumption in the cancer literature that men with prostate cancer face the same psychological consequences post-diagnosis as the general cancer population, and that they demonstrate the same treatment needs as the general cancer population as well (e.g., Kiss & Myryn, 2001; Kunkel, Bakker, Myers, Oyesanmi, & Gemolla, 2000; Poole, Poon, Achille, White, Franz, Jittler, Watt, Cox & Doll, 2001; Weber, Resnick, Deimling, Zauszniewski, Musil & Yarandi, 2004). However, in contrast to individuals with other cancer diagnoses, men with prostate cancer experience a high incidence of sexual dysfunction and incontinence that is frequently associated with the treatments for even early stage disease (Berteroe, 2002; Kao, Jani & Vijayakumar, 2003). Thus, the assumption of similarity of experience found within the literature may be erroneous.

Although the original intention of this project was to develop a group therapy approach for men with prostate cancer based on the assumption that these men shared a similarity of experience post-diagnosis with women with breast cancer, and that supportive-expressive therapy groups would produce the same beneficial effect for them as has been demonstrated for the breast cancer population, that project met with failure. Despite the dispersion of 700 contact letters, posted signs in numerous oncology and urology offices, and posters in every radiation oncology waiting room in

CancerCare Manitoba (the only radiation therapy center in Manitoba), over the course of two years a total of only 10 men agreed to participate in two closed 10-week facilitated support groups. Thus, a second and more pressing research question emerged: what are the actual psychological consequences of being diagnosed with prostate cancer, and what are the subsequent support needs of these men?

In order to explore this issue, the available research on the psychological consequences of being diagnosed with and treated for cancer will be reviewed, as will the literature on gender differences in the availability and mobilization of social support, and the efficacy of supportive-expressive therapy groups for individuals diagnosed with cancer. The rationale of the first project will also be discussed, as will the reasons why the questions regarding the actual incidence of depression in men following the diagnosis of prostate cancer and the social support needs of this population, need to be addressed.

Psychological Distress Associated with the Diagnosis and Treatment of Cancer

The occurrence of affective disorders in individuals who have been diagnosed with cancer is well documented. A number of studies have shown that depression is the most common affective disturbance following a diagnosis of cancer, and it has been suggested that between twenty-five and forty percent of individuals will demonstrate depressive symptoms following this diagnosis (e.g., Grassi, Malacarne, Maestri & Ramelli, 1997; McDaniels, Musselman, Proster, Reed & Nemeroff, 1995; Mermelstein & Lesko, 1992). In addition, up to forty percent of individuals diagnosed with cancer may experience dysthymia (Bayle, Gibertini, Scott, & Endicott, 1992), and between thirty and thirty-five percent of cancer patients will experience an adjustment disorder (Razavi, Delvaux, Farvacques, & Robaye, 1990). This is in contrast to the general population, of which approximately eight to ten percent have been shown to

demonstrate symptoms of clinical depression (Magni, Caldieron, Rigatti-Luchini, & Merskey, 1990; Radloff, 1977). Consistent with this, in direct comparisons of the incidence of depression between cancer patients and healthy control populations, both Ritterband and Speilberger (2001) and Schroevers, Sanderman, Van-Sonderen and Ranchor (2000) have documented significantly higher levels of depression among cancer patients than in healthy controls.

Although it has been found that these mood disturbances tend to remit over time (Ell, Nishimoto, Morvay, Mantell, & Hamovitch, 1989; Meyer & Aspergren, 1989; Parle, Jones, & Maguire, 1996), this is not necessarily the case for all cancer patients. For example, it has been found that almost twenty percent of cancer patients continue to demonstrate symptoms of psychological distress for up to two years post-diagnosis (Ell, et. al., 1989), and approximately thirty percent will develop new symptoms of an affective disorder sometime within those first two years (Meyer & Aspergren, 1989; Parle, Jones, & Maguire, 1996).

These findings appear to be consistent across all cancer patient populations studied (mainly women with breast cancer, and both women and men with colo-rectal and lung cancers). Although men tend to report less emotional distress or anxiety than the women in these studies (e.g., Baider et al, 1995; Friedman, Lehane, Webb, Weinberg, & Cooper, 1994; Grassi et. al., 1997; Servellen et. al., 1996), they consistently demonstrate a similar prevalence of depression or other mood disorders to that found in samples of women within the first two years following diagnosis (Baider et al, 1995; Grassi et. al., 1997; Servellen et. al., 1996). It has, therefore, been suggested that men may experience a much greater level of distress following a cancer diagnosis than they are willing to report. However, the idea that men are less willing or able to report distress is not uncontested. In two more recent studies, no significant

differences were found between male and female cancer patients on self-report measures of depression (Ciaramella, & Poli, 2001; Hann, Baker, Denniston, Gesme, Reding, Flynn, Kennedy & Kieltyka, 2002).

Hann, et. al. (2002) administered the Center for Epidemiological Studies-Depression Scale (CES-D) to 342 cancer patients who were over the age of 18 and who had no known history of previous psychiatric disorders. They found no statistical difference in levels of depression between the genders as assessed by this measure. Consistent with previous findings in the literature (e.g., Grassi, et. al., 1997; McDaniels, et. al., 1995; Mermelstein & Lesko, 1992) they also found that 25% of their sample met the cut-off score of 16 on the CES-D, which is indicative of clinical depression.

Ciaramella and Poli (2001) assessed 100 cancer patients aged 28 to 86 years old using the Structured Clinical Interview for the DSM III-R (SCID) and the Hamilton Depression Rating Scale. Again, no significant differences were found between male and female cancer patients on either measure; 28% of their sample was found to be clinically depressed when both measures were used.

Unfortunately, Ciaramella and Poli (2001) did not provide information as to the specific diagnoses of their participants, and Hann, et. al., (2002) reported that only 9% of their sample was made up of men with prostate cancer.

Of the studies specific to men with prostate cancer, Mundy (2002) explored psychological morbidity in men following the diagnosis and treatment of prostate cancer in comparison to men with benign genito-urinary disease. Using structured clinical interview measures of Acute Stress Disorder and Post-Traumatic Stress Disorder, she determined that men with prostate cancer demonstrate significantly more symptoms of these disorders than do men with benign genito-urinary disease within the first two weeks post diagnosis, although these differences were no longer present by the end of

treatment. Consistent with the literature on risk factors associated with psychological morbidity, she determined that both disease stage and previous incidence of psychological disturbance was highly predictive of psychological morbidity following a cancer diagnosis.

Pirl, Siegel, Good and Matthew (2002) investigated the role of androgen deprivation therapy (ADT) in the development of depressive symptoms using the Beck Depression Inventory, and concluded that men receiving ADT were at higher risk of developing symptoms of depression than the general population of healthy males over the age of 65. However, this provides little information about the prevalence of depression among the general prostate cancer population. In addition to the very limited scope of this study, another limitation was their use of the Beck Depression Inventory as a measure of depression for this population. Given its heavy weightings of somatic symptoms that may be confounded with the physical effects of illness, the Beck Depression Inventory has been demonstrated to have poor sensitivity in differentiating side-effects from treatment from symptoms of clinical depression in cancer patients (Ritterband & Spielberger, 2001).

Balderson and Towell (2004) investigated the prevalence of psychological distress using the Functional Assessment of Cancer Therapy – Prostate Scale, a quality of life measure, as well as the Hospital Anxiety Depression Scale (HADS), and reported a prevalence rate of 38% reporting “psychological distress.” However, no differentiation was made between symptoms of anxiety and symptoms of depression, and no prevalence rate for clinical depression was noted.

Despite the limited research specifically aimed at investigating actual prevalence rates of depression in men with prostate cancer, based on the body of literature available in regard to individuals with other cancer diagnoses it has been consistently

assumed that men with prostate cancer are also at high risk for developing symptoms of depression following diagnosis (Kiss & Myryn, 2001; Kunkel, Bakker, Myers, Oyesanmi, & Gemolla, 2000; Poole, Poon, Achille, White, Franz, Jittler, Watt, Cox & Doll, 2001; Weber, Resnick, Deimling, Zauszniewski, Musil & Yarandi, 2004). However, there continues to be a lack of research specifically addressing this issue, and it remains uncertain whether or not this may be an erroneous assumption.

The Role of Social Support Following a Diagnosis of Cancer

Several factors have been shown to increase an individual's vulnerability to psychological disturbance following a diagnosis of cancer, including a previous history of depression or other psychiatric illness, inadequate coping mechanisms, and the occurrence of non-cancer related stressful life events (Grassi et al, 1997). Some researchers have also argued that an advanced or recurrent disease stage is associated with a greater likelihood of psychological disturbance (e.g., Bukberg, Penman, & Holland, 1984; Cella, Orofiamma, Holland, Silberfarb, Tross, Feldstein, Perry, Maurer, Comis, & Orav, 1987), however, more recent evidence suggests that this is not necessarily the case (Friedman, Nelson, Baer, Lane, Smith & Dworkin, 1992; Grassi, et al., 1997). It has also been suggested that persistent side effects of treatment may trigger intrusive thoughts about the cancer and thus increase the incidence of psychological disturbance (Walker, Nail, Larsen, Magill, & Schwartz, 1996). Thus, regardless of the etiology, the development of clinical depression is clearly a significant risk for individuals diagnosed with cancer.

Fortunately, the role of social support in decreasing the incidence of psychological distress in cancer patient populations is also well documented. Many studies have demonstrated that women with adequate social supports from friends and family members experience fewer symptoms of depression, fewer feelings of loneliness

and social isolation, fewer difficulties in the maintenance of interpersonal relationships, and possibly a longer survival time following the diagnosis of cancer than those who do not (Hoskins, Baker, Sherman, Bohlander, Bookbinder, Budin, Ekstrom, Knauer & Maislin, 1996; Manne, Taylor, Dougherty, & Kemeny, 1997; Pistrang, Barker & Rutter, 1997; Smith, Redman, Burns & Sagert, 1985). They also report significantly fewer symptoms of anxiety in medical situations, as well as fewer chemotherapy-related difficulties (Friedman, et. al., 1994). Social support from family and friends has also been demonstrated to be related to a greater tendency to use active coping strategies (Friedman, et. al., 1994), which are related to better psychosocial adjustment following diagnosis (Friedman et. al., 1990). Better social support is also significantly related to a lesser incidence of avoidance coping, which is related to poorer psychological adjustment post-diagnosis (Friedman, et. al., 1990; Friedman et. al., 1994).

In this literature, social support from the spouse has been consistently cited as the most important source of social support by married female cancer patients (Baider, et. al., 1995; Grassi, et. al., 1997; Gurowka & Lightman, 1995; Smith, et. al., 1985). Several studies have demonstrated that women who are able to express their feelings and concerns about their cancer to their spouses consistently score higher on measures of adjustment than those who are not able to do so (Gurowka & Lightman, 1995; Hoskins et. Al., 1996; Manne, et. al., 1997; Smith, et. al., 1985). Smith, et. al. (1985) suggested that this form of emotional support was the most important factor in predicting psychological adjustment following the diagnosis of cancer, and found that the women in their study rated emotional support as significantly more helpful than more instrumental, task-oriented support behaviours such as helping with household chores, bringing food, or baby-sitting.

The role of friends and other family members as social supports also appears to

be important for women in buffering the negative effects of a cancer diagnosis and its subsequent treatment (de Groot, 2002; Friedman, et. al., 1994, Grassi, et al., 1997; Hann, et. al., 2002; Harrison, Maguire & Pitceathly, 1995; Hoskins, et. al., 1996; Michael, Berkman, Colditz, Holmes, & Kawachi, 2002; Smith et al., 1985). For example, Friedman, Baer, Nelson, Lane, Smith & Dworkin (1988) suggested that the need for family closeness and support among women with breast cancer may extend even beyond the norm commonly considered adaptive by medically healthy women. In their study, those women with the highest levels of family cohesion, even those reaching dysfunctionally high levels of cohesion as described by the Circumplex Model, reported the best adjustment to their breast cancer diagnoses.

In a year-long study which tracked women's sources of social support and patterns of psychosocial adjustment, Hoskins, et. al., (1996) also found that as time passes, reliance on friends and family members outside of the spousal relationship increases significantly. They suggested that due to the chronic nature of the disease the couple's resources may become drained, and that this may limit the ability of the spouse to continue to provide intensive emotional support. Thus, outside help from friends and family seems to become increasingly necessary as time goes by. This is supported by Hann, et. al. (2002) who demonstrated that larger social support networks were associated with significantly lower levels of depression during both active treatment (i.e., chemotherapy or radiation treatment) and post-treatment for female cancer patients.

Gender Differences in the Availability and Use of Social Support

Although significantly fewer studies have investigated the relationship between social support and psychological distress for men with cancer, the small amount of available research does demonstrate a relationship between the availability and quality

of social support for these men and their psychological adaptation to a cancer diagnosis. Men with better social supports have been shown to demonstrate a decreased incidence of emotional distress, fewer intrusive thoughts, and possibly longer survival times following diagnosis than those with poorer social supports (Baider, et. al., 1995; Balderson & Towell, 2003; Forester, et. al., 1993; Grassi, et. al., 1997; Lepore & Helgeson, 1998; Servellen, Sarna, Padilla & Brecht, 1996).

Despite the apparent similarities of experience between men and women in regard to the relationship between social support and depression following a cancer diagnosis, gender differences in terms of the sources of social support are clear. Several studies have demonstrated that in contrast to women, men tend to limit their self-disclosure to one confidante rather than to a network of social supports, which is the more typical female pattern (Baider et. al., 1995; Hann, 2002; Harrison, Maguire & Pitceathly, 1995). This confidante is also most likely to be his spouse (Baider et. al., 1995; Hann, 2002; Harrison, Maguire & Pitceathly, 1995). The explanation offered for this is that men have been socialized to avoid the discussion of emotional issues outside of the home, and focus instead on pragmatic topics such as work, shared activities, or world events (Baider, et. al., 1995; Harrison, Maguire & Pitceathly, 1995, Zakowski, Harris, Krueger, Laubmeier, Garrett, Flannigan & Johnson, 2003). Thus, when a crisis occurs, men may feel unable to overcome the social constraints regarding the non-discussion of emotion with their friends and family members, and thus, rely exclusively on their partner for emotional support (Baider, et. al., 1995; Harrison, Maguire & Pitceathly, 1995; Zakowski, et. at., 2003).

Unfortunately, this typical reliance on the spouse as the sole source of social support may leave some men particularly vulnerable. Although men with higher levels of perceived social support from a spouse or significant other have been shown to

demonstrate no greater levels of depression than women despite their having smaller social network sizes (Hann, et. al., 2002), this may not be representative of all men. It seems that the potential for being without adequate social support could be quite great, especially if the individual is single, widowed, or divorced, if the marital relationship is not supportive, or if the spouse's resources become drained over time. Several studies have demonstrated that the spousal relationship is not always adequately supportive (Clark, Wray, Brody, Ashton, Giesler, & Watkins, 1997; Hannum, Giese-Davis, Harding, & Hatfield, 1991; Lepore & Helgeson, 1998), or that the quality of the relationship may become strained due to the stressors associated with the diagnosis and treatment of cancer (Clark, et. al., 1997; Hannum, et. al., 1991; Lepore & Helgeson, 1998). In addition, even within the context of a supportive relationship, both men and women report difficulties in communicating with their partners about their cancer, particularly in regard to issues surrounding mortality (Friedman, Lehane, Weinberg, Mirabi, & Cooper, 1993).

Men may also experience particular difficulty in sharing their feelings and needs with their partners, especially when the diagnosis involves issues of sexual functioning, as it does in prostate cancer. For example, Lepore & Helgeson (1998) found that men with prostate cancer often find it difficult to talk to their spouses about their experiences and feelings. They also found that those men who experienced difficulties with self-disclosure also experienced intrusive thoughts about their cancer significantly more frequently than those who were able to self-disclose, and that these thoughts were associated with significantly higher levels of psychological distress. Clark et. al., (1997) also found that men with prostate cancer experienced significant difficulties in sharing their fears and experiences with their wives. The men who participated in their study expressed feelings of shame and wounded pride, fear of becoming dependent and of

no longer being able to perform self-care tasks, fear of no longer being capable of being a "strong husband," and misgivings about the treatment choices they had made. The men in this study also indicated that intimacy with their wives was, as a result, problematic.

In summary, it seems that several issues occur for men which may differ from the experiences of women. First, men may be less inclined to report distress, even if distress is present – although this finding appears to still be in question. Second, men tend to mobilize fewer social supports than do women, and typically rely almost exclusively on their spouses for support. Third, their spousal support may not be available or adequate, or they may feel unable to access this support. Thus, men with cancer may be experiencing equal levels of psychological distress following their diagnosis as women with cancer, while at the same time experiencing greater barriers to obtaining adequate social support.

The Role of Group Therapy for Cancer Patients

Group therapy has consistently been shown to improve the quality of life (Cunningham & Edmonds, 1996) and psychological well-being of cancer patients (Forester, et. al., 1993; Fobair, 1997; Harman, 1991; Timms, 1990). Individuals who have participated in group therapy programs have been shown to experience fewer feelings of social isolation (Harman, 1991), less mood disturbance, fewer psychiatric symptoms, and less anxiety post-diagnosis (Cunningham & Edmonds, 1996; Fobair, 1997; Harman, 1991). In addition, they have been shown to experience less distress while undergoing radiation therapy than cancer patients who receive no group therapy intervention (Forester, et. al., 1993). It has also been consistently suggested that the social support offered within these groups is the mechanism responsible for these improvements (Forester, et. al., 1993; Fobair, 1997; Harman, 1991).

This idea has been reinforced by the few studies available which have compared traditional cognitive-behavioural techniques with groups emphasizing the expression of emotion and the development of social supports. In 1991, Harman compared a cognitive-behavioural group, an expressive-supportive group and a control group, and found that the expressive-supportive group was more effective across all measures than the cognitive-behaviour group in reducing psychological distress among cancer patients, although participants in both groups demonstrated significantly better psychological adjustment than those receiving no support group intervention.

Evans and Connis (1995) also compared cognitive-behaviour groups to supportive-expressive groups and control groups for a sample of depressed cancer patients. They found that while the cognitive-behaviour groups were effective in reducing psychological disturbance, the expressive-supportive groups produced the most positive change for their sample of depressed cancer patients.

Fobair (1997) also reported that while cognitive-behaviour therapy groups produced significantly greater improvement in terms of psychological functioning (as measured by the incidence of self-reported mood disturbance on the Profile of Mood States) than either control groups or self-help support groups, it was the groups which emphasized the expression of emotion and the provision of social support which produced the greatest benefits for cancer patients. In these supportive-expressive groups, cancer patients were encouraged to express "their thoughts and feelings about their illness and its effects on their lives, and to develop close personal ties with each other both inside and outside the group" (Fobair, pp. 75).

Finally, Watson, Fenlon, McVey and Fernandez-Marcos (1996) failed to find any treatment effects whatsoever of a cognitive-behavioural group therapy program for women with breast cancer. Thus, it seems that supportive-expressive groups may be

the most effective group therapy treatment modality for cancer patients in terms of the alleviation of psychological distress, and it would seem that the mechanism for change may be the provision of a safe environment in which cancer patients can discuss the emotional aspects of their illness and receive social support from their peers.

These findings are well supported in the breast cancer literature. Taken as a whole, it seems that regardless of disease stage, women who participate in group therapy programs demonstrate decreased symptoms of anxiety and depression and an improved quality of life relative to those who are not offered this type of psychosocial support.

Numerous studies have demonstrated the benefits of supportive-expressive group therapy for women with early stage (i.e., Stage I and II) breast cancer (Edelman, Bell, & Kidman, 1999; Gillbar, 1992; Gore-Felton & Spiegel, 1999; Kissane, Bloch, Miach, et. al., 1997; Montazeri, Javandi, Haghighat, et. al., 2002; Samarel, Fawcett & Tulman, 1997; Targ & Levine, 2002). Each of these studies demonstrated that women newly diagnosed with breast cancer who participated in a supportive-expressive group therapy experience demonstrated reduced anxiety related to recurrence, death and dying (Gilbar, 1992; Gore-Felton, 1999; Kissane, et. al., 1997), reduced generalized anxiety (Edelman, Bell, & Kidman, 1999; Montazeri, et. al., 2002) and reduced fear of radiation treatment and chemotherapy (Kissane, et. al., 1997). All of these studies also demonstrated that for women with primary breast cancer, participation in a supportive-expressive therapy group had significant positive effects in reducing mood disturbance (Edelman, Bell, & Kidman, 1999; Gillbar, 1992; Gore-Felton & Spiegel, 1999; Kissane, et. al., 1997; Montazeri, et. al., 2002; Samarel, Fawcett & Tulman, 1997; Targ & Levine, 2002).

These findings have also been demonstrated for women with metastatic breast

cancer. Again, participation in a supportive-expressive therapy group has consistently been demonstrated to reduce symptoms of anxiety and depression, and to improve quality of life (e.g., Classen, Butler, Koopman, et. al., 2001; Edmonds, Lockwood & Cunningham, 1999; Giese-Davis, Koopman, Butler, et. al., 2002; Goodwin, Leszcz, Ennis, et. al., 2001; Spiegel & Classen, 2000). Classen, et. al. (2001) also measured post-traumatic stress symptoms, and found that these too were reduced by participation in a supportive-expressive therapy group. In addition, both Spiegel & Classen (2000) and Goodwin, et. al. (2001) demonstrated that the women who participated in a supportive-expressive therapy group also reported fewer pain symptoms than those who did not, and Spiegel & Classen (2000) found that the survival times of the therapy group participants was significantly longer than those who were randomized to a no-treatment control.

These findings have also been replicated in populations of women who do not actually have breast cancer, but who are at a genetically high risk of developing it. Again, participation in a supportive-expressive therapy group that allows these women to address the emotional issues associated with being at risk for developing breast cancer has been demonstrated to reduce symptoms of anxiety and depression in this population (Esplen, Toner, Hunter, et. al., 1998; Karp, Brown, Sullivan & Massi, 1999).

Finally, even the partners of women with breast cancer have been targeted for study. Again, having the male partners of women with breast cancer participate in a supportive-expressive therapy group was shown to result in reduced symptoms of mood disturbance for both the partners of the women with breast cancer, and the women themselves (Bultz, Specia, Brasher, et. al., 2000; Streisand, 2002).

Thus, the efficacy of supportive-expressive group therapy has been an area of considerable study, with relatively consistent results. This last study is interesting not

only for its value to the breast cancer literature, but also because it demonstrates that men, too, can benefit from group therapy approaches designed to elicit emotional disclosure and the provision of social support – an area which has been under-investigated in the literature on men with cancer diagnoses.

The Role of Existing Prostate Cancer Support Groups

In recent years, there has been a proliferation of prostate cancer support groups across North America. The original prostate cancer support group, "Us Too" was formed by a urologist in Chicago in 1990. This was in response to the requests of several of his patients who asked if there were any other people who had undergone treatment with whom they could speak about what to expect (Kaps, 1994). In Canada, there are over 50 prostate cancer support groups associated with "Us Too," as well as several associated with "Man to Man" - a Toronto based group, and "Prostate Support and Awareness" - a network of support groups throughout British Columbia (Gray, Fitch, Davis, & Phillips, 1997). Although very little quantitative research has been done on these groups, three qualitative studies about the experiences of men within these groups have been published. All three of these articles discuss the men's desire for accurate information about prostate cancer and its various treatments, and highlight the difficulties they face in discussing their feelings (Calabrese, 1995; Gray, et. al., 1997; Kaps, 1994). The authors indicate that in response to these needs, support groups tend to emphasize the dissemination of accurate information about the disease and its treatment, as well as advocacy and the mobilization of lobby movements (Calabrese, 1995; Gray, et. al., 1997; Kaps, 1994). However, they also suggest that prostate cancer support groups are lacking in a mechanism to respond to the emotional needs of their members. Group members' self-disclosure about their emotional reactions to their experiences with prostate cancer may not occur with regularity and as a result,

these support groups may not be sufficient in terms of the provision of emotional support (Calabrese, 1995; Gray, et. al., 1997; Kaps, 1994).

There may be some factors which influence this. Many of these groups include a large number of people, and membership is open, so that people may not attend regularly. This also results in a lack of a consistent group membership across meetings; each week's group is likely to be comprised of different people. This lack of consistency may make self-disclosure more difficult to initiate. Also, as the groups tend to emphasize the discussion of pragmatic concerns (such as information about the diagnostic procedures one may face, the various treatments available, what to expect from these treatments, and the side-effects they may have, as well as the sharing of individual stories regarding diagnosis and treatment), this may inhibit self-disclosure of an emotional nature. Finally, as was discussed earlier, it seems that men have difficulty sharing their feelings with people other than their spouses, and hence may not feel comfortable with spontaneous self-disclosure.

Only one study has quantitatively investigated the role of the existing prostate cancer support groups and their effect on the emotional functioning of men with prostate cancer post diagnosis. Poole and his associates (Poole et. al., 2001) did a comparison study of men with prostate cancer who attend prostate cancer support groups versus those with prostate cancer who do not. They administered the Functional Assessment of Cancer Therapy Scale (FACT) – a quality of life measure – to a sample of men with prostate cancer, approximately half of whom were involved in an existing prostate cancer support group. They also asked questions about perceived social support and the source of that support. The result of this study indicated that men who participated in a support group did not significantly differ from those who did not in terms of their quality of life. They did, however, note that participants

consistently rated the spouse as their primary source of emotional support, and their satisfaction with this support was directly related to their quality of life. This could suggest that the existing prostate cancer support groups are not providing any additional emotional social support over and above what a man with prostate cancer already receives from his spouse. This hypothesis is further suggested by the men's high ratings of satisfaction with the informational support offered by the support groups they attended, and their low scores for the group as a source of emotional support. Unfortunately, no measures of anxiety or depression were administered, so no conclusion could be made from this study about the level of distress experienced by this population.

More recently, Lepore, Helgeson, Eton and Schulz (2003) investigated the efficacy of a group education intervention addressing issues of coping with sexual dysfunction. Participants were randomized to one of three conditions: a control condition, a group education (GE) condition, or a group education with discussion (GED) condition. In the year post-intervention they determined that men in both the intervention groups reported being "less bothered by sexual problems" than men in the control group, although this effect was only present among non-college educated men. However, it is unclear whether "less bothered by sexual problems" means that these men experienced fewer physical limitations in sexual functioning due to a greater awareness of the various treatments available to them and resultant higher levels of treatment-seeking, or whether they experienced a lesser degree of psychological distress in regard to an unchanged level of sexual dysfunction. Among college graduates, no differences were determined between groups, suggesting perhaps that the result of the educational groups was that men with lesser educational backgrounds became more aware of potential treatments available to them for sexual dysfunction.

Another limitation of this study is that no formal measures of psychological distress were included in their assessment of the efficacy of this intervention.

In 2004, Weber, Roberts, Resnick, Deimling, Zauszniewski, Musil, and Yarandi investigated the effect of dyadic interventions for men with prostate cancer. Instead of a group approach, they paired men who had undergone radical prostatectomy with long term survivors who also underwent radical prostatectomy and who had experienced similarities in residual side-effects as a result. The hope was that these men could thus discuss coping with the side-effects of treatment as well as various survivorship concerns. Although significant differences were noted in levels of depression in the participants after 4 weeks, participants demonstrated no differences in levels of depression compared to control group participants receiving standard medical care after an 8-week period. At no point during the intervention were measures of social support significantly different between the men receiving intervention and those receiving standard medical care, suggesting that the peer support intervention did not access this dimension. Rather, this is suggestive that these peer interventions offered more informational support than emotional-expressive support.

Lintz, Moynihan, Steginga, Normal, Eeles, Huddart, Dearnaley, and Watson (2004) also conducted a survey of men who had undergone non-surgical interventions for prostate cancer in terms of their perceived support needs. They concluded that needs were being well met in terms of patient care and informational support, although half of their sample expressed a desire for more support in terms of sexual functioning post-treatment. Their conclusion was that men with prostate cancer generally function well, with only a minority reporting unmet support needs. However, as no measure of psychological distress was included in this study, and no measure of social support appears to have been included, it seems that this study only addresses informational

support needs, and perhaps misses the issue of psychological distress and emotional/social support needs.

Taken as a whole, this literature seems to suggest that despite the availability of various interventions and prostate cancer support groups that provide excellent informational support, men with prostate cancer may not be obtaining sufficient emotional support throughout their cancer experience. Thus, it seemed there was a need for the development of a prostate cancer therapy group which emphasized the sharing of emotional reactions to the cancer experience, and the provision of social support. This was particularly compelling given the previously reviewed findings which suggest that emotional expression and social support are important mechanisms of resiliency for other cancer patient populations.

Unfortunately, when it came to putting this project into action, a markedly poor response rate to participant recruitment was noted. Despite 700 contact letters being sent, posters posted in all radiation therapy and oncology treatment areas of CancerCare Manitoba (the main oncology hospital and the only site which provides radiation therapy in the province), and the recruitment of both oncology and urology clinic nurses in presenting information about this research project to prospective participants, after two years of recruitment only 10 men had volunteered to participate. Despite the two groups which ensued appearing to have been successful, with feedback from both groups being highly positive – including a high endorsement of perceived emotional support from other group members, the question could not help but be asked: why are men with prostate cancer declining to participate in this project? Two alternative explanations could be postulated. First, it is possible that unlike other cancer diagnoses, men who have been diagnosed with prostate cancer cope well with their diagnosis and the subsequent consequences of treatment, and do not need

additional social support in order to help them cope. Second, it is possible that men with prostate cancer do indeed experience psychological sequelae which parallel the experiences of women with breast cancer, but are reluctant to participate in an expressive-supportive therapy group. Anecdotal evidence from the two therapy groups that I ran suggests that the second hypothesis is more likely the valid one, however, given the relative lack of literature on this subject, this begs further investigation.

Proposed Contributions to Knowledge in the Field of Psychosocial Oncology

As relatively little is known about the psychological experiences and issues faced by men following the diagnosis and treatment of prostate cancer, it was felt that this project had the potential to significantly contribute to our knowledge in this area. One of the goals of this project was to document the incidence of depression in men with prostate cancer, and to investigate their social support needs. It was hoped that this would address the question of whether or not there is a need for additional psychosocial services for this population.

A second goal of this project was to compare and contrast the psychological sequelae and social support needs of men with prostate cancer with a population of women with breast cancer. As the bulk of available research has been conducted with breast cancer populations, and given that this body of research is being used to guide our beliefs about the experiences of men with prostate cancer, it seemed important that the validity of this extrapolation be evaluated. If it was found that men with prostate cancer do, indeed, experience similar reactions to their cancer diagnosis in comparison with women with breast cancer, then it would continue to be appropriate to use the knowledge base gained from studying the breast cancer population when making research, policy, and psychosocial treatment decisions in regard to men with prostate cancer.

In addition, if the results did indicate that men with prostate cancer actually experience similar social support needs as do women with breast cancer, then the third goal of this project was to investigate why men do not appear to be availing themselves of the psychological help that they may need (as evidenced by the extremely poor response to my offer of a prostate cancer support group). For example, are there barriers to obtaining help that can be identified and addressed for this population?

In contrast, if it was found that men with prostate cancer differ significantly in their reactions to the diagnosis and treatment of their illness, then the assumption of similarity found in the current literature would need to be abandoned in favor of more prostate cancer specific research. Policy and treatment implications based on these assumptions would then be of concern. Thus, each of these goals has the potential to make a significant contribution to the area of psychosocial oncology.

Hypotheses

1. As the literature has consistently demonstrated that individuals who have been diagnosed with cancer are at much greater risk of developing symptoms of clinical depression - and that approximately twenty-five to forty percent of all cancer patients develop symptoms of depression at some time following their diagnosis (e.g., Grassi, et. al., 1997; McDaniels, et. al., 1995; Mermelstein & Lesko, 1992) - it is expected that between twenty-five and forty percent of this project's sample of men with prostate cancer will demonstrate symptoms of clinical depression as measured by the Centre for Epidemiological Studies - Depression Scale (CES-D).
2. Consistent with this literature (Grassi, et. al., 1997; McDaniels, et. al., 1995; Mermelstein & Lesko, 1992), it is also expected that the between twenty-five and forty percent of this project's sample of women with breast cancer will demonstrate symptoms of clinical depression as measured by the Centre for Epidemiological

Studies – Depression Scale (CES-D).

3. Given that poor social support has consistently been shown to be related to higher levels of depression (Hoskins, et. al., 1996; Manne, et. al., 1997; Pistrang, Barker & Rutter, 1997; Smith, et. al., 1985), it is hypothesized that a significant inverse relationship will be evidenced between perceived social support as measured by the PSS-Fr/PSS-Fa and depression as measured by the CES-D for this sample.
4. As it has been suggested in the literature that men with cancer tend to experience more barriers to mobilizing social support than do women (Baider et. al., 1995; Hann, 2002; Harrison, Maguire & Pitceathly, 1995; Zakowski, et. al., 2003), it is expected that the sample of men with prostate cancer in this project will demonstrate significantly lower levels of social support as measured by the Perceived Social Support-Friends and Family Scale (PSS-Fr/PSS-Fa) in comparison to the sample of women with breast cancer sample.
5. Given that the literature has consistently demonstrated that poor social support is related to the development of depression following a diagnosis of cancer (Hoskins, et. al., 1996; Manne, et. al., 1997; Pistrang, Barker & Rutter, 1997; Smith, et. al., 1985), and that in comparison to women, men tend to be less willing or able to access social support when it is needed, and are much more limited in their sources of social support (Baider et. al., 1995; Hann, et. al., 2002; Harrison, Maguire & Pitceathly, 1995), it is hypothesized that men with prostate cancer may be more vulnerable to the development of symptoms of depression than women with breast cancer (who do not share the same barriers to accessing adequate social support). Thus it is expected that the sample of men with prostate cancer in this study will demonstrate significantly higher levels of depression as measured by the CES-D than the sample of women with breast cancer.

6. An analysis will also be conducted to determine whether there are gender differences in the relationship between social support and depression. Although Hann, et. al., (2002) found that there were no significant gender differences in the relationship between social support and depression in a sample of individuals with a variety of cancer diagnoses, this has yet to be replicated in the literature.
7. Finally, a qualitative analysis will be performed for the information gathered from the sample of men with prostate cancer regarding their level of interest in support groups, and whether or not there are barriers (beyond lack of perceived need) to accessing this support. This will explore the hypothesis that although men with prostate cancer experience the same psychological challenges following their diagnosis of cancer that women with breast cancer do, and may be in need of equal levels of social support services, they may be experiencing barriers (including psychological ones) to accessing social support through support groups.

Method

Participants

An a priori power analysis with alpha set at 0.05 indicated that in order to achieve a minimum power of .80, a total of 65 participants would be minimally acceptable per group. However, in the interests of also obtaining a representative sample of both women with breast cancer and men with prostate cancer, population statistics generated by the Manitoba Cancer Registry were used to determine the required sample size to achieve this desired goal.

Given that approximately 8000 women with a diagnosis of breast cancer were determined to be living in Manitoba at the time of this project, and there were approximately 5000 men living in Manitoba with a diagnosis of prostate cancer, it was

determined that the project required a minimum sample size of 95 participants per diagnostic group in order to obtain a representative sample within a 95% confidence interval, accepting a sampling error of $\pm 10\%$, (Dillman, 2000).

Based on previous experience with questionnaire-based research using the Manitoba Cancer Registry, a response rate of at least 50% was expected for this project. Thus, a random sample of 190 men with prostate cancer and 190 women with breast cancer was generated from the Manitoba Cancer Registry to allow for this response rate. It was anticipated that through random sampling and the size of the survey, a sample would be generated that was not only adequate in terms of statistical power, but also representative of the general population of women with breast cancer and men with prostate cancer in terms of demographic characteristics as well as disease stage, time since diagnosis, the types of treatments provided, and time since last treatment.

380 questionnaires were, therefore, mailed out to this random sample of 190 men with prostate cancer and 190 women with breast cancer. Unfortunately, a smaller rate of return was obtained than was expected (36% rather than 50%). In total, 69 women with breast cancer and 66 men with prostate cancer returned completed questionnaires. Twenty-six women and twenty-seven men elected to return uncompleted questionnaires as an indication of their desire not to participate in the study, leaving 215 questionnaires unaccounted for. Thus, while this sample size provides a sufficient degree of power to perform all needed statistical analyses, the resulting sample may not be entirely representative of the general breast and prostate cancer populations in terms of demographic information or disease characteristics. Unfortunately, as the Manitoba Cancer Registry does not keep population statistics beyond incidence and prevalence rates, a sample to population comparison could not

be performed to determine how representative this sample is of the breast cancer and prostate cancer populations in Manitoba in regard to demographic information or disease characteristics.

The breast cancer sample had a mean age of 58.16 years ($SD = 10.97$; range 31 – 81). The majority (58.8%) were diagnosed with stage 1 breast cancer (in which the tumor is confined to the breast). Twenty-six percent (26%) had between one and three lymph nodes positive, 16.2% reported more than three positive lymph nodes, and none reported metastatic disease at time of diagnosis. Six women in the sample reported subsequent local recurrence of their cancer (8.8%), and only one (0.9%) reported metastatic spread subsequent to her initial diagnosis. The mean time since diagnosis was 3.66 years ($SD = 2.21$ years), and the mean time since last treatment was 2.93 years ($SD = 1.97$ years). In terms of treatment modalities, 2.9% of the women in the sample underwent lumpectomy without subsequent radiation therapy, and 49.3% underwent lumpectomy with adjuvant radiation therapy. 34.8% were treated with mastectomy, and an additional 11.6% received radiation therapy following mastectomy. Only one woman was offered neither surgery nor radiation therapy for her cancer. The sample was almost evenly split between those who underwent adjuvant chemotherapy (52.2% did; 47.8% did not), and 60.9% were treated with hormone therapy (Tamoxifen or Arimidex).

The prostate cancer sample had a mean age of 70.14 ($SD = 7.42$; range 57 – 90). As with the women with breast cancer, the majority (83.3%) reported stage 1 disease at the time of diagnosis (in which the tumor is confined to the prostate). 10.6% reported that their cancer had spread to the surrounding tissues, and 6.1% indicated that they had lymph node involvement. None of the participants reported metastatic disease at time of diagnosis. Only one participant reported a local recurrence of his

prostate cancer subsequent to his initial diagnosis, and none of the sample reported metastatic spread subsequent to initial diagnosis. The average time since diagnosis was 3.45 years ($SD = 1.82$ years), and the average time since last treatment was 2.92 years ($SD = 1.96$ years). In terms of treatment modalities, 37.5% underwent radical prostatectomy while 34.4% were treated with radiation therapy alone. 10.9% were treated with radical prostatectomy with subsequent radiation therapy, and 16.7% reported neither surgery nor radiation therapy. Just over forty percent (40.6%) of the men in the sample reported being treated with hormone therapy (Lupron, Zolodex, Casodex, or Flutamide), while 59.4% reported receiving no hormone treatment. Just over ten percent (10.6%) also reported orchiectomy. A complete review of both samples' medical status can be seen in Table 1; demographic information can be seen in Table 2.

Unfortunately, the majority of respondents either failed to disclose their ethnic background, or wrote "Canadian" as a response. No analysis of reported ethnic identity was therefore performed.

Table 1

Medical status of the sample

	Men (N)	%	Women (N)	%
Disease Stage at Diagnosis				
Stage 1	55	83.3	40	58.8
Stage 2	7	10.6	18	26.0
Stage 3	4	6.1	11	16.2
Stage 4	0	0	0	0
Disease Stage Post-Diagnosis				
Local Recurrence	1	1.5	6	8.8
Metastatic Disease	0	0	1	0.9
Treatment Modality (women)*				
Lumpectomy			2	2.9
Mastectomy			24	34.8
Lumpectomy and Radiation			34	49.3
Mastectomy and Radiation			8	11.6
No surgery or radiation			1	1.4
Chemotherapy			36	52.2
Hormone treatment			42	60.9
Treatment Modality (men)*				
Radical Prostatectomy	24	37.5		
Radiation Therapy	22	34.4		
Radical Prostatectomy + Radiation	7	10.9		
Hormone Therapy	26	40.6		
Orchiectomy	7	10.6		
No treatment (watchful waiting)	11	16.7		

* note: many people received more than one treatment modality

Table 2

Demographic characteristics of the sample

	Men (N)	%	Women (N)	%
Age				
31 – 55	0	0	27	39.1
55 – 65	15	22.7	24	34.8
over 65	50	75.6	16	23.2
no disclosure of age	1	1.5	2	2.9
Marital Status				
Married/living with partner	55	83.3	37	53.6
Common-law relationship	1	1.5	3	4.3
Single/Never Married	0	0	7	10.1
Divorced	4	6.1	9	13.0
Separated	0	0	4	5.8
Widowed	6	9.1	9	13.0
Education				
Elementary School	8	12.1	0	0
Junior High School	2	3.0	1	1.5
High School	18	27.2	32	46.3
Non-University Diploma	14	21.1	24	34.8
Some University	4	6.1	4	5.8
Bachelor's Degree	4	6.1	5	7.2
Professional Degree	5	7.6	2	2.9
Master's Degree	6	9.0	1	1.5
Doctorate	4	6.1	0	0
Work Status				
Full-time	12	18.2	23	33.3
Part-time	4	6.1	4	5.8
Partial disability	0	0	0	0
Homemaker	0	0	11	15.9
Unemployed	4	6.1	0	0
Full-time disability	1	1.5	7	10.1
Retired	45	68.2	24	34.8
Income				
0	0	0	1	1.4
<5000 but not 0	0	0	4	5.8
5000 – 10 000	0	0	3	4.3
10 001 – 20 00	9	13.6	5	7.2
20 001 - 30 000	5	7.6	8	11.6
30 001 – 50 00	18	27.3	17	24.6
50 001 – 75 00	11	16.7	16	23.2
75 000 – 100 0	6	9.1	2	2.9
> 100 000	4	6.1	6	8.7
no disclosure of income	13	19.7	7	10.1

Materials

Centre for Epidemiological Studies - Depression Scale (CES-D). The Centre for Epidemiological Studies - Depression Scale (CES-D) is a 20-item self-report measure which assesses depressive symptomatology (Radloff, 1977). Its items are based on other measures of depression, such as the Beck Depression Inventory, the Minnesota Multiphasic Personality Inventory, and several other measures of depression (Radloff, 1977). The individual is asked to indicate how often he or she has experienced the queried symptoms along a 4-point scale, ranging from 0 (rarely or none of the time) to 3 (most or all of the time). Items 4, 8, 12, and 16 are scored in reverse, and all items are then totalled. A score of 16 or greater is an indication of clinical depression. This measure is commonly used in epidemiological studies as it has demonstrated high internal consistency (Cronbach's $\alpha = .89$), and strong validity (Radloff, 1977). The CES-D also demonstrated a high internal consistency within this project's sample of cancer patients (Cronbach's $\alpha = .91$).

The CES-D also has demonstrated reliability and validity among cancer patient populations, and has been found to be resistant to confounds due to symptom overlap within these populations (Devins, Oprme, Costello, Binik, Frizzell, Stam & Pullin, 1998; Hann, Winter & Jacobsen, 1999). The CES-D has also demonstrated acceptable reliability and validity among both African-American and Caucasian samples of elderly age groups (Callahan & Wolinaky, 1994; $M = 68.8$ years; $SD = 7.9$ years; Lewinsohn, Seeley, Roberts & Allen, 1997; $M = 63.9$ years, $SD = 7.2$ years). It has also been concluded that neither age, gender, functional impairment, or physical disease have a significant negative effect on the psychometric properties or screening efficacy of the CES-D among these populations (Callahan & Wolinaky, 1994; Lewinsohn, Seeley, Roberts & Allen, 1997). Finally, the CES-D has been shown to be more discriminating

than the Beck Depression Inventory in both college student and depressed outpatient populations (Santor, Zuroff, Ramsay, Cervantes & Palacias, 1995). Thus, the CES-D is appropriate for use in determining both the incidence and severity of clinical depression in cancer populations (Devins, Oprme, Costello, Binik, Frizzell, Stam & Pullin, 1998).

Perceived Social Support, Friends; Perceived Social Support, Family. The Perceived Social Support, Friends (PSS-Fr) is a 20-item measure of perceived emotional support available from one's friends. The Perceived Social Support, Family (PSS-Fa) consists of the same 20-items with the wording changed in order to ask about available emotional support an individual perceives to be available from his or her family members. All items are scored on a three-point scale (yes, no, I don't know). Responses indicating greater social support are given a score of 1; all other responses (including "I don't know") are scored as a 0. Scores range from 0 to 20 for each measure, with higher scores indicating greater social support. The PSS-Fr has demonstrated an internal reliability coefficient of .88 and the PSS-Fa has demonstrated an internal reliability coefficient of .90 (Procidano & Heller, 1983), as well as adequate test-retest reliability and validity (Procidano & Heller, 1983; Procidano, 1992; Streeter & Franklin, 1992). Internal consistency for this study was determined to be within acceptable limits as well (Cronbach's $\alpha = .91$ for PSS-Total, Cronbach's $\alpha = .89$ for PSS-Fa; and Cronbach's $\alpha = .86$ for PSS-Fr.) The PSS-Fa/PSS-Fr has also demonstrated significant positive relationships with other social support indices (Procidano, 1992), and high scores on this measure has been associated with fewer symptoms of anxiety and depression, and fewer reported feelings of stress (Bachar, Canetti, Bonne, Denour & Shalev, 1997; Procidano, 1992).

Demographic Items. In order to obtain as much information about the participants as possible, extensive demographic information was obtained using items

from the Winnipeg Area Study (Michaud & Lewis, 2002).

Health Status. Information was also collected from participants regarding their disease stage at time of diagnosis, their current disease status, and which medical treatments they underwent (e.g. surgery, radiation, chemotherapy, or hormone therapy). Information was also collected in terms of which treatments participants anticipated requiring within the next 6 months. An item assessing satisfaction with medical care was also included, as were questions assessing common treatment side effects (e.g., sleep disturbance due to frequent nocturnal urination, degree of urinary dysfunction, and urinary control). Many of these items were pulled from Litwin's Health Related Quality of Life Scale for Men with Prostate Cancer (Litwin, 1994). These items were reworded for the assessment of the women with breast cancer in order to reflect differences in side effects common to the treatments for breast cancer (e.g., sleep disruption due to hot flashes, degree of lymphedema, and range of arm motion post-surgery). Both the men with prostate cancer and the women with breast cancer were also asked about sexual dysfunction and their degree of distress in regard to their current level of sexual function, as these are also frequent negative effects of treatment for both groups (McKee & Schover, 2001).

Items assessing perceived need for social support. As one of the goals of this project was to determine whether or not men with prostate cancer perceive themselves as having a need for additional social support beyond what is currently offered, several items were included that assessed their perception of need for social support. Specifically, items assessed the men's views on whether or not they perceive a need to participate in a prostate cancer support group, as well as what topics they would like to see discussed. Items were also included with the intention of assessing possible barriers to participation in support groups, including a lack of perceived need,

embarrassment, and the belief that talking about issues not only doesn't make them better, but might make things worse. For comparative analysis purposes, the sample of women with breast cancer was also given these questions. Complete questionnaire packages for both men with prostate cancer and women with breast cancer can be found in Appendices A and B, respectively. The contact letter/consent form is in Appendix C.

Procedure

A random sample of 190 men with prostate cancer and 190 women with breast cancer was generated using the Manitoba Cancer Registry, which is a database of all people diagnosed with cancer in the province of Manitoba. Each individual was mailed a cover letter detailing the purpose and requirements of the study, a consent form, and a questionnaire package. Participants were asked to complete the questionnaires and to return them in the stamped, self-addressed envelope provided. Anyone wishing not to participate was asked to return a blank questionnaire in the provided envelope. Participants were also instructed to return partially completed questionnaires in the event that they elected to withdraw from the study at any point during their participation, and told that their responses in this event would not be analysed. In order to protect the anonymity of each participant, consent forms were immediately separated from completed questionnaires upon receipt. Questionnaires were then scored and analysed. Any participant wishing written feedback about the study was provided the opportunity to give their name and mailing address (to be kept separate from their questionnaire data) so that they can be mailed a summary of the study findings at the conclusion of the project.

For the qualitative analysis, the participants' responses were initially reviewed with an eye towards identifying possible themes. When themes were identified, each

putative theme was assigned a code. A second review of the data was then performed, and responses were coded according to reflected theme. The themes and coding system was then provided to a second rater (a doctoral level psychology graduate student), who independently reviewed and coded the data for the putative themes. Inter-rater reliability was high, $r(135) = 0.94$, as the emerged themes were generally clearly articulated.

Results

Given the condition that partially completed questionnaires were considered an indication of the participant's desire to withdraw from participation in the study, questionnaires with substantive items left blank (more than 1 item on each of the CES-D, PSS-Fr or PSS-Fa, or failure to respond to more than 3 demographic items) were interpreted as an indication of non-participation and were not analyzed. Only 3 questionnaires met this criteria. While it appeared that these individuals had missed the completion of a page rather than made a deliberate decision to discontinue responding (as subsequent pages had been completed) these questionnaires were nevertheless discarded as per the study's protocol.

Participants were generally very consistent in providing complete data. For the total sample, a total of 6 (out of 2700) items were missed on the CES-D (4 items for the sample of women with breast cancer, 2 for the men with prostate cancer), and no more than one item was missed per participant. For measures of perceived social support, only one item (of 2700) was missed for PSS-Fr and one (of 2700) for PSS-Fa; both were from the breast cancer sample. Again, no more than one item was missed per participant. Given the small number of missing values, missing values were replaced using the sample mean.

In regard to the demographic questions, three participants (two from the breast

cancer sample, one from the prostate cancer sample) declined to provide information regarding their age. Thirteen men and seven women declined to provide information regarding income. All participants provided complete information on marital status, level of education, and the number of family members living in their household. Missing data for age and income was, therefore, excluded from subsequent analysis.

Regarding health status, all participants provided detailed information regarding time of diagnosis, treatments received, disease stage, and whether or not they had experienced a local recurrence or metastatic disease progression. All participants provided complete information regarding the following treatment related side effects: sleep disturbance, range of arm motion (women), and urinary control (men). Two men declined to provide information regarding urinary function (ease and frequency of urination), and two women declined to provide information regarding difficulties with lymphedema. Missing data was excluded from subsequent analysis regarding treatment side effects.

The most consistent area of nondisclosure was in the area of sexual function. Twelve women declined to provide information regarding sexual function (many citing widowhood as the reason for their inability to respond to this item), as did four men. Seven women declined to provide information regarding their degree of satisfaction with their sexual function, as did three men. Given that these were clearly not random nondisclosures, these items were not replaced by the sample mean, and these participants were not included in subsequent analyses of sexual function or distress regarding sexual function.

Given the lack of literature to suggest the direction of relationships between variables for the prostate cancer population, two-tailed analyses were performed for all comparisons. A significance level was set at .05 for all analyses.

In order to determine whether there were any significant demographic differences between participants, two-tailed independent samples t-tests were performed for interval data demographic variables (age, education, income), and chi-square analysis was performed regarding categorical data variables (marital status). Not surprisingly, the men with prostate cancer were significantly older than the women with breast cancer, $t(116.25) = -11.974, p < .01$, equal variances not assumed as Levene's Test of Equality of Variance $F(1, 130) = 7.294, p < .01$. Despite this, they reported no significant differences in level of education, $t(102.73) = -0.806, p > .05$, equal variances not assumed as Levene's Test of Equality of Variance $F(1, 132) = 23.75, p < .01$, or family income, $t(113) = 0.228, p > .05$. However, significantly more men were married or living with a common-law spouse than were the women with breast cancer, $\chi^2(1, 135) = 11.862, p < .05$.

In order to determine whether there were significant differences between the prostate cancer and breast cancer samples in terms of acuteness of diagnosis and treatment, two-tailed independent sample t-tests were performed on measures of time since diagnosis and time since last treatment. No differences were found between the prostate cancer group and the breast cancer group in terms of either time since diagnosis, $t(133) = 0.591, p > .05$, or time since last treatment, $t(133) = 0.007, p > .05$. Equal variances were determined between groups for each of these variables (Levene's test for Equality of Variance $F(1, 133) = 2.49, p > .05$ and $F(1, 133) = 0.000, p > .05$ for time since diagnosis and time since last treatment, respectively).

Given the categorical nature of disease stage, the experience of local recurrence, and the experience of metastatic spread, Chi-Square analyses were performed in order to determine whether or not there was any difference in disease stage at time of diagnosis, local recurrence, or metastatic spread between the two

groups. Although the women with breast cancer demonstrated a more advanced disease stage at time of initial diagnosis than the men with prostate cancer, $\chi^2(2, N = 135) = 9.77$; $p < .05$, no significant differences were noted in terms of incidence of local recurrence since the time of diagnosis, $\chi^2(1, N = 135) = 3.61$, $p > .05$, or metastatic disease progression, $\chi^2(1, N = 135)$, $p > .05$, between the two groups.

The groups were also compared in terms of common side effects to the various treatments for the respective disease sites. Although these are not the same side effects for each group, parallels were drawn in order to allow for comparisons regarding the severity of the unique treatment side effects associated with each disease site. For example, the women with breast cancer were assessed in regard to sleep disturbance due to hot flashes as a result of Tamoxifen/other hormone therapy; the men with prostate cancer were assessed in regard to sleep disturbance due to the need to frequently urinate during the night. Lymphedema and range of motion in the affected arm were also assessed for the women with breast cancer, as these are common side effects following the surgical removal of the lymph nodes common to staging procedures, and are exacerbated by radiation therapy post-surgery. The men with prostate cancer were similarly assessed in regard to urinary incontinence and urinary function, as these are common side effects to both radical prostatectomy and external beam radiation therapy for the treatment of prostate cancer.

Thus, two-tailed independent samples t-tests were used in order to determine whether there were any significant differences between the groups in terms of most of these reported treatment side effects. The men reported no significant differences in sleep disturbance than did the women, $t(128.31) = 0.454$, $p > .05$; equal variances not assumed as Levene's Test for Equality of Variances $F(1, 133) = 8.301$, $p < .05$, nor did they report significantly different levels of functional impairment as a result of their

treatment (urinary control vs. range of motion in the affected arm), $t(133) = 3.17$, $p >$

.05. Frequency statistics for each side-effect can be seen in Table 3.

Table 3

Reported side effects as a result of treatment for both men and women

	Men (N)	%	Women (N)	%
Sleep disturbance due to tx				
Very much	7	10.6	11	15.9
A fair bit	12	18.2	14	20.3
A little	35	53.0	18	26.1
Not disturbed at all.	12	18.2	26	37.7
Functional limitation due to poor range of motion of arm (women) or poor urinary control (men)				
Severe limitation	3	4.5	1	1.4
Moderate limitation	3	4.5	6	8.7
Mild limitation	25	37.9	24	34.8
No limitation	35	53.0	38	55.1
Problems with lymphedema (women) or urinary function (men)				
No problem	27	40.9	46	66.7
Very small problem	18	28.1	10	14.5
Small problem	10	15.6	6	8.7
Moderate problem	5	7.8	3	4.3
Very big problem	4	6.1	2	2.9
Did not respond	2	3.0	2	2.9

However, the men with prostate cancer did report experiencing significantly greater problems in terms of urinary function (a common side effect of surgery and radiation therapy for prostate cancer) than did the women in regard to issues with lymphedema (a common side effect to surgery and radiation therapy for breast cancer), $t(129) = -2.525, p < .05$. Just under fourteen percent (13.9%) of the men with prostate cancer reported that their urinary function was either a moderate problem (7.8%) or a very big problem (6.1%) for them, and another 15.6% reported that it was a small problem; in total, 29.5% of the men in this sample reported at least some difficulties with urinary function.

In contrast, only 2.9% of the women with breast cancer identified their symptoms of lymphedema as a very big problem, another 4.3% rated it as a moderate problem, and just over eight percent (8.7%) reported their symptoms of lymphedema as being a small problem. In total only 15.9% of the sample of women with breast cancer reported difficulties with lymphedema, while the remainder (81.2%) described themselves as experiencing either only a very small problem or no problem at all.

The men with prostate cancer also reported significantly higher levels of sexual dysfunction than did the women with breast cancer, $t(104.93) = 7.497, p < .01$; equal variances not assumed as Levene's Test for Equality of Variances $F(1, 117) = 6.81, p < .01$. Over sixty-three percent of this sample (63.6%) rated their sexual functioning as very poor. An additional 9.1% reported their sexual functioning as poor, and 12.1% rated their sexual functioning as being fair. Only 9.1% of the sample rated their sexual function as good (7.6%) or very good (1.5%) following their treatment for prostate cancer.

Although chemotherapy and adjuvant hormone therapies have been shown to create significant levels of sexual dysfunction in women with breast cancer (McKee &

Schover, 2001), only 21.7% of this sample of women with breast cancer reported levels of sexual functioning within the very poor (13.0%) or poor (8.7%) ranges, and 15.9% reported their level of sexual functioning as fair. Almost half of the sample (44.9%) reported levels of sexual functioning as being good (21.7%) or very good (23.2%). For information about reported degree of sexual function, please refer to Table 4.

Table 4

Reported level of sexual function for both men and women

	Men (N)	%	Women (N)	%
Level of sexual function				
Very Poor	42	63.6	9	13.0
Poor	6	9.1	6	8.7
Fair	8	12.1	11	15.9
Good	5	7.6	15	21.7
Very Good	1	1.5	16	23.2
Did not respond	4	6.1	12	17.4

Not surprisingly, the men also reported significantly greater levels of distress in regard to their ability to function sexually, $t(115.75) = 4.121, p < .01$, equal variance not assumed as Levene's Test of Equality of Variance $F(1, 123) = 12.997, p < .01$. Over forty-three percent (43.9%) of the sample reported feeling either distressed or very distressed about their level of sexual function; in contrast, only 10.1% of the women reported this degree of distress (please refer to Table 5 for information about the reported degree of distress regarding sexual function for both men and women).

Table 5

Reported degree of distress in regard to current level of sexual function

	Men (N)	%	Women (N)	%
Level of distress				
Very Distressed	13	19.7	3	4.3
Distressed	16	24.2	4	5.8
Neutral	7	10.6	11	15.9
Not very distressed	7	10.6	9	13.0
Not distressed at all	20	30.3	35	50.7
Did not respond	3	4.5	7	10.1

Collectively, this would suggest that men with prostate cancer experience more profound treatment related side-effects than do women who have undergone treatment for breast cancer, particularly in the area of sexual dysfunction. They also report more profound distress about their loss of sexual function than do the women with breast cancer. Given that individuals with more persistent side effects as a result of their cancer treatments have been shown to demonstrate higher levels of psychological morbidity following diagnosis (Walker, et. al., 1996), the men in this sample may be more likely to demonstrate higher levels of depression as a result.

Despite the greater degree of functional limitation and sexual side effects reported by the men with prostate cancer, no significant differences were noted in terms of reported satisfaction with their medical care when compared to the women with breast cancer, $t(133) = 1.414, p > .05$. They also reported no greater or lesser fear that the cancer would ultimately take their life than did the women with breast cancer, $t(133) = -0.997, p > .05$. However, despite fewer persistent side effects of treatment,

the women with breast cancer expressed a significantly higher fear of recurrence than did the men with prostate cancer, $t(107.919) = -3.152, p < .01$, equal variance not assumed as Levene's Test of Equality of Variance $F(1, 133) = 15.57, p < .05$. This is likely reflective of the ability to monitor tumour activity via PSA testing for men with prostate cancer, thus reducing the degree of uncertainty in regard to whether or not they are experiencing a recurrence of their disease.

In terms of accessing social support, no significant differences were evident between the groups in terms of whether or not they had ever sought out psychotherapy as a means of coping with their cancer diagnosis, $\chi^2(1, N = 133) = 0.22, p > .05$, or in their level of attendance at support group meetings, $t(127.81) = 1.601, p > .05$, equal variance not assumed as Levene's Test of Equality of Variance $F(1, 133) = 4.48, p < .05$. Surprisingly, they also expressed no significant difference in their interest in participating in a support group, $t(133) = 0.574, p > .05$, although women with breast cancer are known to be significantly greater consumers of both psychotherapeutic services and support group services in the community.

Also of interest, no significant differences were found in regard to men and women's conceptualizations of support. Both groups endorsed the idea of support involving the provision of information about their disease, $t(133) = 0.462, p > .05$, as well as the idea that support involves the ability to discuss the emotional aspects of their illness, $t(133) = -1.974, p > .05$. No significant difference between groups was also evidenced in regard to the perception of being able to discuss both the physical and emotional aspects of their illness with their friends and members of their family (physical, $t(133) = 0.492, p > .05$; emotional: $t(133) = 0.891, p > .05$).

However, the men with prostate cancer and the women with breast cancer did significantly differ in their expressed degree of comfort in terms of actually participating

in a support group. Using a two-tailed independent sample t-test to compare groups, the men with prostate cancer reported anticipating significantly greater levels of embarrassment about participating in support group discussions than did the women with breast cancer, regardless of their conceptualization of emotional and informational support as a positive idea, $t(98.625) = 3.806, p < .01$, equal variances not assumed as Levene's Test of Equality of Variance $F(1, 133) = 27.807, p < .01$. Over twenty-two percent (22.8%) of men indicated that they would feel at either extremely or quite embarrassed about sharing their experiences in a group, with another 21.2% reporting that they would feel at least a little embarrassed. In contrast, only 2.9% of the women reported that they would be either extremely or quite embarrassed, and the majority (76.8%) reported no embarrassment at all (please refer to Table 6 for complete comparison).

Table 6

Reported degree of embarrassment about discussing their disease in a small group

	Men (N)	%	Women (N)	%
Degree of embarrassment				
Very embarrassed	42	63.6	0	0
Quite embarrassed	6	9.1	2	2.9
A little embarrassed	8	12.1	14	20.3
Not embarrassed at all	5	7.6	53	76.8

The men with prostate cancer were also more likely to report that they did not believe that their participation in a support group would be personally helpful to them, or that it might actually make things worse for them, $t(133) = -2.198, p < .05$. Only 10.6% of respondents thought that talking about their prostate cancer would be very helpful to them, and 37.9% thought that participating in a group would be at least

somewhat helpful. Most striking, 47% indicated that they did not think that talking about their experiences with prostate cancer would be helpful at all, and 3.0% actually thought that it would make things worse for them. In contrast, 18.8% of women thought that talking about their experiences with breast cancer would be very helpful, 50.7% thought it would be at least somewhat helpful, and only 27.5% thought it wouldn't be helpful to them at all; 1.4% indicated that they thought it might make things worse (please see Table 7 for a complete comparison).

Table 7

Perceptions of how helpful it would be to talk about one's breast or prostate cancer

	Men (N)	%	Women (N)	%
How helpful do you think talking about your prostate/breast cancer would be for you?				
Very helpful	7	10.6	13	18.8
Helpful	10	15.2	12	17.4
Somewhat helpful	15	22.7	23	33.3
Not helpful at all	31	47.0	19	27.5
It would make things worse	2	3.0	1	1.4
Did not respond	1	1.5	1	1.4

Thus, while the men with prostate cancer seem to intellectually agree with the idea that both the provision of information and the opportunity to share their emotional experiences in regard to their illness is a useful enterprise, they also expressed significantly more embarrassment to actually do it, as well as a significantly higher degree of doubt that it would actually be helpful to them. Many also expressed the fear that it would just make things worse.

Taken as a whole, these data suggest that the men with prostate cancer in this sample are experiencing more profound side-effects in terms of both functional ability and sexual dysfunction post-treatment than are the women with breast cancer. Also, although they endorse the idea that both informational and expressive-supportive domains of support are important to psychological well-being following a diagnosis of cancer, they report significantly greater psychological barriers to accessing this support than do the women with breast cancer. Not only do they report a significantly higher level of anticipated embarrassment about participating in a support group, they also express higher levels of doubt that this embarrassing enterprise would be helpful to them in terms of their ability to cope. This preliminary information seems to support the hypothesis that men with prostate cancer may be more vulnerable to psychological distress following the treatment of their disease (as a result of the more profound treatment side-effects), while simultaneously experiencing greater psychological barriers to accessing social support. This would suggest that they may be more prone to depressive symptoms as well.

Consistent with Hypothesis 1, 25.8% of the sample of men with prostate cancer reported symptoms of depression of sufficient severity as to meet or exceed the threshold value for clinical depression of a score of 16 on the CES-D. This finding is within a 95% confidence interval (25.8% \pm 0.11%) of the prevalence of depression (i.e., between 25 and 40%) consistently reported in the literature for individuals diagnosed with cancer (Grassi, et. al., 1997; McDaniels, et. al., 1995; Mermelstein & Lesko, 1992). This provides evidence that men with prostate cancer are at similar risk of developing depressive symptoms following the diagnosis and treatment of their cancer as are individuals with other cancer diagnoses. This also provides evidence against the supposition that men do not seek out psychosocial support services due to

a lack of psychological distress.

Also as expected, the percentage of the sample of women with breast cancer who met the clinical depression threshold score of 16 on the CES-D also fell within a 95% confidence interval of the prevalence of depression (again, between 25 and 40%) consistently demonstrated for cancer patients in the literature (Grassi, Malacarne, Maestri & Ramelli, 1997; McDaniels, Musselman, Proster, Reed & Nemeroff, 1995; Mermelstein & Lesko, 1992). Of the sixty-nine women in this sample, 30.4% (+/- 0.11%) reported symptoms of clinical depression which met or exceeded the threshold level of 16 on the CES-D, providing evidence to support Hypothesis 2, and suggesting that this sample is relatively consistent in terms of psychological morbidity as those sampled in previous research projects.

In order to test the relationship between social support and depression for the entire sample (Hypothesis 3), a 2-tailed bivariate Pearson Product Correlation was performed between scores on the CES-D and the Perceived Social Support Total Score (the sum of PSS-Fr and PSS-Fa). Given the literature which has consistently demonstrated that high levels of social support are significantly related to lower levels of clinical depression following a cancer diagnosis (Hoskins, et. al., 1996; Manne, et. al., 1997; Pistrang, Barker & Rutter, 1997; Smith, et. al., 1985), a significant negative relationship was expected between perceived social support and depression for this sample. Surprisingly, this relationship was not found, $r(135) = -.137, p > .05$. Table 8 provides a complete description of the correlations between social support and depression, both for the total sample as well as for each disease site group (men with prostate cancer and women with breast cancer).

Table 8

Correlations between perceived social support and depression

	Men (N = 66)	Women (N = 69)	Total Sample (N = 135)
Perceived social support			
From friends	0.079	-0.154	0.015
From family	-0.091	-0.326**	-0.221*
Total	0.006	-0.272*	-0.137

* $p < 0.05$ ** $p < 0.01$

In order to test Hypothesis 4, which suggested that men with cancer may experience more barriers to mobilizing social support than do women with cancer as a result of differences in gender socialization (Baider et al, 1995; Hann, 2002; Harrison, Maguire & Pitceathly, 1995; Zakowski, et. al., 2003), a two-tailed independent samples t-test was performed to determine whether or not the men with prostate cancer in this study demonstrated a significantly lower level of perceived social support than the sample of women with breast cancer. As expected, the men with prostate cancer did demonstrate significantly lower levels of perceived social support than did the women with breast cancer, $t(133) = 1.851$, $p < .05$. The mean perceived social support score for the men with prostate cancer was 27.30 ($SD = 8.074$), and 29.78 ($SD = 7.464$) for the women with breast cancer. This provides further support to the idea that men with prostate cancer experience greater barriers to accessing adequate social support than do women with breast cancer. This also provides support to the hypothesis that this population may be more vulnerable to depressive morbidity than women with breast cancer, as lower levels of social support have been consistently demonstrated to be related to a greater vulnerability to the development of symptoms of depression

following a cancer diagnosis in the general cancer literature (Hoskins, et. al., 1996; Manne, Taylor, Dougherty, & Kemeny, 1997; Pistrang, Barker & Rutter, 1997; Smith, et. al., 1985).

To further test this hypothesis (Hypothesis 5), a two-tailed independent samples t-test was performed to assess whether or not the sample of men with prostate cancer demonstrated significantly higher levels of depression than did the sample of women with breast cancer. Surprisingly, despite significantly lower levels of perceived social support, the men with prostate cancer did not demonstrate significantly different levels of depression than did the women with breast cancer, $t(133) = 0.493, p > .05$. The men with prostate cancer obtained a mean score on the CES-D of 10.78 ($SD = 10.644$); the women obtained a mean score of 11.76 ($SD = 10.222$). This finding is unlikely due to insufficient power, as the sample size provided optimum power for this analysis, and the relationship is not even approaching a significant difference. The lack of difference in depressive symptomology is also supported by the similar prevalence rates of depression in each sample (25.8% for the prostate cancer sample; 30.4% for the breast cancer sample), both of which were consistent with prevalence rates consistently found in the psychosocial oncology literature. A Chi-square analysis of the prevalence rates also demonstrated no significant difference between the two groups in terms of the number of individuals in each sample meeting or exceeding the threshold value of 16 on the CES-D indicating the presence of clinically significant symptoms of depression, $\chi^2(1, 135) = .365, p > .05$. This provides further evidence to suggest that men are not failing to seek out psychosocial services due to a lack of depressive symptomology post-diagnosis. Neither does this suggest that this lesser demand for psychosocial services is related to a lesser proportion of the population being in need of services due to adequate adjustment. Rather, this suggests that the men with prostate cancer are

as distressed as the women with breast cancer, but are not seeking out social support because there are barriers to doing so.

In order to test whether there is a gender-related difference in the relationship between perceived social support and depression (Hypothesis 6), the relationship between perceived social support and depression was investigated independently for each disease site group using a 2-tailed bivariate Pearson Product Correlation. While the women with breast cancer evidenced a significant inverse relationship between social support and depression as expected, $r(69) = -.272, p < .05$, the men with prostate cancer did not $r(66) = .006, p > .05$ (see Table 8 for these correlations). This provides an explanation for the lack of relationship found between perceived social support and depression for the entire sample: when combined into one sample, the contribution of the men with prostate cancer's lack of relationship between social support and depression was sufficient to mask the relationship evidenced by the women. Hence, the unusual finding of no relationship between these two variables in the entire sample.

This also provides an explanation for the lack of significant difference between depressive symptomology for the men with prostate cancer in comparison to the women with breast cancer, despite their significantly lower levels of perceived social support. While perceived social support clearly has a beneficial effect in preventing depression in women with breast cancer, it does not appear to have this effect for men with prostate cancer.

Taking into consideration the body of literature that suggests that men rely much more heavily on family (or spousal) support than on a larger network of friends (Baider, et. al., 1995; Harrison, Maguire & Pitceathly, 1995; Zakowski, et. al., 2003), a post-hoc analysis was performed in order to determine whether an issue in the failure

to find a relationship between perceived social support and depression for men with prostate cancer was the contribution of the Perceived Social Support - Friends scale on this finding. Thus, a second 2-tailed bivariate Pearson Product Correlation was performed using only the Perceived Social Support - Family scale and the CES-D. Again, although a significant inverse relationship was found for the women with breast cancer between higher levels of perceived social support from friends and lower levels of depression $r(69) = -.326, p < .01$, no relationship was found between perceived family social support and depression for the men with prostate cancer $r(66) = -.091, p > .05$ (see Table 8 for these correlations).

In order to determine whether this result was the result of a violation of assumption of normality or a lack of variance in perceived social support, analysis of skewness and kurtosis was performed for perceived social support. The distributions for perceived social support for neither the men with prostate cancer, nor the women with breast cancer were skewed or kurtotic (see Table 9 for these statistics).

Table 9

Assessment of skewness and kurtosis for perceived social support

Men (N = 66)			Women (N = 69)	
Skewness	Statistic	Standard Error	Statistic	Standard Error
Pss-Fr	-0.292	0.295	-0.922	0.289
Pss-Fa	-0.715	0.295	-1.385	0.289
Pss-Total	-0.449	0.295	-0.896	0.289
Kurtosis				
Pss-Fr	-0.277	0.582	0.611	0.570
Pss-Fa	-0.441	0.582	0.805	0.570
Pss-Total	-0.475	0.582	0.395	0.570

When a similar analysis was performed for depression as measured by the CES-D, it was determined that the distribution was not skewed for the sample of men with prostate cancer, however, it was significantly kurtotic. In contrast the distribution of CES-D scores for women with breast cancer was neither skewed nor kurtotic (see Table 10 for these statistics).

Table 10

Assessment of skewness and kurtosis for CES-D scores

	Men (N = 66)		Women (N = 69)	
	Statistic	Standard Error	Statistic	Standard Error
Skewness	1.490	0.295	0.943	0.289
Kurtosis	3.056	0.582	-0.017	0.580

Thus, in order to determine whether or not the lack of variance in the men's CES-D scores may have negatively affected the determined relationship between depression and perceived social support, all scores (both CES-D and PSS-Fr, PSS-Fa, and PSS-Total) were converted into z-scores in order to force the scores into a normal distribution. Given the significant differences between the men and women across these measures, the sample mean was used for this transformation for each group.

The relationship between perceived social support (PSS-Total) and depression was then tested again for the entire sample. Again, no significant relationship was determined, $r(135) = -0.155$, $p > 0.05$. The relationship between perceived social support (PSS-Total) and depression was then tested for the sample of men with prostate cancer, and it also failed to evidence a significant relationship, $r(66) = 0.006$, $p > 0.05$. Finally, the relationship between perceived social support from family (PSS-

Fa) and depression was tested again for the sample of men with prostate cancer.

Again, no significant relationship was observed, $r(66) = -.091$, $p > 0.05$. This suggests that the lack of significant relationship between perceived social support and depression for the sample of men with prostate cancer is not a function of the lack of variance in the CES-D scores for this sample, but is rather a robust finding.

Logistic regression using the categorical depression score (i.e., a categorization of those who were depressed as indicated by a score higher than the cut-off score of 16 for probable depression on the CES-D versus those who were not) and perceived social support from family also failed to determine a significant relationship between these two variables for the men with prostate cancer, $\chi^2(1, 66) = 2.391$, $p > .05$; $B = -.121$, $p > .05$.

Finally, in order to ensure that the relationship between perceived social support and depression for men with prostate cancer was not in the form of a non-linear relationship, scatter plots were produced for both total perceived social support scores (PSS-Total) and depression and for perceived social support from family scores (PSS-Fa) and depression. A best-fit linear regression line was also plotted for these variables. As expected, no evidence of a non-linear relationship was suggested between these variables. Again, this suggests that the lack of significant relationship between perceived social support and depression for the sample of men with prostate cancer is a robust finding.

Although there is no reason to suspect that any of the demographic or health status variables that were significantly different between the women with breast cancer and the men with prostate cancer (i.e., age, marital status, disease stage, sexual function, and distress regarding sexual function) were acting as suppressor variables in regard to the relationship between depression and social support, post-hoc analyses

were nevertheless performed in order to ensure that this was, in fact, not the case. To that end, the effects of these variables were controlled for, and the relationship between total perceived social support, perceived social support from family, and depression for the sample of men with prostate cancer was assessed a final time. Again, a significant inverse relationship was not evidenced between either total perceived social support, or perceived social support from family, and depression for men with prostate cancer under these conditions (please refer to Table 11 for the complete correlational analysis).

Table 11

Correlations between perceived social support and depression (for men only)

controlling for:	Age	Marital Status	Disease Stage	Sexual Function	Distress about Sexual Function
(df)	(62)	(63)	(63)	(59)	(60)
PSS-Total	0.004	0.013	0.005	-0.012	0.038
PSS-Fa	-0.090	-0.091	-0.095	-0.094	-0.084

* $p < 0.05$

** $p < 0.01$

Unfortunately, in light of these findings, the men's self-reported beliefs that participation in a support group would not only be extremely embarrassing, but also unhelpful, may not be inaccurate. Clearly this is a significant finding in providing an explanation for the marked lack of participation noted in men with prostate cancer in regard to support group attendance.

Consistent with the quantitative findings, qualitative analysis of the items designed to elicit information about potential barriers to accessing social support

groups revealed separate themes for the women as for the men in this sample. Thirty-two women provided written responses to questions regarding possible barriers to support-group participation. The remaining thirty-seven did not provide a response to these items (53.6%), for the most part because they felt no barrier to participation in a support group.

The first theme consistently expressed by the women with breast cancer in regard to barriers to support group participation was a feeling of a lack of need because of the presence of a preexisting social support network of friends and family members who already met their emotional support needs. Typical responses suggesting this theme included "I can discuss my ongoing experiences with friends and family at present. When I have a physical question - I talk to my doctor or my oncologist," "at this point I have the moral support of my family and I feel I don't really need to confide in other people" "since being diagnosed with cancer my family, especially my husband has been very supportive. Friends and neighbors and my doctors have been most caring and supportive," "I had friends with the same problem and we were there for each other," "I have very supportive family and a few close friends who have been there for me when I needed them. After my operation they came with food, had cups of tea with me and listened. They still do. I'm very blessed" and the succinct "I have friends". Of the women who provided a written response to questions regarding barriers to participation in social support groups, 40.6% cited this as their primary reason, comprising 18.8% of the total sample.

A second prominent theme emerged with women who were further from the point of diagnosis indicating that their cancer was part of their past, and that they felt comfortable leaving it there. Typical responses for this theme included "because my breast cancer is something in the past and has no bearing on my present day-to-day

life," "I'm perfectly at ease with my past situation. Talking would only be a reminder of what's behind us," "I feel I handled my cancer very well. In the last 3 – 4 months I feel I have returned to my pre-diagnosis state both physically and psychologically," "my breast cancer was surgically taken care of. Over and out – why talk about it" and "I have come to a comfortable/good place emotionally about my cancer. I've dealt with it, put it away in a corner and got on with my life. I feel better than I've ever felt." Of the women who provided a response to these items, 53.1% cited this as their primary reason for their hesitancy in participation in a support group, comprising 24.6% of the total sample.

Finally, to a much lesser extent, the theme of being in the medical profession, or having members of their family with medical backgrounds also emerged, suggesting that this was another route by which these women were obtaining informational support separate from a formal support group, for example "as a nurse I already know that there are others in the same boat," "members of my family are medical professionals and help explain things about my diagnosis to me" and "I have two daughters in the medical profession that if I feel I need to talk to them they find time and answers for me." Approximately three percent of women cited this as a reason not to participate in a support group (2.9%), comprising 1% of the total sample.

Only twenty-eight men (42.4%) with prostate cancer elected to provide written responses in regard to possible barriers to support group participation. The remaining 38 men (57.6%) elected not to provide a written response. In contrast to the women with breast cancer, different themes emerged for the men with prostate cancer in regard to barriers associated with their lack of participation in a support group. While some men expressed themes similar to those expressed by the women with breast cancer (7.1% indicated that they feel that they already have adequate social support,

and another 7.1% indicated that they feel that it is in the past and not a part of their day to day lives), many men described their lack of interest in participating in a support group as being related other reasons.

A common expressed theme was the idea that there was neither a need nor an interest in participating in a group. These men perceived that it would not be helpful to them in any way and that they would have nothing to gain from any discussions, as they already have adequate access to information about their disease. Examples of this type of response are "not interested," "I don't feel that at this time a support group is needed," "It would not help me because I have learned a lot through research via library and internet and pamphlet called 'Our Voice,'" "I feel I would have nothing to gain from discussions," "I have access to all the information I can use right now," and "I am looking forward to my healthy future right now." Of the men who provided written responses to these items, 35.7% cited this as their primary reason for lack of participation, comprising 14.7% of the total sample.

In addition, many men expressed psychological barriers to participating in a support group, even when they did perceive that it might be of benefit to them. They expressed fears that it would be depressing, upsetting, or embarrassing. Examples of this included "I would find the discussion to be emotionally distressing," "I find these support group meetings somewhat depressing, sometimes cannot sleep afterward," "would feel uncomfortable," "embarrassing, uncomfortable," and "I am too shy." Several men also cited past experiences of humiliation while attending support group meetings during discussions of sexuality and sexual function as a barrier to future participation. For example "I have been humiliated by the coordinator when the topic is ED [Erectile Dysfunction]." While many men expressed that they would only participate in a group if it would help others (for example, "If my experience can help others, I could attend"),

other men reported that their inability to give a positive message to others was a barrier to group participation. One man poignantly wrote "It hurts to see people with false hope in their eyes. I've been there. I would not and could not tell a person with cancer 'I've beaten cancer.'" A surprising 21.4% of men who provided written responses cited this as their primary reason for lack of participation in a support group, comprising 8.8% of the total sample.

A lack of understanding about the nature and purpose of self-disclosure was also noted; these men indicated that they could not see the point in participating since they couldn't offer anything new each week. Very few men appeared to appreciate that the discussion of emotional issues, the development of friendships, and the provision of emotional support could be a component of a support group. Examples of this are "I've already told my story and I don't see the point in telling it over and over again," "I have been to some Us Too meetings. Told my story and don't want to tell the same thing over and over." Other examples of this theme are "Must deal with your own issues. Condition is yours and your reality," and "Don't want to listen to everyone's problems." Of those who provided written responses to these items, 7.1% cited this as their primary reason for their hesitancy in participating in a support group, comprising 2.9% of the total sample.

Themes of not feeling like they would be able to openly discuss their experiences or concerns also emerged, particularly in regard to sexual functioning (e.g. "can't talk about sex"). 3.6% of the men who provided written responses to these items cited this as their main barrier to participating in a support group, comprising 1.5% of the total sample.

Finally, several men cited physical location as a barrier to accessing support, indicating that they would be interested in participating in a group but that none was

offered in their rural area. Examples of this included: "live 100km north of Winnipeg," "no group in my area," and "distance." Almost eighteen percent of those who provided written responses (17.9%) cited this as their primary barrier to support group participation, comprising 7.4% of the total sample.

In regard to what participants thought they would like to see discussed in a group, while the majority of the women indicated that they would like to discuss emotional issues post-diagnosis and how to cope with the emotional aspects of their disease (including how to help their family cope), only a very small subset of men (N=3) reported an interest in talking about feelings or psychological consequences post-diagnosis. Perhaps not surprisingly, the men who responded to the question about what they would like to see discussed if they were to attend a support group frequently cited a desire to discuss sexual dysfunction and ways to cope with this (10.6%). Facing mortality (3.0%), and the living with the threat of recurrence (1.5%) were also cited as topics of interest, as was interest in informational topics such as the various treatments for prostate cancer (16.7%) and the use of alternative medicines (1.5%). The remainder of the men in this sample responded to this question by means of a question mark (or by leaving it blank), suggesting that they do not know what they would like to discuss were they to participate in a support group, and several indicated that while they did not know what should be discussed, they would like to participate if it could help someone else. Again, barriers to participation most strongly related to either fears of increasing their own distress (embarrassment, feeling depressed afterwards), or to the constraints of physical location (living in a rural community without access to a group).

Discussion

The findings of this project clearly document the physical and psychological effects of treatment for prostate cancer in this sample. Despite the fact that all of the men in this sample reported early stage prostate cancer at the time of diagnosis, with only one participant reporting the experience of a local recurrence, and no participants reporting metastatic spread since the time of diagnosis, significant functional limitations were nevertheless reported. Almost thirty percent (29.5%) of these men reported at least some degree of difficulty with urinary function, and over seventy-two percent (72.7%) rated their sexual function as either poor or very poor. In addition, over forty-three percent (43.9%) of this sample reported significant distress in relation to their level of sexual dysfunction. These functional limitations were significantly greater than those reported by the women with breast cancer who participated in this study, despite their reports of more advanced disease stage at time of diagnosis, a higher incidence of local recurrence, and one participant who reported metastatic disease. In addition, significantly fewer women with breast cancer reported significant distress in regard to their level of sexual function (10.1%), despite findings in the literature that women treated for breast cancer are also at risk of developing sexual dysfunction as a result of various treatment modalities (McKee and Schover, 2001).

Given the high incidence of persistent functional limitations following the treatment of even early-stage prostate cancer, the first goal of this study was to document the incidence of psychological distress and depression among men with prostate cancer. Given that these men consistently choose not to access social support by means of support group participation (as evidenced by the poor participation rate in my first project), and that the literature has consistently only measured rates of depression in either very small samples of men with prostate cancer, or in large

samples of men and women with other cancer diagnoses (e.g., Grassi, Malacarne, Maestri & Ramelli, 1997; McDaniels, Musselman, Proster, Reed & Nemeroff, 1995; Mermelstein & Lesko, 1992), it was questioned whether their lack of support group participation may have been related to a lack of psychological symptoms post-diagnosis, and a resulting lack of need for psychosocial services.

Consistent with the literature which indicates that between twenty-five and forty percent of cancer patients will develop symptoms of clinical depression following a diagnosis of cancer (e.g., Grassi et. al., 1997; McDaniels, et. al., 1995; Mermelstein & Lesko, 1992), this project found that men with prostate cancer do experience an incidence of depression post-diagnosis consistent with that of the general cancer population. Just over twenty-five percent (25.8%) of the sample of men with prostate cancer who participated in this project reported clinical threshold levels of depressive symptoms as measured by the CES-D, which is clearly consistent with the incidence of clinical depression consistently found within the psychosocial oncology literature for individuals with other cancer diagnoses (e.g., Grassi et. al., 1997; McDaniels, et. al., 1995; Mermelstein & Lesko, 1992).

In addition, the men with prostate cancer who participated in this study were found to demonstrate no significant difference in levels of depression than that demonstrated by the sample of women with breast cancer. This clearly suggests that their lack of participation in offered support groups is not the result of a lesser degree of psychological morbidity in this population, as has been frequently assumed by health care providers as a result of the men with prostate cancer's lack of expressed desire for psychosocial support services. Rather, this lends further evidence to suggest that their lack of utilization of psychosocial support services may be a function of greater social and psychological barriers to accessing this support than is experienced by women with

breast cancer. However, an alternate consideration was that men with prostate cancer may not be seeking out psychosocial support services because they feel adequately supported by their existing social support networks.

Thus, a second goal of this project was to assess the degree of perceived social support reported by men with prostate cancer, and to compare this level of perceived social support to a sample of women with breast cancer, a group known to seek out both extensive social support networks and social support services. Clear gender differences in the availability and mobilization of social support have been documented in the literature. Several studies have suggested that men tend to limit their self-disclosure to one confidante, and that this tends to be their spouse (Baider et. al., 1995; Hann, et. al., 2002; Harrison, Maguire & Pitceathly, 1995). However, this typical reliance on the spouse may render men more vulnerable to a lack of adequate social support should the spousal relationship not be adequately supportive (Clark, et. al., 1997; Hannum, et. al., 1991; Lepore & Helgeson, 1998), or strained by the additional stressors associated with coping with a cancer diagnosis (Clark, et. al., 1997; Hannum, et. al., 1991; Lepore & Helgeson, 1998). In addition, men with prostate cancer may experience psychological barriers to the reliance on their spouse for social support (Clark, et. al., 1997; Lepore & Helgeson, 1998), or they may be unmarried, again leaving them more vulnerable to a lack of adequate social support. Thus, it was expected that the men with prostate cancer in this sample would evidence less social support than did the women with breast cancer.

Consistent with this expectation, the sample of men with prostate cancer in this study did report significantly less perceived social support than did the women with breast cancer. This was consistent regardless of the source of support; men reported consistently less perceived support from both friends and family members than did the

sample of women with breast cancer.

The implications of this initially seemed clear: the men with prostate cancer not only demonstrated an equal incidence of clinical depression following their diagnosis than did the women with breast cancer, but they also reported significantly lower levels of perceived social support than did the women with breast cancer. In addition, they reported no lesser interest in participation in a support group than did the women in this sample, nor did they express any differences in their conceptualizations of support. Both the men and the women also expressed the belief that support constitutes both the provision of information about one's illness, and the ability to share the emotional effects as a result. Thus, given their lesser degree of perceived social support, with their similar conceptualization of the need for such social support, it seemed that the men's lack of participation in the offered supportive-expressive therapy groups was solely related to psychological barriers in accessing this offered support.

Consistent with this hypothesis, the men with prostate cancer did report significantly greater psychological barriers to participation in support groups than did the women with breast cancer. The men in this sample clearly expressed significantly higher levels of embarrassment in regard to discussing their disease-related difficulties within a small group setting than did the women. They also reported a significantly higher degree of doubt that this type of sharing would be helpful, and many actually expressed a fear that it would make things worse.

Similar themes emerged in the qualitative analyses. In contrast to the women, whose most frequently cited reason for lack of participation in a support group was the existence of a pre-existing network of supportive friends and family members, a large number of the men with prostate cancer (21.4%) cited the belief that talking about their side-effects would not change anything and would just be depressing and

embarrassing as barriers to their participation in a group. Several also expressed a concern that they would not feel comfortable discussing their real issues in the context of a group, and would as a result leave group meetings with their needs remaining unmet.

These reported fears of embarrassment and worry about not being able to fully self-disclose also appeared to support the hypothesis that the current prostate cancer support group format may not be meeting the emotional support needs of these men. Consistent with the limited research performed on the role of current support groups available to men with prostate cancer (Calabrese, 1995; Gray, et. al., 1997; Kaps, 1994; Poole, et. al., 2001), which suggested that men may obtain excellent informational support from the existing groups, but may experience barriers to obtaining sufficient emotional support due to large meeting sizes, the time between meetings, and a lack of continuity in the membership meeting to meeting, several men in this sample disclosed that they had experienced feelings of public humiliation during discussions of sexual dysfunction during the monthly Manitoba Prostate Cancer Support Group meetings. This was also an expressed theme during the two closed groups that were run for the previous project; members clearly articulated that it was easier and more satisfying to discuss their emotional and sexual issues in the context of a small, closed, facilitated group which allowed for the development of a safe environment in which to explore these issues.

However, while this initially suggested that men with prostate cancer demonstrate an equal or greater need for facilitated supportive-expressive social support groups in comparison to women with breast cancer, the results of this study suggest that this hypothesis may not be entirely accurate. In contrast to the findings of Hann, et. al., (2002), clear gender differences were found in the relationship between

perceived social support and depression when the sample of men with prostate cancer was compared to the sample of women with breast cancer. While the women with breast cancer clearly demonstrated a significant relationship between adequate perceived social support and fewer symptoms of depression, this relationship was not found for the men with prostate cancer. Surprisingly, they neither demonstrated a significant relationship between total perceived social support and depression, nor a significant relationship between perceived family social support and depression. In light of these findings, the provision of an intervention aimed at increasing perceived social support seems unlikely to have a positive effect on ameliorating symptoms of depression in this population.

These findings suggest clear implications in terms of the provision of psychotherapeutic services for this population. Despite a lack of requested service, men with prostate cancer clearly experience significant levels of psychological distress following the diagnosis and treatment of their disease, particularly in regard to treatment-related sexual dysfunction. Thus, agencies offering medical treatment services to these men need to be more fully aware of the psychological morbidity associated with this diagnosis, the need for more accurate screening of distress among men with prostate cancer, and the need to provide psychological services for this population.

However, given the finding of a lack of a significant relationship between perceived social support and depression for men with prostate cancer, a more difficult issue arises as to the best approach for the provision of service for this population. Clearly, the provision of traditional expressive-supportive support groups is not an appropriate option given the results of this study. Thus, while the extrapolation of the current body of literature regarding the incidence of depression among men with

prostate cancer was a valid assumption, making related assumptions regarding their resultant social support and/or psychotherapeutic intervention needs based on extrapolations from the current literature on the role of social support and depression for women with breast cancer was not. What has demonstrated efficacy for women with breast cancer seems unlikely to be effective for this population. Thus, further research in regards to effective treatment options specific to men with prostate cancer is clearly indicated.

Limitations of the Study

The most clear limitation of this study is that the sample obtained of both men with prostate cancer and women with breast cancer is clearly not representative of the general population of men living with prostate cancer or women living with breast cancer in Manitoba. Not only did the study fail to obtain its projected sample size of 95 participants per group in the interests of obtaining a representative sample of men with prostate cancer and women with breast cancer in the province of Manitoba, but there was a clear response bias in terms of the physical status of the participants. Unfortunately, individuals with advanced disease at time of diagnosis chose not to participate in this project. Additionally, very few who had experienced a local recurrence or metastatic spread returned completed questionnaires. This was clearly not the fault of the selection process; participants were randomly selected from the Manitoba Cancer Registry in sufficient number to produce a representative sampling in regard to disease stage. Unfortunately, one cannot control who then chooses to participate. It is likely that those with more advanced disease experience more significant functional limitation and/or psychological distress than those with early-stage disease, and may have been less able to complete the questionnaire. To support this idea, many of the returned questionnaires were accompanied by notes from either the

individual with the cancer diagnosis or a family member of that person indicating that they were simply too ill to participate.

The time since diagnosis of the participants also appears to reflect a bias in the sample. The mean time since diagnosis for the women was 3.66 years ($SD = 2.21$ years); the men reported a mean time since diagnosis of 3.45 years ($SD = 1.82$ years). The average time since last treatment was 2.93 years ($SD = 1.97$ years) for the women, and 2.92 years ($SD = 1.96$ years). While this provides considerable evidence for the longevity of both psychological morbidity and the experience of significant treatment side-effects following the diagnosis and treatment of cancer, even within those with early-stage disease that has neither recurred nor developed into metastatic disease, this sample does not accurately capture the experience of those within the active treatment phase. It also does not significantly include the experiences of men and women within the first year post-diagnosis when the physical, psychological, and social stressors may be the most acute. Again, this was not able to be controlled during the recruitment of participants. While individuals closer to diagnosis would have been included in those approached to participate via random sampling through the Manitoba Cancer Registry, those in the more acute phases of their diagnosis and treatment may not have had sufficient psychological or physical resources to contribute to this project, given that treatments for both breast and prostate cancer are clearly both physically and psychologically taxing.

A final limitation was in regard to the collection of demographic information in regards to ethnic identity. Although the item assessing this factor was used from the Winnipeg Area Survey and had been designed exclusively for residents of Manitoba, most respondents either misunderstood the question or did not wish to disclose that information. While many participants responded as expected to the item (for example,

indicating that they were of Scottish, English, Native Canadian or Métis descent), a considerable number either left the item blank or simply identified themselves as "Canadian." It was, therefore, felt that this item could not be reliably interpreted.

Thus, while the conclusions of this project can be generalized for individuals with early stage disease who are between approximately one to five years post-diagnosis, these generalizations may not accurately reflect the experience and support needs of individuals with breast or prostate cancer during the acute treatment phase of their illness. As a result, this remains an area for further investigation. However, given the reported degree of ongoing psychological distress of both of these populations, psychological interventions are clearly indicated for individuals during this post-treatment phase. Thus, even with these limitations, the findings of this study are relevant and useful.

Proposed Areas of Future Research

A clear finding of this project is the high incidence of sexual dysfunction and urinary dysfunction reported by men treated for even early stage prostate cancer, and the resultant distress which is associated with this. In addition, based on the qualitative data, this appears to be the area for which many men are requesting support. However, it seems that even should the challenge be met of overcoming the psychological barriers experienced by men with prostate cancer in regard to their participation in psychotherapeutic interventions for these issues, it remains unclear as to what the most effective approach may be in providing psychological services for this issue. Given the lack of relationship between perceived social support and depression found for this population, expressive-supportive approaches designed to increase perceived social support seem unlikely to provide much benefit; the men's expressed perceptions of this merely increasing their feelings of embarrassment and distress may

not be entirely inaccurate. Although this was not my experience with the small sample of men who did participate in the initial expressive-supportive therapy groups associated with the first project, they were clearly not representative of the prostate cancer population at large; when only 10 men agree to participate in an intervention offered to over 700 men with the same illness, a response bias is clearly indicated.

Given the reported desire to address issues of sexual dysfunction, the recent information/discussion group intervention designed by Lepore, et. al. (2003) may be a promising avenue of investigation. However, as their measured end-points only included having accurate information about prostate cancer and issues related to "being bothered by sexual problems," it is unclear how related this is to symptoms of depression in this population. Their groups were also only effective for men with lower levels of education; no difference was found for college-educated men.

Didactic interventions as suggested by Weber et. al. may also hold promise, although they were unable to find any differences in depressive symptomology after only 8 weeks between those meeting with a long-term survivor of prostate cancer and those who received standard medical care without the benefit of this support.

It is also possible that a physiological approach may be ultimately be the most effective treatment approach for this population. Adequate diagnosis and psychopharmacological treatment of depressive symptoms may be an effective approach to symptom management for this population, particularly in light of their reluctance to participate in psychotherapeutic interventions.

Although the reduction in the physical side-effects of treatment is also a clearly needed area of investigation, cognitive-behavioral approaches in challenging these men's belief systems about the implications of their sexual dysfunction and urinary incontinence may also be of benefit. Although cognitive-behavioral approaches have

not been demonstrated to be the most effective treatment modality for women with breast cancer, men with prostate cancer clearly demonstrate different intervention needs than do women with breast cancer. An expressed belief noted in the expressive-supportive support groups that were run for the first project was that the inability to have intercourse due to insufficient erectile function meant that all sexual activity needed to be abandoned. It was also noted in the men's discussions of their post-treatment sexual dysfunction that a common belief was that their sexual dysfunction made them lesser quality husbands than they were prior to their illness. This also suggests room for further investigation of the efficacy of confronting and challenging these beliefs.

In sum, the body of literature regarding psychotherapeutic services for individuals with cancer has been based on a foundation of the known relationship between an adequate level of social support and a lower incidence of depression. Given that this relationship does not appear to hold true for men with prostate cancer, further study of what does buffer men with prostate cancer from developing symptoms of depression following diagnosis is needed, with clear emphasis on the design of effective intervention techniques. The assumption that men with prostate cancer will benefit from the same interventions as individuals with other cancer diagnoses is clearly erroneous, and needs to be addressed with further study.

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Appendix A: Questionnaire Package for Men with Prostate Cancer

**Quality of Life Survey for Men with Prostate
Cancer**

Protocol #P2003:035

Principal Investigators:

**Carey Mintz, M.A.
Marvin Brodsky, Ph.D., C.Psych.**

**Department of Psychology
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In Association with CancerCare Manitoba

These first questions are about your experiences with prostate cancer. Some of these items may be personal, but they are very important for our research. Please answer honestly, and DO NOT WRITE YOUR NAME ANYWHERE ON THIS SURVEY.

1. When were you first diagnosed with prostate cancer (month/year)?

2. Have you ever had any of the following treatments for prostate cancer?
(Please circle YES or NO for every item)

- | | No | Yes | |
|---|----|-----|---------------------------------------|
| a. Radical prostatectomy
(surgery to remove the prostate through an incision in the abdomen) | 1 | 2 | Month & year of surgery: _____ |
| b. Radiation | 1 | 2 | Month & year of last treatment: _____ |
| c. Orchiectomy
(removal of testicles) | 1 | 2 | Month & year of surgery: _____ |
| d. Lupron/Zoladex shots | 1 | 2 | |
| e. Flutamide pills | 1 | 2 | |
| f. Casodex | 1 | 2 | |
| g. Other (please specify in space provided): | | | |

3. If you have received any treatment more than once, please use this space to detail what treatments you have had, and when.

4. Do you anticipate that you will be having any upcoming treatments for your prostate cancer within the next 6 months? (please circle one answer)

No Yes

If yes, what treatments do you anticipate having, and when do you anticipate having them? (please specify in the space below)

5. When you were first diagnosed, what was your PSA level?

6. When you were first diagnosed, what was your Gleason score?

7. At what stage was your cancer when you were first diagnosed?

- | | |
|---|---|
| Confined to the prostate | 1 |
| In the prostate and the tissue surrounding the prostate | 2 |
| The prostate cancer had also spread to my lymph nodes | 3 |
| The prostate cancer had spread to other parts of my body
(e.g., bones, bowel, lung, liver, etc.) | 4 |

8. Since you were diagnosed, have you experienced a local recurrence (i.e., recurrence in the area surrounding the prostate)? (if so, please indicate how long after you were first diagnosed that your cancer recurred).

No	Yes
	Time since first diagnosis:

9. Since you were diagnosed, has your cancer spread to any other part of your body? (if so, please indicate to what parts of your body, and how long ago this occurred).

10. How much would you say that your sleep has been disturbed by having to get up to go to the bathroom to urinate at night?

- | | |
|--------------|---|
| Very Much | 1 |
| A Fair Bit | 2 |
| A Little Bit | 3 |
| Not At All | 4 |

11. Which of the following best describes your urinary control during the last 4 weeks?

- | | |
|------------------------------------|---|
| No control whatsoever | 1 |
| Frequent loss of bladder control | 2 |
| Occasional loss of bladder control | 3 |
| Total control | 4 |

12. Overall, how big a problem has your urinary function been for you during the last 4 weeks?

- | | | |
|--------------------|---|---------------------|
| No problem | 1 | |
| Very small problem | 2 | |
| Small problem | 3 | (Circle one number) |
| Moderate problem | 4 | |
| Big problem | 5 | |

13. Overall, how would you rate your ability to function sexually during the last 4 weeks?

- | | | |
|-----------|---|---------------------|
| Very poor | 1 | |
| Poor | 2 | |
| Fair | 3 | (Circle one number) |
| Good | 4 | |
| Very Good | 5 | |

14. Overall, how distressed are you about your level of sexual functioning?

- | | | |
|-----------------------|---|---------------------|
| Very distressed | 1 | |
| Distressed | 2 | |
| Neutral | 3 | (Circle one number) |
| Not very distressed | 4 | |
| Not distressed at all | 5 | |

15. Overall, how satisfied are you with the treatment you received for your prostate cancer?

- | | | |
|------------------------|---|---------------------|
| Extremely dissatisfied | 1 | |
| Dissatisfied | 2 | |
| Uncertain | 3 | (Circle one number) |
| Satisfied | 4 | |
| Extremely satisfied | 5 | |

16. How much do you worry about recurrence?

- | | | |
|--------------|---|---------------------|
| Very Much | 1 | |
| A Fair Bit | 2 | |
| A Little Bit | 3 | (Circle one number) |
| Hardly ever | 4 | |
| Not At All | 5 | |

17. Do you ever worry about the prostate cancer ending your life?

- | | | |
|--------------|---|---------------------|
| All the time | 1 | |
| Often | 2 | |
| Sometimes | 3 | (Circle one number) |
| Hardly ever | 4 | |
| Not at All | 5 | |

18. Do you attend any support group meetings for your cancer?

- | | |
|--|---|
| Yes, regularly (rarely miss a meeting) | 1 |
| Yes, often (go to most meetings) | 2 |
| Yes, but infrequently (go once in a while) | 3 |
| Yes, but only for interesting guest speakers | 4 |
| I used to go when I was first diagnosed, but not anymore | 5 |
| No, not at all | 6 |

19. Have you ever seen a therapist to talk about issues related to your cancer?

Yes No

20. Would you be interested in participating in a support group for the purposes of discussing your personal experiences with cancer? (please circle yes or no)

Yes No

a) If no, could you specify why not?

21. If you **were** interested in participating in a support group to discuss your personal experiences with prostate cancer and the effects of its treatments, would there be any reasons why you might choose not to participate in one? (If yes, please explain what factors might make you hesitant to participate in a group of this type)

22. If you were to attend a support group for your cancer, what would you like to discuss at the meetings?

23. Do you think that "support" includes being provided with information about your disease?

Yes 1
No 2

24. Do you think that "support" includes sharing your feelings and reactions about your cancer with others who have had the same experience?

Yes	1
No	2

25. When you discuss your illness with people to whom you are close do you tell them about:

The physical details of your condition?

Yes	1
No	2

How this condition has affected your life?

Yes	1
No	2

26. Do you think you would feel embarrassed to talk about your experiences with your prostate cancer within a small, private group?

Very embarrassed	1
Quite embarrassed	2
A little embarrassed	3
Not embarrassed at all	4

27. How helpful do you think talking about your prostate cancer would be for you?

Very Helpful	1
Helpful	2
Somewhat Helpful	3
Not Helpful At All	4
It has made (or would make) things worse	5

27. If you indicated in the previous question that you don't think that talking about your experiences with prostate cancer would be helpful to you, please specify why in the space below.

Here is a series of questions which describe the way people sometimes feel or behave.
Please circle the answer that describes how often you have felt this way **during the past week.**

Use the following Scale

- 1 = Rarely or none of the time (less than 1 day)
2 = Some or a little of the time (1 to 2 days)
3 = Occasionally or a moderate amount of the time (3 to 4 days)
4 = Most or all of the time (5 to 7 days)

- | | | | | | |
|-----|--|---|---|---|---|
| 1. | I was bothered by things that usually don't bother me | 1 | 2 | 3 | 4 |
| 2. | I did not feel like eating, my appetite was poor | 1 | 2 | 3 | 4 |
| 3. | I felt that I could not shake off the blues even with the help of my friends | 1 | 2 | 3 | 4 |
| 4. | I felt that I was just as good as other people | 1 | 2 | 3 | 4 |
| 5. | I had trouble keeping my mind on what I was doing | 1 | 2 | 3 | 4 |
| 6. | I felt depressed | 1 | 2 | 3 | 4 |
| 7. | I felt that everything I did was an effort | 1 | 2 | 3 | 4 |
| 8. | I felt hopeful about the future | 1 | 2 | 3 | 4 |
| 9. | I thought my life had been a failure | 1 | 2 | 3 | 4 |
| 10. | I felt fearful | 1 | 2 | 3 | 4 |
| 11. | My sleep was restless | 1 | 2 | 3 | 4 |
| 12. | I was happy | 1 | 2 | 3 | 4 |
| 13. | I talked less than usual | 1 | 2 | 3 | 4 |
| 14. | I felt lonely | 1 | 2 | 3 | 4 |
| 15. | People were unfriendly | 1 | 2 | 3 | 4 |
| 16. | I enjoyed life | 1 | 2 | 3 | 4 |
| 17. | I had crying spells | 1 | 2 | 3 | 4 |
| 18. | I felt sad | 1 | 2 | 3 | 4 |
| 19. | I felt people disliked me | 1 | 2 | 3 | 4 |
| 20. | I could not get "going" | 1 | 2 | 3 | 4 |

Please circle the answer that describes how you have felt **during the past 4 weeks** (1= Yes, 2 = No, ? = I don't know).

	Yes 1	No 2	? 3
1. My friends give me the moral support I need.	1	2	3
2. Most other people are closer to their friends than I am.	1	2	3
3. My friends enjoy hearing about what I think.	1	2	3
4. Certain friends come to me when they have problems or need advice.	1	2	3
5. I rely on my friends for emotional support.	1	2	3
6. If I felt that one or more of my friends were upset with me, I'd just keep it to myself.	1	2	3
7. I feel that I'm on the fringe in my circle of friends.	1	2	3
8. There is a friend I could go to if I were just feeling down, without feeling funny about it later.	1	2	3
9. My friends and I are very open about what we think about things.	1	2	3
10. My friends are sensitive to my personal needs.	1	2	3
11. My friends come to me for emotional support.	1	2	3
12. My friends are good at helping me solve problems.	1	2	3
13. I have a deep sharing relationship with a number of friends.	1	2	3
14. My friends get good ideas about how to do things (or make things) from me.	1	2	3
15. When I confide in friends, it makes me feel uncomfortable.	1	2	3
16. My friends seek me out for companionship.	1	2	3
17. I think that my friends feel that I'm good at helping them solve problems.	1	2	3
18. I don't have a relationship with a friend that is as intimate as other people's relationships with their friends.	1	2	3
19. I've recently gotten a good idea how to do something from a friend.	1	2	3
20. I wish my friends were much different.	1	2	3

Please circle the answer that describes how you have felt **during the past 4 weeks** (1= Yes, 2 = No, ? = I don't know).

	Yes	No	?
1. My family gives me the moral support I need.	1	2	3
2. I get good ideas about how to do things or make things from my family.	1	2	3
3. Most other people are closer to their family than I am.	1	2	3
4. When I confide in the members of my family who are closest to me, I get the idea that it makes them uncomfortable.	1	2	3
5. My family enjoys hearing about what I think.	1	2	3
6. Members of my family share many of my interests.	1	2	3
7. Certain members of my family come to me when they have problems or need advice.	1	2	3
8. I rely on my family for emotional support.	1	2	3
9. There is a member of my family I could go to if I were just feeling down, without feeling funny about it later.	1	2	3
10. My family and I are very open about what we think about things.	1	2	3
11. My family is sensitive to my personal needs.	1	2	3
12. Members of my family come to me for emotional support.	1	2	3
13. Members of my family are good at helping me solve problems.	1	2	3
14. I have a deep sharing relationship with a number of members of my family.	1	2	3
15. Members of my family get good ideas about how to do things or make things from me.	1	2	3
16. When I confide in members of my family, it makes me uncomfortable.	1	2	3
17. Members of my family to seek me out for companionship.	1	2	3
18. I think that my family feels that I'm good at helping them solve problems.	1	2	3
19. I don't have a relationship with a member of my family that is as close as other people's relationships with family members.	1	2	3
20. I wish my family were much different.	1	2	3

These final questions are about you and your household. These items are very important for our research. Please answer honestly, and DO NOT WRITE YOUR NAME ANYWHERE ON THIS SURVEY.

1. How old were you on your last birthday? _____ Years

2. What is your current living arrangement?

- | | | |
|--|---|---------------------|
| Now married and living with spouse | 1 | |
| Common-law relationship or live-in partner | 2 | |
| Single - never married | 3 | (circle one number) |
| Divorced | 4 | |
| Separated | 5 | |
| Widowed | 6 | |

3. What was your marital status before your present relationship?

- | | | |
|------------------------|---|---------------------|
| Divorced | 1 | |
| Separated | 2 | (Circle one number) |
| Widowed | 3 | |
| Never married (single) | 4 | |

4. Including yourself, how many persons altogether live in your home, related to you or not?

5. What is your highest level of education? (Please circle one number)

- | | | |
|---|----|--|
| No Schooling | 1 | |
| Elementary School | | |
| Incomplete | 2 | |
| Complete | 3 | |
| Junior High School | | |
| Incomplete | 4 | |
| Complete | 5 | |
| High School | | |
| Incomplete | 6 | |
| Complete (or GED) | 7 | |
| Non-University (Voc/Tech, Nursing Schools) | | |
| Incomplete | 8 | |
| Complete | 9 | |
| University | | |
| Incomplete | 10 | |
| Diploma/Certificate (e.g. Hygienists) | 11 | |
| Bachelor's Degree | 12 | |
| Professional Degree (Vets, Drs., Dentists, Lawyers) | 13 | |
| Master's Degree | 14 | |
| Doctorate | 15 | |

6. How would you describe your ethnic identity? (Examples of ethnic or cultural groups would be: Ukrainian, German, Japanese, etc.)
-

7. Are you now working at a paying job?

- | | | |
|---|---|-------------|
| Full-time | 1 | |
| Part-time | 2 | (Circle one |
| My work is partially subsidized by disability insurance | 3 | number) |
| I'm a full-time homemaker | 4 | |
| I'm unemployed and looking for work | 5 | |
| I'm on disability insurance | 6 | |
| I'm retired | 7 | |

8. What is the total income of all the members of your household for this past year before taxes and deductions?

- | | | |
|--------------------------------|---|-------------|
| Zero | 1 | |
| Less than \$5,000 but not zero | 2 | |
| \$ 5,000 - 10,000 | 3 | |
| \$10,001 - 20,000 | 4 | (Circle one |
| \$20,001 - 30,000 | 5 | number) |
| \$30,001 - 50,000 | 6 | |
| \$50,000 - 75,000 | 7 | |
| \$75,000 - \$100,000 | 8 | |
| More than \$100,000 | 9 | |

Thank you so much for participating in this study! Your completion of this questionnaire is valuable to us so that we can better understand men's experiences and resource needs following the diagnosis of prostate cancer.

Appendix B: Questionnaire Package for Women with Breast Cancer

**Quality of Life Survey for Women with Breast
Cancer**

Protocol #P2003:035

Principal Investigators:

**Carey Mintz, M.A.
Marvin Brodsky, Ph.D., C.Psych.**

**Department of Psychology
University of Manitoba**

In Association with CancerCare Manitoba

These first questions are about your experiences with breast cancer. Some of these items may be personal, but they are very important for our research. Please answer honestly, and DO NOT WRITE YOUR NAME ANYWHERE ON THIS SURVEY.

1. When were you first diagnosed with breast cancer (month/year)?

2. Have you ever had any of the following treatments for breast cancer?
(Please circle YES or NO for every item)

	No	Yes	
a. Lumpectomy	1	2	Month & year of surgery: _____
b. Mastectomy	1	2	Month & year of surgery: _____
c. Radiation	1	2	Month & year of last treatment: _____
d. Chemotherapy	1	2	Month & year of last treatment: _____
e. Tamoxifen	1	2	
f. Arimidex	1	2	
g. Other (please specify in space provided):			

3. If you have received any treatment more than once, please use this space to detail what treatments you have had, and when.

4. Do you anticipate that you will be having any upcoming treatments for your breast cancer within the next 6 months? (please circle one answer)

No Yes

If yes, what treatments do you anticipate having, and when do you anticipate having them? (please specify in the space below)

5. When you were first diagnosed, how large was your tumour (approximately)?

6. Was your breast cancer estrogen receptor positive (ER +)?

Yes

No

7. At what stage was your cancer when you were first diagnosed?

- | | |
|---|---|
| Confined to the breast | 1 |
| My cancer had spread to 1 - 3 lymph nodes | 2 |
| My cancer had spread to more than 3 lymph nodes | 3 |
| My cancer had spread to other parts of my body
(e.g., bone, lung, liver, etc.) | 4 |

8. Since you were diagnosed, have you experienced a local recurrence (i.e., recurrence in your breast)? (if so, please indicate how long after you were first diagnosed that your cancer recurred).

No

Yes

Time since first diagnosis:

9. Since you were diagnosed, has your cancer spread to any other part of your body? (if so, please indicate where, and how long ago this occurred).

10. How much would you say that your sleep has been disturbed by hot flashes as a result of hormonal therapy (e.g. tamoxifen or arimidex) or treatment induced menopause?

- | | | |
|--------------|---|---------------------|
| Very Much | 1 | (Circle one number) |
| A Fair Bit | 2 | |
| A Little Bit | 3 | |
| Not At All | 4 | |

11. Which of the following describes your level of post-surgery range of motion for your affected arm?

- | | | |
|--|---|---------------------|
| Severe limitations in range of motion | 1 | (Circle one number) |
| Moderate limitations in range of motion | 2 | |
| Only mild limitations in range of motion | 3 | |
| Full range of motion | 4 | |

12. Overall, how big a problem has lymphedema been for you during the last 4 weeks?

- | | | |
|--------------------|---|---------------------|
| No problem | 1 | |
| Very small problem | 2 | |
| Small problem | 3 | (Circle one number) |
| Moderate problem | 4 | |
| Big problem | 5 | |

13. Overall, how would you rate your ability to function sexually during the last 4 weeks?

- | | | |
|-----------|---|---------------------|
| Very poor | 1 | |
| Poor | 2 | |
| Fair | 3 | (Circle one number) |
| Good | 4 | |
| Very Good | 5 | |

14. Overall, how distressed are you about your level of sexual functioning?

- | | | |
|-----------------------|---|---------------------|
| Very distressed | 1 | |
| Distressed | 2 | |
| Neutral | 3 | (Circle one number) |
| Not very distressed | 4 | |
| Not distressed at all | 5 | |

15. Overall, how satisfied are you with the treatment you received for your breast cancer?

- | | | |
|------------------------|---|---------------------|
| Extremely dissatisfied | 1 | |
| Dissatisfied | 2 | |
| Uncertain | 3 | (Circle one number) |
| Satisfied | 4 | |
| Extremely satisfied | 5 | |

16. How much do you worry about recurrence?

- | | | |
|--------------|---|---------------------|
| Very Much | 1 | |
| A Fair Bit | 2 | |
| A Little Bit | 3 | (Circle one number) |
| Hardly ever | 4 | |
| Not At All | 5 | |

17. Do you ever worry about your breast cancer ending your life?

- | | | |
|--------------|---|---------------------|
| All the time | 1 | |
| Often | 2 | |
| Sometimes | 3 | (Circle one number) |
| Hardly ever | 4 | |
| Not at All | 5 | |

18. Do you attend any support group meetings for your cancer?

- | | |
|--|---|
| Yes, regularly (rarely miss a meeting) | 1 |
| Yes, often (go to most meetings) | 2 |
| Yes, but infrequently (go once in a while) | 3 |
| Yes, but only for interesting guest speakers | 4 |
| I used to go when I was first diagnosed, but not anymore | 5 |
| No, not at all | 6 |

19. Have you ever seen a therapist to talk about issues related to your cancer?

Yes No

20. Would you be interested in participating in a support group for the purposes of discussing your personal experiences with cancer? (please circle yes or no)

Yes No

a) If no, could you specify why not?

21. If you **were** interested in participating in a support group to discuss your personal experiences with your cancer and the effects of its treatments, would there be any reasons why you might choose not to participate in one? (If yes, please explain what factors might make you hesitant to participate in a group of this type)

22. If you were to attend a support group for your cancer, what would you like to discuss at the meetings?

23. Do you think that "support" includes being provided with information about your disease?

Yes 1
No 2

24. Do you think that "support" includes sharing your feelings and reactions about your cancer with others who have had the same experience?

Yes	1
No	2

25. When you discuss your illness with people to whom you are close do you tell them about:

The physical details of your condition?

Yes	1
No	2

How this condition has affected your life?

Yes	1
No	2

26. Do you think you would feel embarrassed to talk about your experiences with your breast cancer within a small, private group?

Very embarrassed	1
Quite embarrassed	2
A little embarrassed	3
Not embarrassed at all	4

27. How helpful do you think talking about your breast cancer would be for you?

Very Helpful	1
Helpful	2
Somewhat Helpful	3
Not Helpful At All	4
It has made (or would make) things worse	5

28. If you indicated in the previous question that you don't think that talking about your experiences with breast cancer would be helpful to you, please specify why in the space below.

Here is a series of questions which describe the way people sometimes feel or behave. Please circle the answer that describes how often you have felt this way **during the past week.**

Use the following Scale

- 1 = Rarely or none of the time (less than 1 day)
 2 = Some or a little of the time (1 to 2 days)
 3 = Occasionally or a moderate amount of the time (3 to 4 days)
 4 = Most or all of the time (5 to 7 days)

- | | | | | | |
|-----|--|---|---|---|---|
| 1. | I was bothered by things that usually don't bother me | 1 | 2 | 3 | 4 |
| 2. | I did not feel like eating, my appetite was poor | 1 | 2 | 3 | 4 |
| 3. | I felt that I could not shake off the blues even with the help of my friends | 1 | 2 | 3 | 4 |
| 4. | I felt that I was just as good as other people | 1 | 2 | 3 | 4 |
| 5. | I had trouble keeping my mind on what I was doing | 1 | 2 | 3 | 4 |
| 6. | I felt depressed | 1 | 2 | 3 | 4 |
| 7. | I felt that everything I did was an effort | 1 | 2 | 3 | 4 |
| 8. | I felt hopeful about the future | 1 | 2 | 3 | 4 |
| 9. | I thought my life had been a failure | 1 | 2 | 3 | 4 |
| 10. | I felt fearful | 1 | 2 | 3 | 4 |
| 11. | My sleep was restless | 1 | 2 | 3 | 4 |
| 12. | I was happy | 1 | 2 | 3 | 4 |
| 13. | I talked less than usual | 1 | 2 | 3 | 4 |
| 14. | I felt lonely | 1 | 2 | 3 | 4 |
| 15. | People were unfriendly | 1 | 2 | 3 | 4 |
| 16. | I enjoyed life | 1 | 2 | 3 | 4 |
| 17. | I had crying spells | 1 | 2 | 3 | 4 |
| 18. | I felt sad | 1 | 2 | 3 | 4 |
| 19. | I felt people disliked me | 1 | 2 | 3 | 4 |
| 20. | I could not get "going" | 1 | 2 | 3 | 4 |

Please circle the answer that describes how you have felt about your friends **during the past 4 weeks** (1= Yes, 2 = No, ? = I don't know).

	Yes 1	No 2	? 3
1. My friends give me the moral support I need.	1	2	3
2. Most other people are closer to their friends than I am.	1	2	3
3. My friends enjoy hearing about what I think.	1	2	3
4. Certain friends come to me when they have problems or need advice.	1	2	3
5. I rely on my friends for emotional support.	1	2	3
6. If I felt that one or more of my friends were upset with me, I'd just keep it to myself.	1	2	3
7. I feel that I'm on the fringe in my circle of friends.	1	2	3
8. There is a friend I could go to if I were just feeling down, without feeling funny about it later.	1	2	3
9. My friends and I are very open about what we think about things.	1	2	3
10. My friends are sensitive to my personal needs.	1	2	3
11. My friends come to me for emotional support.	1	2	3
12. My friends are good at helping me solve problems.	1	2	3
13. I have a deep sharing relationship with a number of friends.	1	2	3
14. My friends get good ideas about how to do things (or make things) from me.	1	2	3
15. When I confide in friends, it makes me feel uncomfortable.	1	2	3
16. My friends seek me out for companionship.	1	2	3
17. I think that my friends feel that I'm good at helping them solve problems.	1	2	3
18. I don't have a relationship with a friend that is as intimate as other people's relationships with their friends.	1	2	3
19. I've recently gotten a good idea how to do something from a friend.	1	2	3
20. I wish my friends were much different.	1	2	3

Please circle the answer that best describes how you have felt about your family **during the past 4 weeks** (1= Yes, 2 = No, ? = I don't know).

	Yes	No	?
1. My family gives me the moral support I need.	1	2	3
2. I get good ideas about how to do things or make things from my family.	1	2	3
3. Most other people are closer to their family than I am.	1	2	3
4. When I confide in the members of my family who are closest to me, I get the idea that it makes them uncomfortable.	1	2	3
5. My family enjoys hearing about what I think.	1	2	3
6. Members of my family share many of my interests.	1	2	3
7. Certain members of my family come to me when they have problems or need advice.	1	2	3
8. I rely on my family for emotional support.	1	2	3
9. There is a member of my family I could go to if I were just feeling down, without feeling funny about it later.	1	2	3
10. My family and I are very open about what we think about things.	1	2	3
11. My family is sensitive to my personal needs.	1	2	3
12. Members of my family come to me for emotional support.	1	2	3
13. Members of my family are good at helping me solve problems.	1	2	3
14. I have a deep sharing relationship with a number of members of my family.	1	2	3
15. Members of my family get good ideas about how to do things or make things from me.	1	2	3
16. When I confide in members of my family, it makes me uncomfortable.	1	2	3
17. Members of my family to seek me out for companionship.	1	2	3
18. I think that my family feels that I'm good at helping them solve problems.	1	2	3
19. I don't have a relationship with a member of my family that is as close as other people's relationships with family members.	1	2	3
20. I wish my family were much different.	1	2	3

These final questions are about you and your household. These items are very important for our research. Please answer honestly, and DO NOT WRITE YOUR NAME ANYWHERE ON THIS SURVEY.

1. How old were you on your last birthday? _____ Years

2. What is your current living arrangement?

- | | | |
|--|---|---------------------|
| Now married and living with spouse | 1 | |
| Common-law relationship or live-in partner | 2 | |
| Single - never married | 3 | (circle one number) |
| Divorced | 4 | |
| Separated | 5 | |
| Widowed | 6 | |

3. What was your marital status before your present relationship?

- | | | |
|------------------------|---|---------------------|
| Divorced | 1 | |
| Separated | 2 | (Circle one number) |
| Widowed | 3 | |
| Never married (single) | 4 | |

4. Including yourself, how many persons altogether live in your home, related to you or not?

5. What is your highest level of education? (Please circle one number)

- | | | |
|---|---|----|
| No Schooling | 1 | |
| Elementary School | | |
| Incomplete | 2 | |
| Complete | 3 | |
| Junior High School | | |
| Incomplete | 4 | |
| Complete | 5 | |
| High School | | |
| Incomplete | 6 | |
| Complete (or GED) | 7 | |
| Non-University (Voc/Tech, Nursing Schools) | | |
| Incomplete | 8 | |
| Complete | 9 | |
| University | | |
| Incomplete | | 10 |
| Diploma/Certificate (e.g. Hygienists) | | 11 |
| Bachelor's Degree | | 12 |
| Professional Degree (Vets, Drs., Dentists, Lawyers) | | 13 |
| Master's Degree | | 14 |
| Doctorate | | 15 |

6. How would you describe your ethnic identity? (Examples of ethnic or cultural groups would be: Ukrainian, German, Japanese, etc.)
-

7. Are you now working at a paying job?

- | | | |
|---|---|-------------|
| Full-time | 1 | |
| Part-time | 2 | (Circle one |
| My work is partially subsidized by disability insurance | 3 | number) |
| I'm a full-time homemaker | 4 | |
| I'm unemployed and looking for work | 5 | |
| I'm on disability insurance | 6 | |
| I'm retired | 7 | |

8. What is the total income of all the members of your household for this past year before taxes and deductions?

- | | | |
|--------------------------------|---|-------------|
| Zero | 1 | |
| Less than \$5,000 but not zero | 2 | |
| \$ 5,000 - 10,000 | 3 | |
| \$10,001 - 20,000 | 4 | (Circle one |
| \$20,001 - 30,000 | 5 | number) |
| \$30,001 - 50,000 | 6 | |
| \$50,000 - 75,000 | 7 | |
| \$75,000 - \$100,000 | 8 | |
| More than \$100,000 | 9 | |

Thank you so much for participating in this study! Your completion of this questionnaire is valuable to us so that we can better understand women's experiences and resource needs following the diagnosis of breast cancer.

Appendix C: Contact Letter and Consent Form

Dear Sir or Madam,

Dr. Marvin Brodsky and Ms. Carey Mintz at the University of Manitoba are currently conducting a research project which is investigating the factors which influence an individual's psychological well-being following the diagnosis and treatment of cancer, and they are hoping that you might like to participate in this study. The information which you can provide will be invaluable to furthering the understanding of the issues which people like you face following a diagnosis of cancer, and the effect that this illness has on their lives. CancerCare Manitoba supports research projects such as this, and hopes that you will be able to participate in this study, however, we also understand that you may not be able to participate at this time. **The services you receive from CancerCare Manitoba will in no way be affected by whether or not you are able to participate in this study.** If you do decide to participate, please know that your responses to this questionnaire will remain completely anonymous, and there will be no way to link your answers to these questions back to you.

To help you decide whether you wish to be a participant in this research project, we would like to provide you with some information about what you would be required to do, as well as with some information about the individuals conducting the research.

Dr. Marvin Brodsky is a clinical psychologist, and an associate professor at the University of Manitoba. Carey Mintz is a doctoral student under his supervision, and is training to become a clinical psychologist. This research project is part of Ms. Mintz's clinical psychology doctoral training, and once it is complete, she will be near to completing her Ph.D. in clinical psychology.

As a participant in this research project you will be asked to complete the questionnaire package enclosed with this letter. This package will ask you questions about both your physical and emotional well-being, and whether or not you have experienced any difficulties in continuing your daily activities. These questionnaires should take less than an hour to complete, and the return postage will be pre-paid. Your name will never go on the information which you disclose, and there will be no way of matching the information which you provide with who you are. This is to protect your rights to confidentiality. We would like to emphasize that the information which you provide will be invaluable to furthering our understanding of the issues which people face when diagnosed and treated for cancer cancer, as well as the effect this has on various aspects of their lives. **Again, whether you decide to participate in this study, or whatever information you are able to provide, will have no absolutely no effect on the services you receive through CancerCare Manitoba.**

If you would like to participate in this study, please fill in the enclosed consent form and return it along with your completed questionnaire package in the self-addressed and stamped envelope provided. This will indicate to us that you have given your consent for us to use your answers to these questionnaires in this research project. Remember, your name will **not** go on the questionnaires you return, so it will never be

matched up to the information you choose to disclose. To further ensure your privacy, all signed consent forms will be immediately separated from the completed questionnaires, so there will be no way to match your answers to any identifying information. Thus, your responses will remain anonymous. Completed questionnaires will only be viewed by Ms. Carey Mintz, and/or by her clinical supervisor Dr. Marvin Brodsky. They will be stored in a locked cabinet, and will be destroyed following the termination of the study, according to the University of Manitoba's procedures for destroying confidential materials.

If you decide that you **would prefer not** to participate in this study, please simply return the blank consent form and the uncompleted questionnaire package using the stamped, self-addressed envelope provided.

If at any time you have any concerns regarding your participation in this study please do not hesitate to contact Dr. Marvin Brodsky at the University of Manitoba, at **474-9626**. If you find that you are feeling upset as a result of any of the issues explored in the questionnaires and would like to talk about your concerns with someone, **a list of psychological resources is included with this questionnaire package**. All of these services are provided for either no cost, or at reduced-cost (the reduced-cost services usually determine their fees according to income). Any complaints regarding this project should be directed to the Human Ethics Secretariat of the University of Manitoba, at **474-7122**.

Once the study is completed, if you are interested we will be happy to send you a summary of the results in the mail. All you need to do to indicate your interest is to fill out your name and address in the designated area of the consent form included with this package.

We hope you will be interested in participating!
Sincerely,

Jeri Kostyra,
Manager, Manitoba Cancer Registry
CancerCare Manitoba

Consent Form

Title of study: Is there similarity of experience? A comparative analysis between men with prostate cancer and women with breast cancer on their experiences following a diagnosis of cancer

Principle Investigators:

Carey Mintz, M.A., Ph.D. (Cand)
Department of Psychology
University of Manitoba

Marvin Brodsky, Ph.D., C.Psych
Department of Psychology
University of Manitoba

Purpose of Study: The purpose of this study is to investigate the factors which influence an individual's psychological well-being following the diagnosis and treatment of cancer, and whether or not there are similarities between the experiences of men diagnosed with prostate cancer and those of women diagnosed with breast cancer.

This study has been reviewed and approved by the Psychology/Sociology Research Ethics Board of the University of Manitoba. Any complaints regarding this project should be directed to the Human Ethics Secretariat of the University of Manitoba

I _____ would like to participate in the study
(please print your name here)

which was described to me in the enclosed letter. I am aware that I am being asked to complete the enclosed questionnaire package, and that this will be the total extent of my participation. This questionnaire package should take less than an hour to complete.

I understand that my name will never be associated with the information which I provide so that my right to confidentiality will be protected. I am also aware that the responses that I provide will be kept in a secure location, and will be destroyed following the termination of the study according to the University of Manitoba's procedures for the destruction of confidential materials.

I am also aware that I have the right to stop participating in this study at any time. Should this be the case, I may indicate this by returning either an **uncompleted** or **partially completed** questionnaire in the self-addressed, stamped envelope provided. I also understand that I am not obligated to answer any question in the questionnaire that I would prefer not to, and I may skip any question(s) that I do not wish to answer. Finally, I understand that being unable to participate, or withdrawing from this project will have **absolutely no effect** on the services which I will receive from CancerCare Manitoba, either now or in the future.

Some of the questions are very personal and they may raise some difficult issues for you. If you would like to talk to somebody about these issues, a list of psychological services is included with this questionnaire package.

I have read this consent form. I understand that my participation in this clinical trial is voluntary and that I may choose to withdraw at any time. I freely agree to participate in this research study.

(signature)

(date)

If you would like to receive the results of this study through the mail, please complete the following form. Once the study is complete and you have been mailed the information regarding the results of this study, this form will be destroyed in order to protect your privacy.

Yes, I would like to receive information regarding the results of this study through the mail. Please send this information to:

Name: _____

Address: _____

Postal Code

Psychological Services Available for Individuals with Cancer and Their Families

1. Patient and Family Support Services

CancerCare Manitoba

787-4119

Offers free support services for individuals with cancer and their families.

2. Psychological Service Centre

University of Manitoba

474-9222

Offers free services. Please call for more information.

3. Interfaith Marriage and Family Institute

University of Winnipeg

786-9251

Services offered at reduced cost (based on income)

4. Family Centre of Winnipeg

947-1401

Services offered at reduced cost (based on income)

5. Klinik Community Health Centre

24-hour crisis line: 786-8686 (no charge)