

**RURAL FARMERS' EXPERIENCE IN LIVING WITH  
PROSTATE CANCER FOLLOWING DIAGNOSIS  
AND TREATMENT**

A Thesis Submitted to the College of  
Graduate Studies and Research  
for the Degree of Master in Nursing  
University of Saskatchewan  
Saskatoon

By

Darren Gronvold

Winter 2004

© Copyright Darren Gronvold, 2004. All rights reserved

## PERMISSION TO USE

I hereby grant to University of Saskatchewan and/or its agents the non-exclusive license to archive and make accessible, under the conditions specified below, my thesis, in whole or in part in all forms of media, now or for the duration of my copyright ownership. I retain all other ownership rights to the copyright of the thesis, dissertation or project report. I also reserve the right to use in future works (such as articles or books) all or part of this thesis.

I certify that the version I submitted is the same as that approved by my advisory committee.

Request for permission to copy or to make other use of material in this thesis, in whole or in part, should be addressed to:

Dean of the College of Nursing

University of Saskatchewan

107 Wiggins Road

Saskatoon, Saskatchewan, S7N 5E5

## ABSTRACT

In Canada, prostate cancer is the most frequently diagnosed cancer among men. The incidence continues to rise. Although there is a growing empirical literature on the prostate cancer experience of men who live and work in urban areas, little is known about the experience of men who live and work in rural settings where access to treatment and support may present unique challenges. The purpose of this qualitative research was to explore the experiences of men diagnosed and treated for prostate cancer who live and work (farm) in rural Saskatchewan. Using a Naturalistic Inquiry approach and methods of Grounded Theory Analysis, six participants were recruited through a physician's office, advertisements, and cancer support groups, and interviewed. The interview data were audio-taped, transcribed verbatim, and analyzed. Data analysis revealed five common themes: farming and rural life, physical and emotional concerns, sexuality, masculinity, thoughtfulness and reflection, helping others and being helped. There was no evidence of rural isolation or concern with travelling to the cities for treatment. Depression and anxiety were not reported as major concerns. Participants explained that while continuing to farm helped them cope, fatigue reduced their ability to farm and increasingly they relied on help from family and neighbours. Participants experienced a sense of urinary urgency and/or incontinence following treatment and managed their daily activities to lessen the impact. All were impotent following treatment. They coped with loss of sexual function through a renewed life perspective or use of medication to restore sexual function. Traditional masculine behaviours can be a barrier to health screening for men with prostate cancer. Participants used their prostate cancer experience to engage in activities of new learning, new meaning, and new perspectives and to educate and support other men with prostate cancer.

This study highlights the need for further research on the health experiences of farmers and other rural men, and to uncover the variety of masculine and behavioural responses with respect to men's health issues. Although the range of health issues may be similar from one man to another, it is important for health care providers to understand individual differences.

## ACKNOWLEDGMENTS

First and foremost I would like to thank the participants who took part in this study. Their candour and enthusiasm for this work was inspiring to me and their stories will no doubt enrich other people's lives. My sincere appreciation goes to my thesis supervisor Dr. Karen M. Semchuk who guided me along this path of new research and new learning. I would also like to thank my advisory committee of Dr's Wright, Morgan, and Leis for their expertise and input into the final copy. Further, I would like to thank the faculty and staff at Institute of Agricultural Rural and Environmental Health (I.ARE.H) at the University of Saskatchewan for the Founding Chairs Fellowship awarded to me which provided invaluable financial, office, and collegial support.

Finally, a special thanks to my wife Tracy and our boy's Austin and Brayden. Their love and support made the final product possible. Also, the working weekends and the long nights are finally over.

## TABLE OF CONTENTS

PERMISSION TO USE	i
ABSTRACT	ii
ACKNOWLEDGEMENTS	iv
TABLE OF CONTENTS	v
LIST OF TABLES	viii
LIST OF FIGURES	ix
1. CHAPTER ONE - INTRODUCTION	1
1.1 Introduction	1
1.2 Importance of the Study	1
1.3 Study Aim	2
1.4 Literature Review	2
1.4.1 Incidence of Prostate Cancer in Canada	2
1.4.2 Diagnosis and Treatment of Prostate Cancer	3
1.4.3 Rurality	7
1.4.4 Psychosocial Concerns and Adjustments	9
1.4.5 Review of Selected Studies of Prostate Cancer	11
1.4.5.1 Literature Review Prior to the Study	12
1.4.5.2 Literature Review Following the Study	16
1.4.6 Summary of the Literature	19



4. CHAPTER FOUR - DISCUSSION	92
4.1 Discussion	92
4.1.1 Common Themes	92
4.1.1.1 Farming and Rural Life	92
4.1.1.2 Physical and Emotional Concerns	99
4.1.1.3 Sexuality	101
4.1.1.4 Masculinity	103
4.1.1.5 Thoughtfulness and Reflection	108
4.1.1.6 Helping Others and Being Helped	112
4.1.1.7 Summary of the Common Themes	115
4.1.2 Implications of the Research	118
4.1.2.1 Implications for Practice	118
4.1.2.2 Implications for Further Research	119
4.1.2.3 Strengths of the Study	120
4.1.3 Conclusion	120
REFERENCES	122
APPENDIX A - Introduction Letter	131
APPENDIX B - Change in Recruitment Procedure	134
APPENDIX C - Interview Guide	138
APPENDIX D - Transcript Release Form	140
APPENDIX E - Study Phases	142
APPENDIX F - Consent Form	143

## LIST OF TABLES

1. Demographic Attributes of Study Participants	36
---	----

## LIST OF FIGURES

1. A Model of Transition

41

## CHAPTER ONE - INTRODUCTION

### 1.1 Introduction

Little Canadian research has addressed the potential issues and concerns that rural farmers may have in living, following treatment for prostate cancer. It is the personal knowledge of this researcher, who has connections with rural Saskatchewan, that many rural farmers do not retire from active farming and remain financially linked to the productivity of the farm. It was a hunch of this writer that some issues surrounding this disease may present unique challenges for farmers who live in isolated areas removed from major treatment centres and professional support services (Burman & Weinert, 1997; Long, 1998; Thurston & Meadows, 2003). Also, farmers need to remain robust and active to carry out farming operations. Incontinence, impotence, anxiety, depression, family and role dysfunction, and death, are simply a few of the potential issues that with which rural farmers may have to live and cope with after being diagnosed and treated for prostate cancer (Balderson & Towell, 2003; Bertero, 2001; Burman & Weinert, 1997; Jakobsson, Rahm-Hallberg, & Loven, 1997; Kornblith, Herr, Ofman, Scher, & Holland, 1994).

### 1.2 Importance of the Study

The importance of this study can be directly related to the large number of male farmers who are found throughout rural Saskatchewan. Based on the Statistics Canada 1996 census, there were 58,315 male farmers in Saskatchewan. With the current incidence rate of being diagnosed with prostate cancer at 1 in 7 men (Klotz, 2002; Levy, Iscoe, & Klotz, 1998;) clearly, many rural farmers are affected or will be affected by this disease. It is essential that health care professionals gain knowledge of the unique needs that rural farmers may have in order evaluate the current and future use of human and financial resources that best meet the needs of this

population.

### 1.3 Study Aim

The aim of this study was to explore the experiences of rural farmers' who were living with prostate cancer, following diagnosis and treatment to gain an understanding of their world from their perspective and to understand the psychosocial aspects surrounding prostate cancer. Information was collected from the men in their own words. The essential question that was asked of the participants was, "What has been your experience in having been diagnosed and treated for prostate cancer? "How had they been living? What were the most significant issues with which they had to come to terms? How negative or positive was the experience?"

### 1.4 Literature Review

#### *1.4.1 Incidence of Prostate Cancer in Canada*

Prostate cancer in Canada is now the most frequently diagnosed cancer among the adult male population, and is second only to lung cancer in the cause of cancer related deaths (National Cancer Institute of Canada, 2003). In Canada, for the year 2003, the estimated number of new cases of prostate cancer in men was 18,800 and the estimated number of deaths due to prostate cancer was 4,200 (National Cancer Institute of Canada, 2003). Overall, the incidence of prostate cancer has grown 3% annually from the period of 1979 to 1990 (Levy et al.,1998). In 2003, the estimated age-standardized rates in Canada for incidence and mortality were 117.4 per 100,000 men and 27.5 per 100,000 men, respectively (National Cancer Institute of Canada). Morrison, MacNeil, Miller, Levy, Xie, and Mao (1995) estimated that future incidence rates will rise from 11,800 new cases in 1990 to 35,200 new cases by 2016. As Morrison et al. (1995) pointed out, the future demands on the health care system to treat effectively and support this group of men

will be an increasing challenge for healthcare resources.

#### *1.4.2 Diagnosis and Treatment of Prostate Cancer*

There are many issues that surround the diagnosis and treatment of prostate cancer.

Diagnosing prostate cancer is difficult because there is a lack of overt signs and symptoms during the early stages of the tumour's growth. As such, many men present as asymptomatic with normal sexual function at the time of diagnosis (Moul, Anderson, Penson, Klotz, Soloway & Schulman, 2003). Over time however, prostate cancer presents with a variety of initial signs and symptoms, which include frequent painful urination, reduced force of urinary stream, and possibly blood in the urine (Held, Osborne, Volpe, Waldmen, 1994; Zinner, 1995). Prostate cancer may also cause compression on the urethra causing acute urinary retention (Held et al., 1994). Prostate cancer may metastasize beyond the prostate gland to the bones, symptoms often include bone pain in the spine and pelvis, and the increased risk of fractures (Held et al., 1994). Pain may be evident in the back, legs, hips, thighs, or shoulders (Zinner, 1995). Further risks include intra-vascular coagulation and thrombophlebitis with the associated risk of pulmonary emboli, plus chronic edema in the scrotum and lower extremities (Held et al., 1994).

Screening and diagnosis of prostate cancer begins with the blood screening procedure known as the prostate specific antigen (PSA) test. This test detects blood antigens specific to the prostate and may indicate a prostate cancer diagnosis if the test results indicate high levels of the antigens. The second method of screening is known as the digital rectal exam, in which a physical exam is conducted from within the colon to palpate for a lump or enlarged prostate which could indicate the presence of prostate cancer (Glanze, 1990). If evidence of possible prostate cancer is indicated by one or both of the procedures, a biopsy of the prostate for cancer

cells is performed (Held et al., 1994). There are, however, reported limitations to both the PSA and the digital rectal exam screening methods. Elevated PSA levels could indicate benign prostatic hyperplasia, urinary tract infections, or ischemia (Saad, 1999). Limitations of the digital rectal exam include the proficiency and skill of the physician, the un-palpable nature of anterior prostate cancer, and the possibility that the cancer may already be malignant by the time it is palpable (Karakiewicz & Aprikian, 1998). Karakiewicz and Aprikian (1998) reported that the most effective screening method should involve both diagnostic procedures (PSA and digital rectal exam).

A noted issue with prostate cancer is that 50% of the tumors have spread beyond the prostate by the time they are diagnosed. Consequently, curing prostate cancer by medical treatment at that point is highly unlikely (Zinner, 1995). Treatment in this case would usually indicate the combined use of hormone therapy with surgery and/or radiation therapy. If the tumor has been confined to the prostate, the disease may be considered curable through surgical methods, radiation therapy, or watchful waiting (Balderson & Towell, 2003; Held et al., 1994; Moul et al., 2003; Stoller & Carrol, 2003; Zinner, 1995).

Treatment choices (like all intensive, invasive medical procedures) come with potential adverse risks, side effects, and irreversible consequences. Surgery, radiation therapy, and hormone therapy are no exception. Surgery involves the procedure known as a radical prostatectomy or the surgical removal of the surrounding connective tissue, a portion of the bladder neck, and attached seminal vesicles (Bottomely, 1997; Held et al., 1994; Stoller & Carrol, 2003). The most common surgical techniques use the radical retropubic prostatectomy which involves the removal of the prostate gland through an incision between the navel and the

pubic bone (Klotz, 2000; Sheppard, Harris, & Thompson, 2001). The second surgical technique called the radical perineal prostatectomy, involves accessing the prostate gland through an incision between the anus and the scrotum (Klotz, 2000; Shepherd et al., 2001). A technique called nerve sparing is used during a prostatectomy to maintain a patient's sexual function when it is clear that the cancer has not spread beyond the two neurovascular bundles responsible for erectile function located on each side of the prostate gland which allows the surgeon to leave the nerve bundles intact (Shepherd et al., 2001). Two of the most significant negative outcomes of surgery include impotence and incontinence. Results of one study suggest that 32% of men undergoing prostatectomy will be impotent following the procedure (Waxman, 1993). There is, however, much controversy over the actual or expected rates of impotence post-surgery. Further, literature reviews are unclear and indicate that impotence rates have ranged from 9% to 100% (Harris, 1997). Similarly, incontinence rates have been reported in the ranges of 2% to 87% (Henke-Yarboro, & Estwing-Ferrans, 1998). Current information on the surgical treatment indicate that "refinements in techniques have allowed maintenance in urinary continence in most patients and erectile function in selected patients" (Stoller & Carrol, 2003, p.937 ).

Radiation therapy involves the use of either external beam radiation directed at the prostate gland and nearby lymph nodes or internal radiation therapy (brachytherapy) which involves the implantation of radioactive pellets into the prostate gland (Klotz, 2000; Stoller & Carrol, 2003; Tester & Brouch, 2000;). The course of the treatment for external beam radiation involves 30 to 35 radiation treatments that can take up to six weeks to complete (Klotz, 2000; Zinner, 1995). This treatment is, of course, not as invasive as surgery; however, side effects can be equally devastating as impotence rates have been reported in the ranges of 22% to 84%

(Bottomely, 1997). Problems with incontinence, however, appear to be much lower when compared with those who have had surgery. Henke-Yarbro and Estwing Ferrans (1998) stated that daily urine leakage was more than three times higher for men who had surgery versus those who had radiation therapy.

Brachytherapy involves the use of needles to insert approximately 40 to 100 radioactive seeds into the prostate gland ( Klotz, 2000; Stoller & Carrol, 2003; Tester & Brouch, 2000). Side effects reported from internal beam radiation include incontinence, bowel problems, and impotence (Klotz, 2000). Seed implants deliver a higher dose of radiation to the urethra, causing urinary symptoms to occur in nearly all men. Urinary symptoms tend to be more severe and longer lasting with seed implants than with external-beam radiation.

Watchful waiting is most often reserved for men over the age of 70, because life expectancy may not be endangered by withholding treatment (Moul et al., 2003; Tester & Brouch, 2000). However, the inability to target specific men whose survival rates or quality of life would not be jeopardized by waiting has raised many concerns (Heyman & Rosner, 1996). In a study by Litwin et al., (1995) which examined the quality-of-life outcomes for men treated for localized prostate cancer, the men who chose the watchful waiting approach scored lower on quality of life measurements than men or who chose treatment actions. Litwin et al. (1995) concluded that watchful waiting and no treatment may have created more stress for this group of men.

Hormone therapy is used when the cancer has progressed past the prostate gland into other areas of the body, or if the cancer has returned after treatment. Also, it is used with clients who are considered to be poor candidates for other treatments such as surgery (Gregoire,

Kalogeropoulos, & Crocus, 1997; Klotz, 2000; Labrie, 2001; Stoller & Carrol, 2003; Tester & Brouch, 2000; Zinner, 1995). The intent of hormone therapy is to slow the tumour's growth. Tumour cells are dependent on the male hormone of testosterone for growth; consequently, removal of the male hormone helps to slow the growth of the tumor (Held et al., 1994; Zinner, 1995). Course of treatment modalities involve the ingestion or injection of estrogen, or the surgical removal of the testis with a procedure called orchidectomy (Held et al., 1994; Zinner, 1995). Side effects of hormone treatment can include hot flashes, breast pain and enlargement, loss of sexual desire, erectile dysfunction and the possibility of muscle mass loss, osteoporosis, and reduced physical energy (Gregoire et al., 1997; Klotz, 2000; Zinner, 1995). Also, the obvious psychological concerns with sexual confidence, self esteem, and altered body image occur with the surgical removal of the testis (Gregoire et al., 1997; Klotz, 2000; Montgomery & Santi, 1996).

#### *1.4.3 Rurality*

This study focussed on the personal experiences of a sample of rural dwellers in living with prostate cancer following diagnosis and treatment. It is important, therefore, that the concept of rurality within the context of health be addressed. Rural health is a concept that continues to be challenged and debated. For the purposes of this study, rural in this study, included communities and regions with a population of less than 10,000 persons. This definition of rural has been cited in previous publications (Jennissen, 1992; Saskatchewan Institute on the Prevention of Handicaps, 1996). In their study of health indicators in rural Canada, Pitblado et al. (1999) concluded that there are problems in coming to a clear understanding of rural health and its meaning. Understanding rural health is difficult because the concept of health can be

related to the values and the culture of individual people who create many of their own perceptions of the “quality” and “well-being” (p.2-1) of their lives. Pitblado et al. (1999) indicated that health is more than the absence of disease and that people who live in rural communities face unique challenges (geographic isolation, unemployment, aging population, lack of health facilities, shortage of doctors and nurses), which influence their health. The literature also suggests that there are positive social aspects to living in rural settings. Hence, rurality may be viewed as a “social construct, that is, a range of social relationships and social processes associated with rural environments” (Thurston & Meadows, 2003, p. 1). If healthcare is to be improved within rural communities an understanding of rural health conditions is needed in order to compare urban and rural health indicators. Pitblado et al. (1999) explained that rural is only meaningful in relation to non-rural.

Long (1998) indicated that there is no greater understanding of health within a rural context than there is within an urban setting. However, certain meanings and understandings tend to be more prevalent among people in rural settings versus people in urban settings. Long (1998) stated that because rural people tend to be geographically located away from health, education, and government services, they tend to see themselves as more “independent and self reliant” (p. 212). Further, rural people are required out of “necessity to function as generalists, for example, those people managing rural ranches must function as bookkeepers, veterinarians, market analysts, and carpenters” (p. 213). In terms of health issues, Long (1998) indicated that rural people understand when illness concerns can be delayed in the short-term in order to complete work, and when illness concerns need to be addressed quickly because of the potential for the illness to interfere with their ability to perform work in the future. Also, it is noted that

rural people tend to equate their ability to do their work with being in good health (Long, 1998). Although urban dwellers also consider work related factors in defining good health, they tend to “focus on the comfort, cosmetic, and life prolonging aspects of health. In contrast rural dwellers tend to determine health needs primarily in relation to work activities” (Long, 1998, p. 213). Long acknowledged that when a healthcare issue is a concern for rural people, family, friends, and the larger rural community provide support. Long (1998) concluded that individuals conducting health research need to build concepts around urban and rural differences and be attuned to differences across the various rural settings.

#### *1.4.4 Psychosocial Concerns and Adjustments*

The diagnosis of any type of cancer has an overwhelming psychological effect on individuals and their families, creating feelings of helplessness, hopelessness and uncertainty about the future (Gregoire et al., 1997). Psychosocial manifestations of distress could be related to decisions about complicated treatment options, distressing uncomfortable symptoms, family disruptions, social relationship disruption, fatigue, financial implications, and role imbalances when affected individuals may need to change their work, family, or social commitments. For example, Mellon (2002) found that the “meaning of the illness has significance at both the individual and family levels and is interrelated closely with the family quality of life” (p. 1117). Individuals diagnosed with cancer may fear the process of dying and have “images of loneliness, isolation, and pain” (Bottomely, 1997, p.325). They may interpret the threat of cancer as an attack on their sexual identity, bodily integrity, and function (Montgomery & Santi, 1996). It has been reported that despite the similarities in psychosocial issues that cancer patients have, many of their issues remain unresolved (Bottomely, 1997) and 20% will have “substantial and

sustained psychological distress” (Bottomely, 1996, p.143).

The concept of masculinity is key to understanding men's experiences in living with prostate cancer and their psychosocial needs. Masculinity can be described as the "inner psychic process that is tied to an outer web of sex roles and gender expectations" (Sabo, 1996, p. 347). Gender includes the expectations and behaviours that men and women learn about femininity and masculinity (Sabo, 1996). The gender identity is the inner self of the person that is created by internal and external social cues and expectations. The inner self is the perception of being womanly or manly, feminine or masculine. The gender identity is developed through a social, cultural, and historical context (Sabo, 1996).

The implications of gender for men is that western society has reinforced men's behavior to be assertive, autonomous, decisive, dominant, and to display strength and power (Forrester, 1986; Piper, 1997). A related issue is that men tend to downplay psychological symptoms, which prevents them from admitting to or recognizing their needs to maintain their masculine identity, particularly so in the areas of sexuality and incontinence (Forrester, 1986). Forrester (1986) observed that masculinity is related to poor health practices, ignoring symptoms, delaying treatment, and refusing to discuss symptoms.

If the masculine identity is considered with men who have prostate cancer, potential challenges and issues can be envisioned. If men are denying or unable to deal with the psychological and mental health concerns, they may in fact be suffering from more psychosocial distress than health professionals are aware, particularly when the more serious side effects of prostate cancer treatment can involve sexuality and incontinence.

#### *1.4.5 Review of Selected Studies of Prostate Cancer*

There is limited research data on the impact of prostate cancer on the quality of men's lives. In Canada, Gray et al. (1998) were the first published researchers to ask men to comment on their personal experiences with prostate cancer. Prior to the start of the present study, I conducted a search for published qualitative information on Canadian men's experiences with prostate cancer. Using the electronic databases of MEDLINE(R) (1989-1999), CINAHL (1989-1999), PSYCLIT (1989-1999), and HEALTHSTAR (1990-1999) I was unable to locate published studies in which they had conducted face-to-face interviews of Canadian men with prostate cancer about their experiences. Previous studies of men with prostate cancer most often included men who were retired from their professional lives and the papers give no indication of the urban or rural residential status of the participants (Clark et al., 1997; Gray et al., 1998; Henke-Yarbro, & Estwing-Ferrans, 1998; Heyman, & Rosner, 1996; Krongrad, Litwin, Lai, & Lai, 1998).

On completion of the data analysis for this study, a subsequent literature review was conducted to search for qualitative information on Canadian men's experiences with prostate cancer, using the electronic databases of MEDLINE(R) (1999-2003), CINAHL (1999-2003), PSYCINFO (1999-2003), SOCIAL WORK ABSTRACTS (1999-2003), and SOCIOLOGICAL ABSTRACTS (1999-2003). This updated search located four Canadian qualitative research articles that were based on two research studies.

In the first article (Gray, Fitch, Phillips, Labreque, & Fergus, 2000) from the first study, Gray et al. (2000) reported on how men with prostate cancer and their spouses managed the impact of being diagnosed with prostate cancer. In the second article (Phillips, Gray, Fitch,

Labreque, Fergus, & Klotz , 2000) from the first study Philips et al. (2000) reported on the early post-surgery experiences of men with prostate cancer and their spouses following treatment. The first article (Fergus, Gray, & Fitch, 2002) from the second study reported on sexual dysfunction and preservation of manhood from men's experiences with prostate cancer. In the second article (Gray, Fitch, Fergus, Mykhalovskiy, & Church, 2002) from the second study Gray et al. (2002) reported on hegemonic masculinity and the experiences of prostate cancer.

The following sections provide a review of the qualitative research studies published prior to the start of this study and the updated literature review conducted on completion of the present study. Relevant articles are reviewed that address the broader psychosocial issues or concerns that men with prostate cancer may have.

#### *1.4.5.1 Literature Review Prior to the Study*

Heyman and Rosner (1996) used qualitative methods including focus groups and personal interviews to explore the experience of prostate cancer of men and their wives. Conducted in Cleveland, Ohio, this study involved 20 couples. Twelve couples participated in the focus group discussions; the remaining eight participated in one-to-one interviews. Criteria used to select participants included men who had prostate cancer and who were currently involved in a relationship. No information is provided about whether the participants resided in an urban or rural community. From Heyman and Rosner's (1996) thematic analysis, two different phases to the illness emerged: the early phase during the diagnosis and treatment time, and the later phase, which included an adjustment time for the husband and wife as they lived with prostate cancer and the side effects of treatment. During the early phase, men identified fear of death, inability to make treatment decisions, and feelings of a loss of control, as their significant concerns. The

most dominant concern was the fear of death. The men and their wives coped during the early phase by searching for information, finding professionals in health care who were perceived as caring, and by linking with others who had shared the experience. Late phase issues that were identified included treatment side effects, recurrence of the cancer, and treatment. The treatment side effects of impotence and incontinence generated the most concern and impact on how the couples lived their lives, and significantly affected the men's self esteem and sense of personal control over the prostate cancer. For the men, impotence created a sense of loss of "manhood" as intimacy had been linked to sexual performance. Because of the prostate cancer, they were required to adjust to different meanings of intimacy. Most of the men and many of the women indicated that impotence was a "real loss" in their relationship. Incontinence was another quality of life issue that was a constant concern and altered every moment of every day, as the couple had to plan for frequent bathroom stops when out of the home, and pick routes based on availability of washrooms. The incontinence continually reminded them that a recurrence of the cancer was always a possibility. Coping methods used by the men during this phase included keeping a positive attitude, redefining intimacy, and expanding their knowledge base.

Clark et al. (1997) conducted 13 focus groups with men with advanced metastatic prostate cancer who had received either medical or surgical removal of the testis, and two focus groups with the men's wives, to identify and describe quality of life issues that were important to these men. The purpose of the focus groups was to develop a tool to measure men's quality of life following treatment for prostate cancer. The survey component involved 201 respondents. The study took place in Houston, Texas. No information was provided about the urban or rural residential status of the participants. Analysis of the data from the focus groups revealed three

major domains of quality of life: self perceptions, anxiety about treatment side effects, and the process of making decisions about treatment. The survey identified nine indicators of prostate cancer related to quality of life concerns: body image, sexual problems, spouse affection, spouse worry, masculinity, cancer-related self image, cancer distress, cancer acceptance, and regret of treatment decisions. Through the focus group format the researchers were able to learn, first-hand, from men about the relevance of some of these quality of life issues. Some men reported feeling closer to their wives, while others feared they could no longer be a "strong husband" (p. 1304). Most of the men felt a sense of loss with being impotent, which they felt affected their ability to be "intimate" (p.1304) with their wives. Some men reported that they felt distressed over the side effects of hormonal treatment, which included weight gain, hair loss, and hot flashes; and many also indicated a fear of losing "vitality" (p. 1302).

Henke-Yarboro and Estwing-Ferrans (1998) compared the perceived quality of life of men who had received treatment for prostate cancer with surgery and those who had received radiation therapy. The study was a two-group descriptive design involving 68 men treated by radical prostatectomy and 53 with radiation therapy. The criteria for selection of participants included men who had received only one form of treatment between 1991-1994. The study took place in Chicago, Illinois. No information was provided in regards to the urban or rural residential status of the participants. The researchers mailed survey questionnaires, which asked about quality of life issues and included prostate-specific scales that examined urinary, bowel, and sexual function, and the impact of any dysfunction on their lives. The quality of life scales measured four domains: health and functioning, social and economic, psychological/spiritual, and family. The overall quality of life was rated as higher by both treatment groups compared to

results of another study done by Ferrans, Cohen, and Smith (1992) which used a similar instrument to measure quality of life in a population of healthy men. While Henke-Yarboro and Eastwing-Ferrans (1998) found no significant difference in quality of life between the two treatment options, individuals who had undergone surgery reported significantly worse urinary and sexual function, 32% used protective pads for protection against urine leakage, and 98% reported that they had a poor to very poor ability to have an erection. Sixty-five percent of those who received radiation therapy indicated that they had a poor to very poor ability to have an erection and 6% had to wear protective pads for urine leakage. The radiation therapy group also reported more problems with bowel function than the group of men who underwent surgery.

Another study by Krongrad, Litwin, Lai, & Lai (1998) explored dimensions of quality of life of men with prostate cancer in Southern California. The aim of the study was to gain a better understanding of how certain interventions could assist in improving the men's quality of life. The study involved 207 men who had either localized prostate cancer or metastatic prostate cancer. The design involved an analysis of cross sectional data on the quality of life of men with prostate cancer. No information was provided about the urban or rural residential status of the men. In this study the quality of life scale measured physical functioning (urinary, sexual, and bowel), role limitations due to physical problems, social functioning, bodily pain, emotional well-being, role limitations due to emotional problems, energy or fatigue, and general health perceptions. The researchers concluded that in studies of prostate cancer, measures of quality of life should include disease-specific items, for example, urinary, sexual, and bowel function. In addition, findings of this study suggested that physical and emotional health were closely associated for the men in the sample; this indicated to the researchers that a dysfunction

observed in one area required further assessment in an other.

In Canada, Gray et al. (1998) reported on data they collected from 448 men who responded to a open-ended question that was part of a larger cross Canada survey of 945 men. The men were asked to provide “comments, suggestions, experiences, views and thoughts about how things could be improved for the future” (p. 542). Of the 965 survey participants, 39% indicated that they lived in a community of less than 50,000 people and the remainder indicated that they lived in a community of more than 50,000 people. A similar residential breakdown was not given for the 448 men who responded to the open-ended question. Criteria for selection included men who had a diagnosis of cancer at some time in the past and who spoke English or French. The written responses indicated that prostate cancer and the treatment process created significant difficulties in the lives of many men. Issues of incontinence and impotence were frequently reported as major concerns. The researchers observed that the written responses to the open-ended questions appeared to conflict with the quantitative survey data, which suggested that men's quality of life had not been lowered by the diagnosis and treatment for prostate cancer. The researchers concluded that the survey data may have underestimated the impact of the prostate cancer on the men's quality of life and that when men are given an opportunity to discuss the issues in their own words, the findings may be a more accurate representation of their true experience.

#### *1.4.5.2 Literature Review Following the Study*

The first study, which was reported in two articles (Gray et al., 2000; Phillips et al., 2000), used semi-structured interviews and qualitative methods to explore men's experiences during the early recovery period following surgery for the treatment of prostate cancer. The study

involved 34 patients and their spouses. The interviews took place during the 8 to 10-week period following surgery. The research involved separate interviews with men and their spouses, followed by joint interviews with the men and their spouses. The study took place with urban participants from within the greater Toronto area. In the first article, Phillips et al. (2000) reported that their qualitative analysis yielded five major categories in which related themes from the data analysis were grouped. The five categories were: hearing about the extent of cancer, recovering physical capacity, connecting with each other, dealing with side effects, and meaning of cancer. The researchers found that during the post-treatment recovery period the couples focused on being positive and trying to get everyday life "back to normal" (p. 169). There were limited periods of distress for the men as reported by the men's spouses, who indicated that the men's moods ranged from "grouchiness to depression" (p. 169). The wives also reported that the men were concerned about erectile dysfunction, while the men downplayed their concern when discussing sexuality issues. The researchers indicated that although most men downplayed their concerns with erectile dysfunction, there were a few men who indicated that the erectile dysfunction made them question their "identity and self worth" (p. 170). Recovery from treatment also was gauged by the men's perception of how quickly they could become physically active again.

In the second article, Gray et al. (2000) reported on the participants' perceptions of how they managed with the impact of the prostate cancer illness. The men's perceptions were categorized into five "domains," (p. 276): dealing with practicalities, stopping illness from interfering with everyday life, keeping relationships working, managing feelings, and making sense of it all. Concluding remarks by the researchers indicated that most of the men treated by

surgery for prostate cancer attempted to avoid discussing their issues and concerns with other people. The researchers concluded that the men's reluctance to discuss their issues reflected their desire to "minimize the threat of illness to aid coping, practical necessities in the workplace, and the desire to avoid burdening others" (p. 281).

The second study, which was reported in two articles (Fergus et al., 2002; Gray et al., 2002) was a qualitative study of 18 urban men with prostate cancer from the greater Toronto area. The sample included four gay men, four heterosexual Afro-Canadian men, and 14 heterosexual men of Anglo or European descent. Participants were located through a local prostate cancer support group, and selected using theoretical sampling methods. The selection criterion was limited to men who were one year post-diagnosis for prostate cancer. The one-to-one interviews involved four to five individual interviews with each participant conducted approximately two weeks apart. In the first article, Fergus et al. (2002) reported that their data analysis developed the main core category of "preserving of manhood" (p. 303). In addition, five themes emerged that were related to the core category. The five themes were: enhancing the odds, disrupting a core performance, bearing an invisible stigma, effort-mechanical sex, and working around the loss. Fergus et al. (2002) indicated that all the men in their study identified sexual dysfunction as a major issue and a major loss in their life. Also, the perception of lost sexuality can have a significant effect on men's masculine self concept. Fergus et al. (2002) concluded that this loss of masculinity crosses sexual orientation and cultural ethnicity, which implies that sex is very important to all men. It was reported that to counter the loss of manhood associated with the loss of sexual function or potential loss of sexual function, men in the study took deliberate actions to minimize nerve damage, maintain or regain sexual function, and

minimize or hide the sexual dysfunction.

In the second article Gray et al. (2002) reported their findings of analyses of intensified "descriptive narratives" (p. 48) of three participants in the larger study. The researchers indicated that the intensive descriptive narrative method of reporting was intended to "demonstrate (not just reflect on) the value of temporal, contextual accounts" (p. 46). The contention is that narrative story telling gives meaning to specific life events and that men can be better understood through more emphasis on their individual lives. From the three narratives, the researchers found that work and the language of work affected the types of experiences the men had with prostate cancer. Work phrases of "purchasing, managing, and dealing," (p. 53) were reflected in the men's comments on how they coped with prostate cancer. The researchers hypothesized that the construct of men's lives prior to the prostate cancer influenced their response to this life threatening illness. They observed that all three men needed to "renegotiate their performances of masculinity" (p. 43); this entailed adaptation to new realities, which was achieved within the boundaries of traditional masculine behaviors and resulted in new "expressions of masculinity" (p. 59).

#### *1.4.6 Summary of the Literature Review*

In summary, it is clear that many considerations need to be taken into account when studying rural farmers' experiences in living following diagnosis and treatment for prostate cancer. It is known that a large number of Canadian men, including farmers, are currently being diagnosed with prostate cancer. Also, the incidence rates of prostate cancer in Canada will continue to rise for a number of years into the future. It is encouraging to know that prostate cancer has the potential to be effectively treated when it is diagnosed early. However, it is known

that many men will wait too long to seek help or will not undergo regular health screening which could assist in the early detection of prostate cancer. Although good outcomes in terms of life expectancy can be realized from early treatment it is important to acknowledge that even successful treatment can bring out many concerns from impotence and incontinence, to difficult psychological and emotional concerns. As well, the prostate cancer can have a far reaching effect on spouses, children, families and friends. It is also important, when appropriate, to describe the rurality aspect within studies to ensure that the concepts and beliefs expressed by rural participants can be added to the increasing knowledge and understanding of rural issues. When studying men it is helpful and useful to pay attention to the concepts of masculinity and how traditional male behaviors can have negative consequences for men's health and how it may interfere with effective healthcare seeking behavior by men. From the literature it is known that men can have a great deal of fear and discontent over many aspects of prostate cancer treatment. We also know that many men will seek out as much education and information about prostate cancer as they can, and that their identity and manhood can be threatened by the treatment side effects of incontinence and impotence. Finally, it is known from the research that men with prostate cancer find it important to remain positive about their circumstance and to return to normal activities and carry on, as soon as possible following treatment and diagnosis.

### 1.5 Research Question

In summary, the purpose of this qualitative research was to talk with rural men who have received treatment for prostate cancer to explore their personal experiences in living with this disease. The aim of the study was to have a clearer picture of how prostate cancer has affected these men's lives, from their perspective. The essential question that was asked of the participants was, "What has been your experience in having been diagnosed and treated for prostate cancer?"

## CHAPTER TWO - METHODS

### 2.1 Design

The aim of the study was to explore rural farmers' experiences with prostate cancer following diagnosis and treatment. Because of the limited and contradictory empirical knowledge about men's experiences and the exploratory nature of this research, qualitative methods were warranted. The aim of qualitative research is to understand reality - from the perspective of those studied - and give meaning to a social world of people's experience. The intent is inductive, that is meaning emerges from the data (Morse & Fields 1994).

The methodology chosen for this research project was that of Naturalistic inquiry as proposed by Lincoln and Guba (1985). The main components of the naturalistic inquiry is that researchers listen to individuals describe their experience of the phenomenon. It is essential that the phenomenon is studied in its natural environment as the phenomenon and the natural environment are woven together and inseparable. The focus of the research is to inductively generate clearer understanding of the phenomenon in question within its natural environment (Streubert & Carpenter, 1995).

Positionality of the researcher refers to the values, beliefs, and biases that each researcher holds (Gubrium & Sankar, 1994). Researchers need to recognize and appreciate their own issues and perspectives to reduce the amount of influence they may have on the incoming data during the interview process. Researchers using naturalistic inquiry learn what is already known about the phenomenon and then set it aside prior to the start of the research. I did not undertake this research study because I had any personal or familial experience with prostate cancer. In fact, cancer has had little impact on my own family. However, during the course of my research I did

have conversations with various family members and friends who told me about other people they knew with prostate cancer and how the cancer had affected the individuals they knew. The general information given to me about these other men with prostate cancer ranged from a perception of little impact on the person with prostate cancer to major concerns such as clinical depression. One challenge that I had during the research was to remain objective during the interview process. I believe that being born and raised on a family farm myself gave me credibility as a interviewer with the participants and I was likely viewed as someone who understood farming and their way of life. This was evidenced by the fact that a lot of time was spent talking about my own family farm both before and following the interview. Gaining rapport with the participants was not difficult. However, being seen as someone who was familiar with their way of life may have limited my ability to uncover more personal stories of the experience. Based on the stereotype of men who do not openly divulge information to other men, in interviewing the men regarding sensitive personal experiences, my being a man may have limited the depth of the data provided by the participants. The depth of my probing during the interview process also may have been limited by a general sense that these men were familiar and similar to my father who is the same age as the participants. My practice as a community mental health nurse, I believe, was an advantage for me in that much of my practice is spent listening to and talking with clients. The interview process with the participants in this study was comfortable and easy for me to do. The personal aspect and interest in this topic area, however, did play into my own interest of men's health and illness and how men see the world around them. As a reflective learner and a reflective person in my own life it was important to be objective about what the participants were telling me and ensure that the themes emerged from the data. I did not want to

see and hear what I thought that men should be telling me about their lives. Certainly the data from the interviews have affected my own life and perceptions about life and what gives me meaning in life. During the research in my own life I became married, a stepfather, and new father. I certainly took the understandings of life that the participants in this study put forward and reflected upon them in the context of my own life.

## 2.2 Participant Selection

The exact number of participants was not known at the onset of the study. With qualitative research the number of participants depends on the richness or depth of the data that are received as the study progresses. However, as time and funding was available, it was hoped that approximately 10-12 participants would take part.

A criterion for the participant selection was that they lived in a rural community or on a farm. Rural, in this study, included communities and regions with a population fewer than 10,000 persons. This definition of rural, which has been cited in previous publications (Jennissen, 1992; Saskatchewan Institute on the Prevention of Handicaps, 1996), allowed for the recruitment of more potential participants, because many older farmers in Saskatchewan commute to the farm from smaller towns and communities after handing over their farm properties to younger family members. Other inclusion criteria included the ability to speak English; active participation with their own farm or family run farm; prior prostate cancer treatment by surgery, radiation or a combination of both procedures; and a minimum of one year since receiving their initial treatment. Because the nature of this study was exploratory, no sampling was conducted based on a particular stage of the cancer.

The initial method for selecting the participants who were interviewed was snowball

sampling, also known as network sampling (Burns & Grove, 1997). This technique used "social networks" (p. 307) in that once a few participants were identified to take part in the study, they assisted me to identify similar participants who meet the sample criteria and who may wish to participate in the study. This snowball method was to be accomplished by providing participants with copies of the introduction letter (see Appendix A) to be forwarded to other potential participants with whom they were familiar. Potential participants would then have the opportunity to privately review the introduction letter and determine on their own if they would like to volunteer for the study. Directions for contacting the researcher were included in the introduction letter. The researcher had identified three physicians and one nurse in four different Saskatchewan Health Districts who agreed to initiate the process of snowball sampling by forwarding a letter of introduction from the researcher to potential participants with whom they were familiar. After four months this approach generated only one participant. With the approval of the committee members for this study, revisions were made to the recruitment procedure and approved by the University of Saskatchewan Advisory Committee on Ethics (see Appendix B). The changes in the recruitment procedure included the following: (1) print advertisement through newspapers, agency newsletters, and community posters for the enlistment of volunteers; (2) widen the distribution of the introduction letter to include additional contacts (co-workers, friends, family members, and others) who may have knowledge of individuals who meet the criteria for the study and are willing to distribute the letter to other potential participants; and (3) distribute the introduction letter to the Chairs of local prostate cancer support groups for general distribution to support group members who might know individuals who meet the criteria for study and were willing to distribute the letter to other potential participants. Changes in the

recruitment procedure yielded two more participants in the fall of 2000 and three more in the winter and spring of 2001. All six participants were left with introduction letters to pass out to other men with prostate cancer men in their communities to re-initiate the snowball sampling techniques; however, no new participants were located this way. As participant selection took longer than expected, further selection was stopped at six participants, in total, all of whom were interviewed for the study. Therefore, the six study participants constituted a convenience sample of all the identified eligible men who volunteered for the study.

### 2.3 Data Collection and Analysis

Semi-structured interviews were conducted to gather information from the participants. Not all the exact questions to be asked were predetermined however. General topic areas for exploration were raised when they did not occur naturally during the interview process. Topic areas included sexuality issues, incontinence, coping methods, masculinity, and perceptions of the experience. The interview style that was followed when questioning was that of the open-ended question, which allowed participants to explore the meaning of the prostate cancer experience with their own interpretations and understanding. New questions, or avenues of deeper exploration, evolved out of the participants' responses to the researcher's probes for greater depth and understanding. Very broad questions and topic areas were examined in the initial interviews to gain a comprehensive grasp of the relevant issues and concerns of these men. Subsequent interviews continued with more focused exploration and built on the emerging themes from the previous interviews. The exact wording of all questions was not always known in advance. Appendix C lists the initial interview question guide.

The interviews took place in the participants' homes or at a location of their choice that

was both comfortable and convenient for them, and which afforded them the utmost in privacy. Information was recorded by audio tape and transcribed verbatim immediately after each interview. In addition, field notes were taken simultaneously to assist with interpretation of the data. Documentation in the field notes included the impressions of the participant's behavior, affect, body language, and voice tone. As well, pertinent information was highlighted during the interview by the researcher so that it could be explored in more depth during the same interview. Further, data from the interview transcript were not used for analysis until the participant had been given the opportunity to read, revise, and approve the transcript. Each participant did acknowledge the accuracy of the interview transcript and gave the researcher permission to use the transcript for analysis by signing a transcript release form (see Appendix D).

Demographic information was gathered including the participant's age, marital status, children, work status, current residence (in town or on a farm), age at diagnosis, disease status and treatment received for prostate cancer. The study was conducted in three phases. See the table in Appendix E for a display of activities with each phase (Erlandson, Harris, Skipper, & Allan, 1993; Lincoln & Guba, 1985).

Phase one of the study involved the "orientation and overview" (Lincoln & Guba, 1985, p. 225). This phase involved two interviews that approached men's experience with prostate cancer from a very broad perspective. The purpose of the initial interviews was to engage in open-ended questions that allowed the participants to provide insight into the realities of living with prostate cancer and the important issues as they understood them (Streubert & Carpenter, 1995). Following the interviews the data were analyzed in phase two, which began the process of identifying the themes that emerged from the data (Lincoln & Guba, 1985; Strauss & Corbin,

1998; Streubert & Carpenter, 1995). Phase two involved more "focused exploration" (Lincoln & Guba, 1985 p. 235). Data from the first two interview were analyzed and a more focused interview guide was generated to explore the emerging components in more depth with the four remaining participants.

Phase three was the "member check" (Lincoln & Guba, 1985, p. 236). During this phase the data received during phase two were analyzed and summarized into a written format. This written report was taken back to selected participants to check with them whether the written report reflected, correctly, the information they had provided. These participants were provided with the opportunity to make changes or add more information at this time. One participant and his spouse responded to the report indicating that it was, "very good" and that it, "Should be put into a book and put in all cancer offices," and "it would be good for all men to read this." It should be noted that each phase was not, necessarily, a distinct phase. Data analysis took place after each interview and common themes were identified and tentative hypotheses emerged in an ongoing fashion.

#### 2.4 Methods of Analysis

Methods of grounded theory analysis were used (Strauss & Corbin, 1998). With grounded theory analysis, data analysis occurs simultaneously with data collection and coding. The coding begins through generating several categories derived from the study data. Each interview and the emerging categories are compared with all the previous collected data, looking for similarities and differences both within and among categories. The emerging categories are given titles and descriptive attributes in order to differentiate between the various categories (Erlandson et al., 1993). Understanding and meaning is created by hypothesizing and testing the

relationship between the categories with new, incoming data from subsequent interviews (Gillis & Jackson, 2002). When a large number of categories are developed, they are further reduced and merged into a “higher order category” (Burns & Grove, 1997, p. 547 ). The analysis proceeds until the core variable emerges from the data that becomes the main theme for the theory.

Throughout the process opportunities are taken to use theoretical sampling to examine negative case instances that might contradict or challenge the emerging themes (Erlandson et al., 1993).

The aim of grounded theory analysis is emergent, that is to build theory through theoretical sampling procedures to constantly seek out specific participants who identify with a specific category or theme and follow that until you reach data saturation within a particular phenomenon. Because of limitations of this study (i.e., participant involvement in the sampling, the amount of time and financial resources available) theoretical sampling was not used and it was not possible to search for negative cases or to reach theoretical saturation of the data. However, I was able to use the coding and the constant comparison method of grounded theory analysis. Within Strauss and Corbin's (1998) grounded theory analysis, the extent of this research analysis was limited to open and axial coding, which was used in this study. Open coding involves "conceptualizing, defining, and developing categories in terms of their properties and dimensions, and then later relating categories through hypotheses or statements of the relationship" (p. 121). Axial coding involves the "systematic development and relationship of categories" (p. 142).

Analysis of the data from the first two interviews in this study yielded 43 initial categories. The codes were described and recorded with initial interpretations. The initial codes were reviewed and studied again prior to the third and fourth interview in order to refocus the

interview guide and to examine the current codes with the incoming data. Following the third and fourth interview the number of categories was collapsed and reduced to 23 codes. This was accomplished by further reorganization of all the categories from all four interviews by looking for the similarities and differences between the categories and identify the linkages between certain categories. During the final two interviews and data analysis, the 23 categories were organized, combined, and collapsed into six final broad themes. At this point a description of the relationships among the six themes was developed, which represented a broad understanding of the experiences of prostate cancer following diagnosis and treatment for this group of rural farmers.

The computer software program known as QSR Nud\*ist Vivo was used as a tool for data management and analysis for this study. The intent of the software program is to promote swift sorting and searching of data according to the coding categories and to simplify thematic analysis of the data. The computer program can also provide a visual display of the relationships between categories (Qualitative Solutions & Research 1.0, 1999).

## 2.5 Quality of the Research

Ensuring quality is essential to good research. There are strategies for ensuring that the quality of qualitative research is maintained. Lincoln and Guba (1985) referred to "trustworthiness" (p.289) of findings in the terms of credibility, transferability, dependability, and confirmability.

Credibility is the "accuracy of the description of the phenomenon under investigation. The portrayal of the reality must be faithfully represented and plausible to those who have experienced that reality" (Gillis & Jackson, 2002, p. 702). Credibility of the findings was

enhanced by including 6 participants with different opinions and experiences. It was further enhanced by the interview settings. For the majority, the interview was conducted in the participant's home to enhance the participant's ease and comfort while discussing intimate aspects of his life. As suspected prior to the study, the researcher's background of being raised on a family farm contributed to the quick establishment of a genuine rapport between the researcher and the participant. Also, "member checks" were carried out at two different times on the collected data and the researcher's interpretations were confirmed as to the validity of the findings with the study participants.

Transferability is “concerned with the generalizability or fittingness of the study findings to other settings, populations, and contexts. In assessing transferability of the findings, the research consumer hopes to show that the results are not context bound” (Gillis & Jackson, 2002, p. 715 ). Transferability in this study involved the use of "rich," "thick" descriptions so that future studies and researchers can use the outcomes of this research as "working hypotheses" for research conducted in other contexts. Themes that emerged from the data in this study can be further investigated in future studies to examine similarities and differences that may be present.

Dependability refers to the “stability and the trackability of changes in the data over time and the conditions. The issues of qualitative investigations reflects the reality that situations constantly change and peoples reality differs” (Gillis & Jackson, 2002, p. 703). Dependability is achieved by what Guba (1981) called "trackable variance." Trackable variance is achieved by an "audit trail" that provides documentation and an ongoing record of the research project. The audit trail was maintained by the researcher to document rationales and information, and accounts for research decisions and events. The audit trail also included the various drafts and

revisions of the data analysis outcomes, which were recorded and saved as a paper copy and on computer disk. Further, the recorded audio tapes of the interviews will be stored securely for a period of five years.

Confirmability is the “objectivity of the data. Meanings emerging from the data have to be tested for their plausibility, their sturdiness, their ‘confirmability,’ so that two independent researchers would agree about the meanings emerging from the data” (Gillis & Jackson, 2002, p. 701). Confirmability can be established through the audit trail, which will allow an external auditor to retrace the final “conclusions, interpretations, and recommendations” (Erlandson, Harris, Skipper, & Allan, 1993, p. 935) back to the primary sources and then determine if the inquiry has sufficiently supported them.

## 2.6 Ethical Issues

The proposal for this study was reviewed and approved by the University of Saskatchewan Advisory Committee on Ethics in Behavioral Science Research. Prior to the interview, participants in the study were provided with a written consent form (see Appendix F), which described the expectations and responsibilities of the participant, and the researcher. The Participants' signatures on the consent forms indicated their understanding of the study, responsibilities, and their willingness to participate.

A subsequent issue was the possibility that individuals being interviewed could disclose or be assessed to be suffering from distress as a result of the prostate cancer, or situations of distress that may become apparent during the interviews. If this situation had arisen the researcher, whose clinical practice is that of community mental health nursing, would have assisted the participant to locate resources and referrals for further medical or supportive

services, as needed. Also, further participation in the research would not have been expected. At no time during the interviews for this study did the participants report or display any symptoms of distress. Contact numbers for the researcher were provided should the need for assistance arise subsequent to the interviews.

## 2.7 Setting

To set up the foundation for the discussion of the findings of the men's experiences following diagnosis and treatment for prostate cancer it is important to lay the ground work and provide a brief description of the participants, the setting in which the interviews took place, and the related circumstances during the diagnosis and treatment experience of the participants. This information will provide a deeper contextual understanding of the participants and how each participant's life journey unfolded following diagnosis and treatment for prostate cancer.

This study focussed on rural farmers' experiences. Efforts were made to interview the participants within their own homes in the rural environment. The home setting contributed to the ease and the comfort of the participants during the interview process and provided the researcher with a deeper contextual understanding of the participant's personal environment.

Three interviews took place in the participant's home on a farm. Two interviews took place in the participant's home, which were located in a rural town near the family farm. One interview took place within a hospital meeting room in the city, at the participant's request. This particular participant needed to be in the city on other business and he thought that it would be a good use of his time to conduct the interview at that time. He also indicated that it was a long way to his rural home from the city and that it would be a long way for me to come for an interview. It is my opinion, based on the openness and candour demonstrated by the participants

during the interviews, that a good rapport was developed between myself and each participant and was not undermined by the setting in which the interview took place.

For the interviews that took place in the participant's home, the participant's spouse were present within the home at various times during the interview. Privacy for the interview process was achieved by conducting the interview in a location in the house that afforded an appropriate level of privacy. The rapport and ease in the interview process was easily established. In turn, all the interviews that took place in the participant's home included coffee and snacks during the interview. In one instance, I was invited to have dinner with the family following the interview. Following two other interviews, participants stated that I should have timed the interviews better so that I could have had lunch with them. The participants were all keenly interested in where I was from, what kind of farm my parents operated, and the current farming conditions. I think my own farming background helped establish this rapport and enhanced the participants' disclosure of very personal and sensitive information.

The term 'rural' is used throughout this thesis. To get a sense of rural living, as it applies to these participants and their prostate cancer treatment, it is important to take note of provincial geographics and the travel demands required of the participants during the diagnosis and treatment for prostate cancer. There are two major cities and two major cancer treatment centres within Saskatchewan, one in Regina and the other in Saskatoon at the Royal University Hospital. The participants in this study had to travel great distances from their homes to Regina or Saskatoon to see medical specialists and to receive treatment for the prostate cancer. For the participants in this study the average round trip distance to see a specialist was 350 km, which required close to 3.5 hours of highway driving for every round trip. Other costs associated with

this travel included meals and overnight accommodation, when required.

## 2.8 Participants

This section provides some background information for each man in terms how he felt and what he thought about during the initial stages of the prostate cancer. Information about the men's diagnosis and treatment are presented to facilitate understanding of the context of the men's experiences; this will provide a picture of these men, what they went through, and where they were at the time of the interview. Demographic attributes of the study participants<sup>1</sup> can be found in Table 1.

The first interview was with Norman at his home which was located in a small town. Norman lived in town and commuted to the farm. The interview took place in the living room. Following the interview the participant took me to the basement to show me some of his hobby activities. Following the interview and the basement tour I had coffee and cookies with Norman and his wife. At the time of the interview, Norman was 72 years of age, married with adult children, and continued to work on the family farm. He was diagnosed with prostate cancer at the age of 70 years and received radiation treatment for his prostate cancer. Side effects Norman attributed to radiation treatment included fatigue, impotence, a sense of urinary urgency, and bowel problems. Prior to his diagnosis Norman was being screened regularly for prostate cancer by his family physician because his father and two brothers had been diagnosed with various forms of cancer and died. Norman indicated that prior to his prostate diagnosis he had two biopsies within six months of each other, and both biopsies were free of cancer cells and his PSA levels varied from 6 to 7 ng/ml. Following these two tests, his PSA jumped to 22 ng/ml

---

<sup>1</sup>The participants' names have been changed to pseudonyms to protect their identities.

Table 1.

*Demographic Attributes of Study Participants*

Attribute <sup>1</sup>	Participants					
	Norman	Andy	Fred	Irwin	Gary	Carl
Age	72	67	70	60	78	69
Age at diagnosis	70	63	63	57	71	57
Married	Yes	Yes	Yes	Yes	Yes	Yes
Children	Yes	Yes	Yes	Yes	Yes	Yes
Current farming	Yes	Yes	Retired	Yes	Yes	Yes
Type of treatment	Radiation	Radiation	Radiation	Surgery	Radiation	Surgery
Impotence	Yes	Yes		Yes	Yes	Yes
Incontinence			Yes			Yes
Sense of urgency	Yes	Yes	Yes		Yes	Yes
Anxiety			Yes			Yes
Depression			Yes			Yes
Bowel problems	Yes			Yes		
Hot flashes		Yes				
Further treatment		Yes				
Other illness			Diabetes/Hypertension	Cancer		

<sup>1</sup> Self-reported

during a subsequent PSA screening. He was then referred to an oncologist who performed another biopsy in which cancer cells were found in the prostate gland. Following the biopsy, he had a bone scan and laparoscopic surgery to see if the lymph nodes were affected, followed by radiation treatment.

The second interview was with Andy and took place at Andy's home, which was located on the family farm. It was a cold, rainy day and harvesting had stopped because of the rain. The weather provided the participant and his sons with the opportunity to make some farming equipment repairs. It also gave Andy time to participate in the interview. Following the interview, I was invited to join Andy and his family for dinner. At the time of the interview Andy was 67 years of age, married with adult children, and lived and farmed on the family farm. Andy was diagnosed with prostate cancer at the age of 63 years. For Andy, the journey through prostate cancer started with the practice of having routine physical checkups with his doctor. Andy stated, "I didn't have any symptoms that I thought would lead to the cancer." Concerns about the possibility of prostate cancer began when he had a suspect digital rectal exam, which raised some suspicions for his family physician, who referred him to an oncology specialist, who confirmed the prostate cancer diagnosis. Andy first received radiation treatment, which was not successful in treating the prostate cancer. Subsequently, he received additional treatment for his prostate cancer through the removal of the testis through the surgical orchiectomy procedure. Side effects that Andy attributed to his various treatment procedures included fatigue, impotence, a sense of urinary urgency, and hot flashes. The treatment choices that he was given included surgery, radiation, and the "wait and see approach." Reflecting on his decision to be treated by radiation, Andy stated, "at the time I had some friends who were going through this radiation

thing and thought, 'Well, yeah, what the heck! It's good for them. It should be alright for me.' "

The third interview was with Fred and occurred in the evening at his farm house. Fred and his wife owned a house in town but they preferred the house on the farm during the summer. The interview took place at the kitchen table while Fred's wife sat in the living room. At the time of the interview, Fred was 70 years old and married with adult children. His prostate cancer was diagnosed at the age of 63 years. Although Fred lived on the family farm during the summer months he was retired from active farming, in part, due to his prostate cancer. Fred received radiation treatment for his prostate cancer. Side effects that Fred attributed to his radiation treatment included incontinence, impotence, a sense of urinary urgency, and anxiety. Fred was also being treated for diabetes and hypertension. He stated that prior to his diagnosis of prostate cancer he had been having pain related to sexual intercourse. He was referred to a urologist who performed a biopsy and a PSA test. His first PSA score was 5 ng/ml and his doctor indicated that they would check it again in three months. Following that three month period his PSA was found to be substantially higher and another biopsy confirmed the diagnosis of prostate cancer. Fred stated that because he had friends who were receiving radiation treatment for prostate cancer, he opted for the same treatment.

The fourth interview was with Irwin and took place on Irwin's farm during lunch hour in the living room. At the time of the interview Irwin was 60 years old, married with adult children, and lived and worked on the family farm. He was diagnosed with prostate cancer at the age of 57 years. His choice of treatment was surgery. Side effects that Irwin attributed to his treatment included bowel problems and impotence. Prior to the prostate cancer Irwin had been treated for esophageal cancer. Because of the esophageal cancer, his doctor had been monitoring him for

prostate cancer. The prostate cancer was discovered through routine screening measures.

The fifth interview was with Gary and took place in a meeting room at the Royal University Hospital in Saskatoon. At the time of interview, Gary was 78 years of age, married with adult children, and active on the family farm. His age at diagnosis was 71 years. Gary stated that he was "struggling with a flu bug" prior to being screened for prostate cancer. He indicated to his family physician that it had been two years since he had received a physical examination. His family physician performed a physical examination that included a digital rectal exam, followed by a PSA test as he felt there were some abnormalities with the digital rectal exam. Gary's choice of treatment for prostate cancer was radiation. Side effects that Gary attributed to his radiation treatment included impotence and a sense of urinary urgency.

The sixth interview was with Carl and took place in the small town where the participant lived. Carl and his wife lived in town and he drove out to the farm to work. His wife was at home but was in another room during the interview. The interview took place at the kitchen table. At the time of the interview Carl was 69 years, married with adult children, and he remained active on the family farm with his son. He was 67 years of age when the diagnosis of prostate cancer was made. Carl had been having regular checkups, including screening for prostate cancer, for about two years prior to the diagnosis of prostate cancer. When diagnosed with prostate cancer his first concern was he didn't know "how bad it was" or whether they would "catch it soon enough." In describing the diagnosis he stated, "I guess it didn't bother me too much . . . I guess it did, but it didn't, you know? . . . I was just hoping that we could get to it as quick as we can." Carl's choice of treatment for the prostate cancer was surgery. Side effects that he attributed to his treatment included impotence, incontinence, and a sense of urgency.

## CHAPTER THREE - FINDINGS

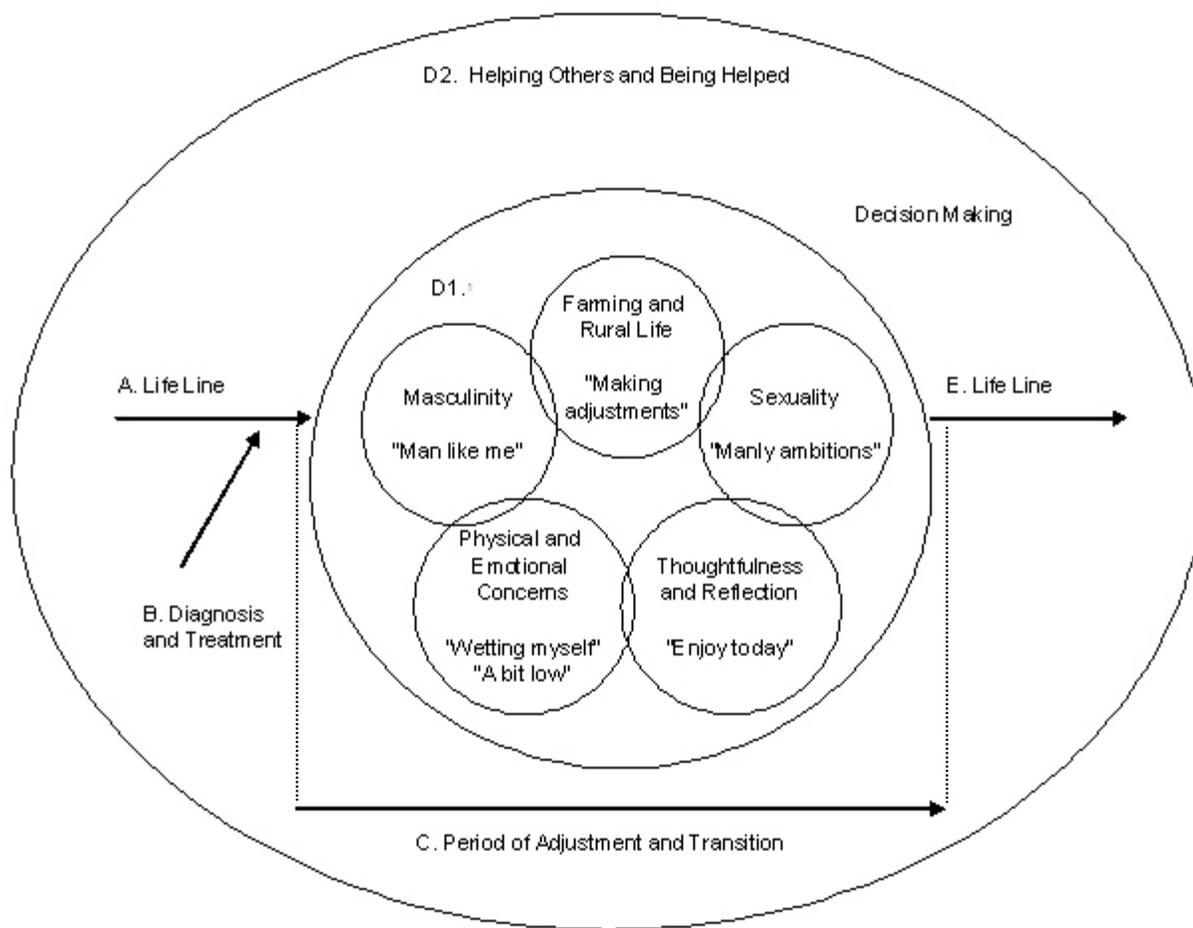
### 3.1 Findings

For each participant, his journey has been an individual experience shared with family and friends who have also been a part of this journey. The perceptions, feelings, and thoughts in regards to the participant's life experience, however, are uniquely understood and best explained by the participant, himself. The naturalistic inquiry approach to qualitative research is based on the premise that each person has his or her own unique individual experience or life story. The aim of the research is to understand the unique individual experience as well as the similarities and differences in perspectives that may exist between people. This study used qualitative methods of naturalistic inquiry and grounded theory analysis to describe the experience of a group of farmers who were treated for prostate cancer and to identify common themes in the men's accounts of their experiences. The common themes resulting from the analysis are presented schematically in the model shown in Figure 1.

#### *3.1.1 A Model of Transition*

The information obtained through the interviews provided me with data that I was able to group and organize to identify common themes in the participants' experiences with prostate cancer. A model diagram (see Figure 1) was used to schematically illustrate how the different themes and the overall structure of the prostate cancer experience of the participants fit together into a logical sequence. In this section, the model depicting the sequence of events and the

Figure 1. A Model of Transition



<sup>1</sup> The five common themes that emerged from the data

common themes in the participants' experiences with prostate cancer is described.

In the Model of transition depicted in Figure 1, the life line (A) on the diagram represents time as the participants are living their lives forward through time. The life line includes the time period of the prostate cancer diagnosis and treatment (B), followed by the period of adjustment and transition (C), and then life carries on after the prostate cancer diagnosis and treatment and the transition phase (E). The life line (A), reflects the participants' shared view that life had not stopped for these men despite the circumstances that developed because of the prostate cancer. The life line intersects with the period of the prostate cancer diagnosis (B). The participants reflected on the point of time in their lives when the prostate cancer was diagnosed, what the experience was like for them, and some general concerns that the participants had about the prostate cancer treatment. The period of adjustment and transition (C) indicates that as the life line continues forward through time for the participants, following the diagnosis of prostate cancer, they underwent 'adjustments' and 'transitions' in their lives, work, and relationships. The model identifies the common themes (D1) that emerged from the data. All five themes relate to the period of transition. The common themes that emerged from the interviews are presented along with selected quotes from the participants' interviews that illustrate each theme. The five themes are: (1) farming and rural life "making adjustments," (2) physical and emotional concerns "wetting myself" and "feeling down," (3) sexuality "manly ambitions," (4) masculinity "man like me," and (5) thoughtfulness and reflection "enjoy today." Selected quotes from the participants also provide titles, within the quotation marks, for the five themes. As depicted, schematically, by the spheres in the model (Figure 1) all the categories are interrelated and overlap at various

times. Each theme is not an independent theme. The analysis suggested as an overarching theme (D2), the idea of helping others and being helped or "a bit of a lift," as one participant said. The theme of helping others emerged from the participants' expressed thoughts about helping other people, being helped by themselves, and being helped by other people. The data suggest that the helping theme overarched the five common central themes identified within the large sphere in the model. The theme of "helping" appeared to act as backdrop to the discussion of the other five themes throughout the interviews with the participants. Also, within the model is the phrase "decision making." This indicates that decision making is a constant effort that the participants undertake throughout the entire model of transition.

The five central themes (D1) appeared to interact in different ways within a broader context of "helping others and being helped." During the process of being diagnosed and being treated for prostate cancer there was a transition period, which involved lifestyle and relationship adjustments that affected and influenced the participants and their family members. Following this transition and adjustment period, as shown in the model, life continued for the participants with a new reality created by the experience of prostate cancer and the related adjustment period in life.

### *3.1.2 Themes*

#### *3.1.2.1 Farming and Rural Life "Making Adjustments"*

All the participants were actively farming when they were diagnosed and treated for prostate cancer. Accordingly, there were significant adjustments and unique changes that took place on the family farm for each participant. For some participants the changes affected their own physical self and their ability to work. For others, the farm changes involved the entire

family. For all the participants, their experience with prostate cancer did alter the functioning of the family farm, to varying degrees, and for some participants it made them re-think the operation of the farm and what the farm meant to them. The physical effect of fatigue was strongly related to the participants' ability to farm and was discussed by the participants in their reflections on the adjustments that took place on their farms. Therefore, the physical effects of fatigue will be discussed along with the theme "making adjustments." Similarly, some of the men spoke of the direct help they received from people in operating their farm during these difficult moments. For this reason, the theme of helping others and being helped relative to farming will be addressed here. This theme also encompassed selected aspects of the rural communities and the rural culture in which the participants lived and how these aspects inter-played with farming, their way of life, and their prostate cancer experience.

Norman indicated that subsequent to the radiation treatment he received for his prostate cancer he experienced increased levels of fatigue, which remained with him. One effect of Norman's fatigue on the farm operation was that he was unable to remain out in the field for long periods of time, particularly during harvest. For Norman, his concern in regards to this fatigue was not for the productivity of the farm, but for the safety of his son. Because of his fatigue Norman had to leave his son out working alone in the field. Norman discusses his concern here:

I would go in [out of the field] and my son would fill the trucks and that type of thing I didn't like that because you've got one fellow out there and if he has problems and he needs some help . . . he's alone, so that bothered me in the fall. Yeah, it worked out, but if I left him out and, you know, if something was wrong with the combine . . . [I would tell him] "don't get off it." He said he would. I don't know whether he was or not . . . but anyways it worked out well . . . but I tire easier than I did, say, before the radiation.

Norman identified his advancing age as a co-factor coupled with the fatigue that affected

his ability to work on the farm: "No, I guess there is an age where you become a liability."

Despite these concerns, Norman indicated that he would continue to do what he could on the farm, as illustrated here:

I'll just keep on going until they don't want me or I can't . . . I think the body wears out like your car . . . if you have a few hundred thousand on it . . . that's not quite as good as it was when you bought it . . . you know you wear out.

Norman travelled to the city for his prostate cancer treatment. He thought that it would have been better to have the treatments in a location closer to home but he acknowledged that was not possible. Norman thought that maybe living in a rural community had its disadvantages during the treatment phase of his prostate cancer because of the distance he needed to travel for the treatment. This however did not seem like an extra burden for him and in fact he stated he felt fortunate because he was able to stay with family members in the city when he was undergoing the radiation treatment. He indicated that having family in the city saved him much extra travel and effort. Despite having to travel to the city for treatment, Norman felt his rural community had strengths that make for a better quality of life in his community compared to the city, as he discusses here:

It's a lot of back and forth [to the city] . . . it would be nice if we had our own [cancer] clinic, but that is not possible . . . I guess we have to accept that, you know, . . . but we have a nice town, but you can't have everything. A lot of things that we have out here that the city doesn't, like the crime rate . . . you can walk down the street without much danger.

For Andy, one of the first problems that involved his farm operation was the timing of his radiation treatment. While he was expecting to receive the radiation treatment in the winter as his wait for the radiation treatment stretched into the early spring and he began to worry about spring seeding and if his radiation treatment was going to interfere with that. His concern about the start

date for the radiation grew until he felt he had to become quite assertive with the medical system to get the treatment started:

We started in February. And I was in kind of a hurry to get these things started so that, you know seeding is coming up. And I didn't know how it was going to affect me and so I was, well, I was wanting to get at it. Yeah, when the doctor, here, says, "I'll set everything up for you in Regina." He said, "they'll give you a call within 2 weeks." Okay, 2 weeks go by and I never heard anything. Most of another week went by and didn't hear anything and I thought to myself, "Well, now, this is ridiculous." So, I went down to the Cancer Clinic in the city and said, "Hey, what's going on here? I'd like to start treatment." And they went through the files. "Well, we don't have any record of anything yet." I said, "What's going on here?" So they got on the phone and that afternoon they had the information faxed to them and an appointment set up. But, if I hadn't been aggressive, when would I have got it? You know . . . I was concerned about seeding, you know. We've got crops to put in. What the hell! Let's get at it, you know, . . . So, anyway, within a week, I think, I was on the road to the city.

Andy acknowledged that his experience with prostate cancer led to what he called "adjustments" in how the farm operated. He related that these adjustments not only affected him, but they affected his family, as well, as shown in the following quote:

. . . when I first got it [diagnosed with prostate cancer] . . . I was, like, really family farming . . . My son had some land beside us, here. He farms . . . you know, together, and when after this [prostate cancer], well, I can't work so much. So, we needed more help on the family farm. The opportunity came up to buy some more land . . . close . . . and so that's what we did . . . and brought the other son home. So there's the three of us and it's all one It's not his and mine . . . It's all one. So that's what we had to do. Yeah. I just can't take the hours like I used to . . . There's been adjustments with every one of us.

Andy thought that one of the more troubling problems he experienced following the prostate cancer treatment was the increased fatigue. Because of the increased fatigue, his two sons on the farm had to pick up the extra work that he could not do. He acknowledged that at different times the cancer experience was irritating, particularly when it came to his farm work, as illustrated below:

To have work waiting for you and you can't get to it . . . that when you are tired . . . you

have got to quit . . . It is a source of irritation . . . I can't get the things done I used to . . . but then we've got two sons, now, that's . . . I guess an extra burden's been placed on them . . . No, I can't get things done that I used to.

For Fred following his radiation treatment one of the main side effects was fatigue.

Because he did not have any children involved in the farming operation, he did all the work, himself. He also worked off the farm as a private journeyman contractor. For Fred the concern over fatigue was a real issue in terms of his work productivity. In his situation it became clear to Fred that because of his prostate cancer and the side effects, he needed to adjust the operation of his farm. Prior to his prostate cancer he had a serious injury, which prompted him at that time to rent out some of his land to lighten the workload on the farm. When he was diagnosed with prostate cancer he decided to rent out the entire farm and only do some private contracting work where he could pick and choose the work and the hours worked. Fred rented out his land because he felt too tired following the radiation treatment to maintain all his previous work responsibilities, as he discussed here:

I rented out some land earlier as I had an injury . . . and that made, kind of, things tough for farming . . . so, then, this cancer business, it was around . . . but I rented out . . . the farm, totally, and just did my contracting work for myself. So, I chose my hours when I got tired . . . Whether it is the effects of the radiation or not, but I did tire a lot quicker than before.

I asked Fred if he thought the decision to rent out the entire farm was speeded along because of the cancer. Fred replied:

Yes, it did . . . Between my injury and then this cancer business hurting, you know, the thing was, I come to the realization that maybe time I slowed down a bit . . . I had a lot of all new machinery, nice machinery and that, but I sold it and renting out the farm I just said, "I accept it [finished farming] as a fact of life."

In contrast Irwin indicated that his experience with prostate cancer did not have a major

impact on the productivity of his farm. Although he noticed an increase in fatigue since he had the surgery he adjusted to those periods in the day by taking short breaks, as he stated here:

You know, so I can take power naps. If I get tired out in the field, then I just take the tractor out of gear and I can put my head back on the window and I can sleep for 15 minutes and wake up and feel like I have slept 4 hours.

Irwin's concerns about the farm were more concentrated on the treatment and the recovery time for treatment. When asked about whether he had any concern with the viability of the farm during the treatment phase of the prostate cancer, Irwin responded:

That worried me a bit [keeping the farm going] . . . getting all the work done 'cause my son had to use his holiday time and things like that, but I know it all got done, eventually . . . maybe not the exact way that I would have done it, but it did get done.

Irwin talked about the farm and how he had received tangible help in operating the farm because his treatments occurred during spring seeding. The help he received came from his son and a neighbour, as explained:

The surgeries were in May. So, I had some pretty good neighbours . . . and between my son . . . he took time off work the first year and they [neighbour and son] got the crop in and I was able to help on harvest. My other son came home and between the boys they kept things going through the summer . . . best they could. Then with the next surgery, the same neighbour helped my son with repairs and kept things going. So, it kind of, few things got behind during those couple years.

Irwin stated that he was not concerned about whether his son would be able to get the spring work done because he knew that he could rely on his neighbour for the extra help, as discussed here:

Yeah, well, if we'd have got too far behind the neighbours would have come in and finished up. As it turned out, my son had our crop in before most of our neighbours did. He got pretty good luck in the spring and if things broke down our neighbour helped him . . . fix things up and get them going again and, no, he did very well. I was pleased with how he handled things. He'd stop in every morning. Of course, I was at home with the first surgery and we'd have a little visit in the morning, have coffee about 7 o'clock and then he'd go away . . . he'd go until dark. And so he did real well. 'Cause he'd been helping a bit . . . but not really full bore doing everything . . . the fixing and the fuelling and all

kinds of different things. So, I'd give him instructions in the house and then away he'd go and get it done or our neighbour would come over and help him.

On the same theme, Gary related that during the year in which he was diagnosed and treated for prostate cancer he did not work as much on the family farm with his son as he normally did. He stated that, "I probably didn't do my fair share that spring . . . the family was very understanding." He indicated that although he did not work as much, it did not seem to disrupt the productivity of the farm and, in the end, the family was just happy that he was doing okay: "They were relieved that the old man was still around I guess." Although the fatigue he experienced after treatment was a concern for him, he also thought that his age might be a contributing factor, as discussed here:

Oh yeah, I don't know whether it's old age or what, but I don't have as much energy I should have – I'm only 77, I think I should have more energy. And I'd like to blame it on something besides old age, so I blame it on the radiation . . . I still had some cattle then and the boys, like the wife and I lived in the village long before that. But I probably didn't do my share that spring. The family was very understanding. They were relieved that the old man was still around, I guess.

At 77 years of age Gary was one of older participants in this study. He indicated that prior to the diagnosis and treatment for prostate cancer, he and his family had already begun the transition process of moving the farming operation and decision-making from himself to his sons. Gary stated this transition had started because he knew that he had to be realistic about his life and the operation of the farm as he got older. "I never figured I would be around forever," he stated. He also commented that he and his wife made annual winter trips to Arizona, during which he encouraged his sons to make their own farming decisions. As he stated:

When I am away 3 or 4 months in the winter, my boys have to make decisions of their own and I've encouraged it. . . . they think as long as the old man's around the natural thing to do is for them to ask all the questions.

For Gary, the diagnosis of prostate cancer and the treatment did not seem to interfere with the productivity of the farm as his family had already been making transitional changes to the farm operation.

Of the six participants, Gary lived the farthest away from a cancer treatment centre. When discussing the rural aspect of where he lived and farmed, Gary did not seem to think that his long drive to the city for treatment was a particular disadvantage for him. In fact, he seemed to find the travel into the city as something worthwhile to him. Although he and his wife had to pay for a hotel room for his appointments, he did not view the hotel costs as a burden. Gary indicated that he enjoyed the trip to the city and the opportunity to just get away from home. As he put it, "It's nice to get to the city once in awhile . . . the hotel is handy to the hospital . . . I don't have to worry . . . I have got a place to stay. "

For Carl, when he was diagnosed and treated for prostate cancer, some significant thoughts and changes took place in regards to the viability of his farm. Carl indicated that these changes had a big impact on other family members, as well. He discussed these changes:

Well, I guess it really did [farm changes because of the prostate cancer], but then, 'cause my boy's in Calgary. Is he going to have to move right back again? You know, can he run the farm? Or will the big farm have to be sold? You know, stuff like that comes to mind.

Carl's assessment of the impact of the prostate cancer diagnosis and treatment was that it speeded up making plans for the future of the family farm. He indicated that, in the short-term, he was not too concerned about the timing of the initial treatment process and possible effects of interruptions on the immediate operation and viability of the farm. He indicated that when you have cancer you have to do something about it: "Especially when you've got cancer. It doesn't

wait for nothing. No, I would have went right in [despite the work on the farm]. "

Carl indicated that living within a rural setting and culture was advantageous for him during the process of being diagnosed and treated for prostate cancer relative to the operation of the farm during critical times of the year. Carl stated that if his crop was in the field and he had to get cancer treatment, his neighbours would come to help out. He did not have to ask anyone in advance because it was a given that if he was in a bind and not able to do something on the farm, people within his community would be sure to help him. He explained that this is just what happens in his rural community:

But I have good neighbours and if your harvest is sitting there I'm sure they would come in and clean it up for you if you had to go in . . . They're pretty well a lot like that in this country . . . they tell you that before you even go in . . . Once you tell them that you have trouble, well you know they are right there.

In summary, when diagnosed and treated for prostate cancer the participants in this study experienced fatigue, which led them to make adjustments to the operation of their farms. Adjustments included the enlistment of family members to take on new responsibilities on the farm when the participants could no longer perform as much work as they did before. Adjustments for one participant meant renting out the farm and pursuing a more relaxed, retired way of life. Living in a rural area was not seen as a disadvantage to the participants and was perceived to be an advantage when you factor in the quality of life and available support that exists in a smaller community.

### 3.1.2.2 Physical and Emotional Concerns "Wetting Myself" and "A Bit Low"

The participants indicated that incontinence or the prospect becoming incontinent was troubling for them and, for some, it affected their choice of treatment because they wanted a treatment with a reduced risk of incontinence. This section summarizes the participants' concerns about the physical aspects (e.g., fatigue) of the treatment and their views on the emotional aspects of the prostate cancer including how they felt about themselves and their ability to live with prostate cancer.

As discussed before, Norman indicated that he was generally tired following his treatment for prostate cancer. Fatigue had more of an impact on his farming activities than on his regular day-to-day activities. He experienced problems with incontinence at times, but indicated that he had been able to gain control of the "urination thing." Norman discussed having trouble with occasional bouts of diarrhea which he attributed to his radiation treatment; this was upsetting for him because there was very little warning before it occurred. Norman identified his physical concerns:

I have the urination thing pretty well healed, mastered now. But, uh, I still have diarrhea. Sometimes, okay . . . Other times not. It's boom and I have to go . . . I have to get to the bathroom.

Norman stated that he was careful about his involvement in social activities. Norman explained that being careful for him meant he located the washrooms in each particular place he visited so that he could get to them quickly if he had to. Although accidents could happen, he did not believe that these problems prevented him from doing the things that he would normally do, as illustrated in the next interview excerpt:

I still go to mall or I go to a place . . . I always make sure I know where the bathrooms are . . . No matter where you are travelling, you've got a bathroom picked out before you go . . . I did have one bad accident this summer. I just didn't make it. It was terrible.

When Norman reflected on some of the physical problems he has had since treatment, it led him to wonder about the seriousness of the effects and about his own mortality. Norman stated, "you always know, is this just normal (incontinence and diarrhea), or just what is it . . . or how long do I have?" With respect to the impact of the incontinence and the diarrhea on Norman's ability to farm, he indicated that when it came to farming it was not much of a concern. He explained that when he is out on the farm, he always kept a roll of tissue paper with him. As the following quote illustrates, he did see some humour in his situation:

You have the sign that you have to go to the bathroom. I'm conscious about that. When I am out in the field, that's no problem because I can answer the call of nature right out in the field . . . In a pinch I always carry a paper roll . . . But I'd be embarrassed . . . Well, seeing someone's grandpa out sitting there (laugh) . . . something like that.

Norman did not express any particular concerns about his prostate cancer experience in regards to depression or anxiety related to living with his prostate cancer. He related that he understood how "people" could be affected with depression or anxiety because of the experience with cancer. Norman explained that he did not think he suffered from depression because the first thing he did when he was diagnosed was to look at his cancer from the worst possible scenario, then he tried to put things into perspective for himself. He stated that his prognosis looked good after his initial testing and therefore he had every reason to be positive about how things would go for him. In addition, he thought that his age helped him initially to put things into perspective. He stated, "If I was 50 or 40, then I would really have something to worry about . . . and if the cancer was growing fast . . . the fact is, I'm . . . 70 and the prostate cancer is growing slower." He

did acknowledge that had his prognosis not been so good, he did not know if he would have managed as well as he did: "I don't know if I would stand up so well if I knew it was in my lymph nodes and all over hell." Norman also used comparisons with other men to remind himself how fortunate he was, as illustrated here:

When I was going to the city, they talked very openly . . . this younger man than me . . . he was 6 or 7 [PSA] . . . seems there was something else they were looking, that they thought the cancer was someplace else . . . you know, you look at a fellow like that, you know, you know how lucky I am.

Norman disclosed that some of the physical effects he experienced after the treatment made him wonder about the effects and whether they were normal or not: "well and you always know . . . Is this just normal [side effects] . . . or how long do I have?"

Andy indicated that he experienced a sense of urgency in relation to urination as described here:

Yeah, when you have the urge to go to the bathroom . . . it wasn't, well, in a minute, it was now . . . right now ... maybe a time or two you didn't quite make it . . . but that's something you kind of live with . . . even now . . . You know, very well, that if you've got to go to the bathroom . . . you'd better not look around for it. You want to know where it is.

Andy did not think that he had any particular problems with anxiety or depression. He thought that being a farmer was perhaps helpful for him because he worked through his perceived problems with the knowledge that there was always work to do on the farm to keep himself occupied:

Guess my cure for that [anxiety and depression] was to keep busy . . . You don't just sit down in the corner and worry about it [cancer] . . . because you keep going . . . always something to do. Get out there and do it. You're not thinking about me.

Fred stated that he chose radiation treatment because he was concerned about being incontinent. He thought that the risk of being incontinent would be greater with surgery. Fred reasoned that he still needed to work and that he would not be able to work if he was "wetting

himself," as explained here:

The surgery kind of bothered me in a way because of the incontinence. That was the only thing that really bothered me because working full time on the job and climbing around you couldn't go around wetting yourself . . . I just couldn't see myself getting any of my clothes wet . . . I still had to work for a living. The impotence and incontinence were two of those two circumstances in the surgery . . . you know . . . but the incontinence was the only one that really worried me because the other [impotence] was pretty much over . . .

Despite taking the radiation Fred experienced problems with incontinence which he had hoped to avoid. In his estimation however it did not turn out too bad for him. He acknowledged that the incontinence was frustrating because he had hoped that by taking the radiation he would avoid the incontinence, as indicated in this next interview excerpt:

I had problems with it [incontinence] and probably still do . . . but it was a lot worse at the beginning and the thing was . . . I had to . . . we had to buy . . . a motor home to travel with [had a bathroom], but now . . . I pretty much sleep all night . . . I can sleep 4 hours [without problems] . . . not exactly a young boy anymore . . . it would get better [the incontinence] . . . it got a lot better . . . not perfect, though, . . . but it's something . . . like all the other problems I've got . . . I can live with them.

Fred disclosed that he had trouble with anxiety and depression in the past, for which he was prescribed medication. He stated that he had the advantage of having a history of anxiety and knew the triggers for his anxiety. He also knew how helpful medication could be for his anxiety. He stated that he went to his doctor who prescribed medication for his anxiety which worked "tremendous" for him. He said that he was treated for anxiety with prescribed medication only once. Because of his mental health history, Fred felt he knew and understood how people could get caught up with depression when they are trying to live with the experience of prostate cancer, as illustrated here:

. . . I had problems with anxiety and depression. I take medication for it . . . just once in the cancer business . . . I went to my doctor and told him, I said, "You know . . . my anxiety is bothering me a little bit." . . . I had been to a psychiatrist [in the past] . . . and he

gave me some medication for it [anxiety] . . . and it worked wonders, so my doctor used a prescription of those . . . just enough to get me over the hump. I can understand where people do get depressed. "Why me?" [getting cancer] . . . Everybody says that . . . but why not you? You have to be honest about it . . . you can't always be missed, I guess, . . . but just like anything else . . . you really don't realize it until it hits home [cancer diagnosis] . . . You know when it hits you . . . then you understand.

In contrast with Fred, Irwin indicated that he did not have any major physical concerns. He did note however that prior to treatment he was very concerned about the possibility of being incontinent following treatment. He thought that his mostly good experience with prostate cancer might have been different if he had to wear a diaper for incontinence. Irwin stated that his first concern was being incontinent following treatment and having to wear a "diaper" which was a greater concern for him than the potential for impotence.

With respect to anxiety and depression, Irwin talked about his approach of trying not to dwell on his cancer, which he did by keeping himself as busy as possible on the farm, as illustrated here:

. . . I never sit at home and think, "Well, I had cancer twice and two cancer operations and maybe I'll die tomorrow." I haven't got time to worry about that. Whatever's going to be is going to be, so . . . as long as I carry on with what I'm doing [farming].

Irwin stated that he did experience some low points with his first cancer diagnosis and that his wife really helped him through that difficult time. He often talked about his two cancers, interchangeably. He described his feelings during his first experience with cancer:

Well it wasn't that bad. I think the lowest point, probably, was when I was in the hospital, more than anything. The first go around . . . the wife was there every day from daylight to dark. It was probably harder on her than me, but . . . there were some low days in there . . . I couldn't eat and you'd see the tubes all over the place and I was gall darn sore. Between this opened up [surgical cuts] all the way from here down to here [gestures from neck to stomach] and couldn't eat and I went from 205 lbs down 50 lbs in 2 weeks . . . in 2 weeks . . . You look like you've been through . . . run over by a truck or something, loose skin hanging . . . She [his wife] kind of kept me going when I did get kind of low . . . Yeah,

well, I suppose I had a little bit of depression when I finally figured out what they were going to do because I didn't . . . want to believe them to start with . . . it was a pretty wild couple of years . . . I'll tell you . . . We both wondered [he and his wife] whether life's all worth it . . . You keep plowing along and it all worked out in the end.

Irwin thought that his first bout of esophageal cancer was a more serious threat to him than the subsequent prostate cancer. So, when he went through the prostate cancer experience it did not seem as traumatic as the esophageal cancer. He did indicate however that the prostate cancer made him pause for a while. As he stated, "We did some serious thinking, that's for sure." Irwin reflected on the time he spent waiting for prostate cancer treatment. He indicated that farming can "give one" a lot of time to think about things, and that sometimes this is good, and at other times this is a bad thing. Irwin stated, "I found you've got lots of free time to think. Sometimes it's good. Sometimes it's not. Yeah . . . get out on the tractor and lots of times you're thinking."

From Gary's perspective, his energy level had been down since his prostate cancer treatment. Gary experienced a lot of urinary of problems shortly after being treated. He indicated that he always made sure he knew where the bathroom was when he was out in the community. He felt that a year after his treatment he was able to do his "fair share of work." He also thought that his ability to "hold his bladder" improved. He woke up every night to use the washroom to ensure that he emptied his bladder. Gary explained that if he was able to return to sleep quickly after using the washroom it did not seem to be as much of a problem. Gary also disclosed that prior to treatment the thought of being incontinent was more of a concern for him than the potential loss of sexual function. Gary thought that a person's choice should be to live longer, as he explained here:

And I never had any trouble, but I have to admit I think that all of that radiation (in my layman's terms) destroyed some of the elasticity of my bladder, because I have to get up

pretty well every night. That's a small thing. And if I can get right back to sleep, again, I don't even consider it. Sometimes, if you've got a lot on your mind and you have to get up and go to the bathroom and then you can't get back to sleep. But that's about the size of it, I think . . . I'm still active, a little bit in farming and I was more so 5, 6 years ago. And it came up to harvest time, so there's lots to keep your mind on other things besides your own health at harvest time.

Gary did not feel his prostate cancer experience had been too difficult to deal with. He did not have any physical pain, which he thought was important to his state of mind, as discussed here:

'Cause I never had any pain. I've seen people over there in that Lodge, one guy in particular. He had cancer inside his mouth and, uh, I often wondered why they didn't feed him with the intravenous, but it was just torture for him to eat. It was just terrible, and bad enough for us to watch him try to eat and I never had any pain, really. I was weak and I had that diarrhea . . . but as far as pain goes I was scott free. I think that has had a lot to do with your attitude.

Gary also felt fortunate that he never experienced depression during the diagnosis and treatment period. He had seen people with depression and referred to them as suffering from something that is "bigger than they are." He attributed much of his ability to live through his experience with prostate cancer to his religious beliefs, as he explained here:

Maybe some of it is my religious belief. No, I can't honestly say I had any trouble with depression and I guess I should be thankful? 'Cause I know I've seen people with depression and they can't do much about it. It's bigger than they are.

Carl stated when deciding on surgery treatment he did worry about his bladder and being incontinent. He initially decided on the surgery because he thought he would end up with fewer problems such as incontinence. He indicated that prior to the surgery he already was beginning to have problems with his bladder and he worried it would get worse following treatment. He believed, at that time, that if he took radiation treatment he would have the potential for more problems with incontinence than if he took surgery. He pointed out that he has been wearing a

diaper since the prostate cancer surgery. He stated that while he needed to wear the diaper through the day at night he could sleep without it. Carl stated that he still got the urge to urinate at night and he kept a diaper close at hand in case of an emergency. As for his current concerns, Carl stated, "It's just something that you got to work." Carl's thoughts on his incontinence are illustrated here:

I knew my bladder was weak for 3 or 4 years before that. Always going to the bathroom. And I thought it was just a farmer's habit. So he [the physician] said, "I'm so glad you went for the operation." 'Cause he didn't know what the radiation treatments would do. And so, maybe, I wasn't lucky, because I still ended up with a diaper, which is no hassle.

Carl acknowledged that at certain times he had experienced some anxiety and depression in relation to his prostate cancer diagnosis. He noted that his mood appeared to change once in awhile and that he did have some sleep changes. He pointed out that his everyday patience level was short at time particularly around activities taking place on the farm. He thought that he was not always aware of his behaviour and feelings until after the fact. He described some of the changes here:

Oh yeah. That changes [mood and behaviour]. Ask my son . . . I wasn't easy to get along with. Yeah, it's, if everything is running smoothly it's fine. Some darn thing would break, well, boy oh boy, I'd jump up and down and he's never seen that. Yeah, oh yeah. Yup, and he knew it had to be that (thinking about prostate cancer) doing it because he knew I was never like that . . . even my wife noticed it too . . . If you had time to think, it would never happen, but sometimes something would come up. Well, good Lord, now what are we going to do, you know.

In summary, participants indicated that incontinence was a major concern with respect to the outcomes of prostate cancer treatment. For a few participants, selection of the initial treatment method was based the likelihood of not being incontinent following treatment. Despite the different treatments that were received, several men still had problems with incontinence and

urinary urgency. In retrospect, the problems that some of the men continued to have with incontinence were not perceived to have a major impact on them; these problems were perceived more as an annoyance. Adapting to the incontinence meant wearing a diaper for one participant, and carefully planning out trips and social engagements by remaining aware of the proximity of bathrooms. Depression and anxiety for these study participants were not major concerns or something they experienced a great deal. The exceptions were Fred and Carl. Fred who had a history of depression and anxiety and sought out appropriate help for his anxiety. Carl admitted that at different times he may have had some anxiety and depression. The preferred method of getting through the difficult moments that the participants experienced with prostate cancer involved "getting to work." These men had work to do on the farm, and they used the work to distract themselves and forget about the prostate cancer.

### *3.1.2.3 Sexuality "Manly Ambitions"*

Sexuality and sexual expression is a very personal matter and also a subjective matter that is defined by each individual person. All the participants in this study discussed aspects related to their sexuality and sexual relationship with their spouse in the context of sexual function following treatment for prostate cancer. Each participant was open to the discussion of sexuality and in a few cases the topic was brought forward to the discussion by the participants themselves without any questions or prompting by the interviewer. Of the six participants in this study, all but one indicated that they experienced sexual dysfunction following their respective treatments for prostate cancer. Three of the men concluded that sexual function was a trade-off for surviving the prostate cancer. Two of the men indicated that sexual dysfunction was a real concern for them and they did have the resolve to try and fix that part of their life by seeking out help from their

physicians. One participant indicated that while sexual dysfunction did not concern him or his wife in the past, now, several years following treatment for prostate cancer, he seemed intent on following up a bit more with his physician to see what possible alternatives were available for him.

Norman indicated that the radiation treatment for prostate cancer had left him impotent. He attributed the impotency to the medication [Zolodex] he was taking after the radiation treatment: "I think the Zolodex has stopped those manly ambitions, that type of thing." He stated that while he and his wife had not discussed the sexual dysfunction, she knew that the sexual function was gone: "My wife has never talked about it, but she knows . . . we've never talked about it." Norman felt, however that the sexual dysfunction had not affected his relationship with his wife and had not "created big problems." He indicated that he and his wife were so active and had so many good things in life that the sexual aspect of their relationship did not matter that much:

I think that a person in my case can use Viagra . . . but you know we are so bloody busy, you know, we've got the most beautiful grandchildren that you can have . . . and we have so much to do.

Norman thought that the loss of sexual function needed to be viewed within the context of age. He implied that if you are older when impotence occurs from prostate cancer treatment it may not be as much of a concern for couples. Although he understood that impotence issues could be a potential problem for couples, Norman thought that when dealing with the seriousness of the prostate cancer itself going without treatment to maintain sexual function was not an option:

I guess when you have no alternative [about receiving treatment] you are either going to get worse or better, that type of thing. You can't have everything [sexual function]. No that [loss of sexual function] doesn't bother me?

Although Norman stated that his impotency was not a big issue he had discussed it with his doctor. He described how his first conversation with his doctor went in regards to the impotence: "The doctor asked me about that [sexual function] and I told him about that . . . and that was about the far as that went." He indicated that he planned to see his doctor and discuss his impotence issues again and any medical options that may be available to him.

Andy reported that he became impotent following the radiation treatment and his subsequent orchiectomy. He indicated that his impotence was not much of a concern because of his age: "And then after that operation . . . well (sex was done), but hey I'm sixty." He stated that he and his wife discussed his impotence by putting things into perspective which meant that he needed the prostate cancer treatment to survive. Andy indicated that the loss of sexual function was a trade-off for maintaining other aspects of their lifestyle. Andy's perspective on his impotency is illustrated in the following quote:

Well, like I said to my wife, if I had this second operation, well, that'll be all [impotent]. She said, "that doesn't matter . . . I'd sooner have you than the other anyhow." . . . That's the way she looked at it . . . So, we just carried on.

Fred reported that prior to his treatment for prostate cancer he experienced pain during sexual intercourse. Fred concluded that the pain indicated something was really wrong in his body. He reported that the pain he had before the treatment disappeared after the radiation treatment. Fred stated that if becoming impotent was the price for fixing something that was wrong then that was okay. Fred explained that his impotence might not be completely due to the prostate cancer treatment as he has suffered from hypertension for many years. He believed that the hypertension and related medications may have been responsible for his impotence. He also suffered from diabetes which he felt had a part in his impotence. As well, he indicated that he did

have some sexual dysfunction prior to his prostate cancer treatment, as he explained:

I didn't deny it because I knew something was wrong. Because I had this pain and in intercourse in the climax . . . burn and hurt and terrible . . . So I knew something was wrong down there . . . So, I knew pretty sure there was, there was cancer . . . or there was a tumor or whatever . . . I knew something was wrong and I knew this pain that I had wasn't what it was supposed to be, but after the treatment that all disappeared. I mean the sex disappeared, but the pain disappeared, which was more important . . . in that way I'm glad, you know, that it [the pain] worked out as well. I don't think, uh, that I can blame the cancer [for loss of sexual function]. I think that was pretty much over before . . . because I had other bad health . . . bad . . . high blood pressure and I've been taking medication . . . since I was 44. So, yeah, 64. That's 20 years. I knew of it, the possibility of it [impotence following radiation treatment]. So, if the cancer didn't do it . . . the sugar diabetes sure as heck did . . . put out of that foolishness [sex].

Irwin reported that he experienced impotence following his surgery for prostate cancer.

He said that he and his urologist agreed to discuss impotence following the prostate surgery to see if he had problems. With the assistance of his urologist Irwin was able to seek alternative forms of treatment to aid in achieving an erection and to continue with a having what he considered to be a normal sex life. He stated that prior to treatment he was worried about maintaining a normal sex life because as he stated the loss of sexual function "does change your life."

Gary stated that he experienced sexual dysfunction following treatment and that it was something that had to be "forfeited" in order to be cancer free. Gary explained that when people thought about comparing the treatment and the possibility of impotence they had to get their "priorities on something else." He thought that if men were "sensible" they should not be too concerned about sexual function. He said he had discussed the impotency with his wife but at that particular time he was more concerned about receiving treatment and his survival. He said that if he had to make a choice about being sexually active or not being alive then it was not really a choice. As illustrated in the interview excerpt below Gary thought that people needed to

appreciate that after treatment the period of sexual activity in a person's life is over and you just need to accept that.

Oh, well, that's something [sex] you have to forfeit, yeah . . . I'm just telling you what people have told me . . . that hormonal treatment, that's just another name for medical castration. . . . So, you've just got to learn to get your priorities on something else. I don't know, not if your sensible . . . no . . . I don't think it bothered me . . . oh we [Gary and his wife] discussed it . . . I've probably left the wrong impression . . . I guess I was pretty concerned about my survival and when you're worrying about the fact of whether you're going to be sexually active or whether you're going to be around . . . there really isn't very much comparison . . . [I] think that's as close as I can put it. Sure, maybe other people can do it [sex], but your time of sexual activity is over.

Carl reported that he was impotent following treatment and that it did bother him. As he stated, "It bothered my sex life some, 'cause I'm young." Prior to his treatment for prostate cancer Carl knew that impotence could be a resulting problem, although he thought that his first concern at that time was getting to the cancer and "getting it out." He stated that he and his wife were open with each other about the sexual problems he was experiencing. As a result, Carl went back to his urologist with his concern about his inability to have an erection. In consultation with his urologist, he was able to find alternative methods for helping him achieve an erection so he and his wife could resume their sex life. When I asked him if the impotence was really upsetting in terms of a treatment outcome, his response was, "maybe." Carl framed the discussion about his frustration with sexual dysfunction with the explanation that if he could get out and work on the farm all day, but then was not be able to have sex, then it did not seem to make sense to him. He explained, "You know, when I was out there last summer we worked 10-12 hours on the farm. Well, if you do that, why can't you do the other [sex], you know?"

In summary, sexual function was a real concern for a few of the men and for others not so much. For the participants who indicated that sexual function was a concern they, ultimately,

sought medical therapies that restored sexual function to a satisfactory level for them. For the participants who had lost sexual function the loss was tempered by their acceptance of that fact and by recognizing that they were older, their wives understood, and the period of sexual activity was more important when they were younger. For most of the participants the potential loss of sexual function was the trade-off for not dying from prostate cancer.

#### *3.1.2.4 Masculinity "Man Like Me"*

The topic of masculinity did not emerge as originally anticipated. When discussing the potential concerns that could occur when the stereotyped masculine behaviours are adhered to (e.g., be strong, don't cry, etc.), the participants often referred to the experiences of other men they knew and how these other men acted or coped in certain instances. The participants tended to deflect the idea of masculinity and their own internal beliefs and gender behaviours in favour of stories of how traditional masculine beliefs and behaviours affected other men. The participants in this study demonstrated that perhaps it was easier to discuss negative health seeking behaviour of other men than examining or re-examining their own behaviours. Our conversations, however, yielded some examples of the participants' views of the male gender role and of how these participants understood and discussed masculine behaviour.

The only reference Norman made about masculinity was that he thought men in his own community might find it difficult to attend a support group. He stated that he knew a lot of men in his community who had prostate cancer and would not tell anyone. He also thought that for some of the men to attend a support group, they required a certain amount of anonymity was required. Therefore attending a support group in the city might be better for men living in the rural communities because they would not know some of the other group participants. Norman

reasoned that out of embarrassment some men in his home community would not talk about some of the more intimate issues. Furthermore, he thought there were men in his own community who would not let anyone know they had prostate cancer.

Andy stated that he participated in a prostate cancer support group. He explained how the topics of sexuality and impotence are discussed among the men in the group. Based on his experience with the support group Andy knew that some of the other men could talk about sexuality issues but that it included "a bit of kidding around." He commented that while a discussion of sexual dysfunction and impotence would not occur in a larger general group discussion, the topic might be discussed during a person-to-person conversation. Andy stated that men should not deny the problems they can have as a result of prostate cancer. He stated, "You cannot go to a support group and say, 'I'm a man. This isn't what's happening.' It does happen ."

Andy confided that he often felt disappointed when men attended the group and said they had the treatment but did not need the group's support and then failed to return to the group. He thought that men do need the support even though they might not realize it. He gestured to himself that this "man like me" attitude (clenching his fists and arms) some men display and the belief that difficult personal issues do not happen to them was the wrong kind of attitude because it does happen to them:

These people came once [to the support group] and maybe they didn't seem to like it . . . they didn't come back. But the ones that were really concerned, yeah, they're there . . . They were needing [that support] . . . yeah, they'd postpone everything else to come. Well, one guy [says], "What the heck. I've had the treatment. I'm cured . . . I don't need this [support]." . . . that's too bad . . . because he does need that support.

Andy related the following very personal story about a friend who did not do anything about his prostate cancer:

One fellow was tough for me . . . He knew he had something wrong for two years, but he didn't do a thing about it . . . His wife phoned me up one day . . . and her and her two daughters came over, but hey . . . after two years he didn't live . . . I don't think a week or so after that . . . and that was tough (becomes teary).

Telling his story, Andy reflected on what his doctor told him: "You know it is your life that you are gambling with; so this upsets me . . . The doctor's, well, 'It's slow growing. Don't worry about it.' . . . That doesn't happen to everyone . . . some of it is fast."

In our discussion about his perception of men and their ability to discuss intimate, personal matters, Fred related an experience he had at a prostate cancer support group meeting. Fred stated that one individual had asked the group if anyone there, after receiving radiation treatment, had difficulty in having an erection. Fred stated that of the entire group he was the only one to raise his hand to show that he was, in fact having this problem. As illustrated in the following interview excerpt, Fred discussed this experience with his own doctor, who told him that he did not think all the men in the group were being completely honest:

It doesn't bother me to go to the group and speak . . . and talk in the group . . . That doesn't bother me . . . and to tell my story . . . That doesn't bother me [to talk about] . . . anything that affects me . . . You know, in the beginning at our meetings, after we had our treatments we had a fellow from the city, who passed away now, and one of the first questions he asked is how many of us had radiation and how many could get an erection. Well, nobody was going to be a failure . . . except me . . . and I'm the only one that put my hand up [laughs] . . . I said to my doctor . . . and he said, 'Well, I don't think they're all being honest, Fred.'

Fred explained that the inability of some men to admit they were having sexual problems was likely an indication that the men did not want to admit they were a "failure" because they could not get an erection. Fred explained that discussing sexual issues and some of his own problems with other men was not a problem for him. Fred also thought that there were generational reasons why men could not talk about sexuality matters as illustrated below.

Well, problem for men to talk about [sex]. They're afraid to talk about it . . . I don't know why, but if they had a cut in their hand . . . or some other disease they'd talk . . . If it was taboo [sex topics], well, to be able to talk about your private parts of the body. I know in my dad's family, when we were kids, we'd never ever talked about any sexual parts or sex of any kind. Clearly, I was raised in a quite religious . . . strict home and we just didn't talk about those subjects . . . and you see a pregnant woman, you didn't talk about that . . . That was just the way things were.

Irwin hypothesized that from personal embarrassment most men did not disclose or discuss their concerns about sexuality or impotence. He thought that men in general are not good at discussing any health issues, and because of this male attitude many men put themselves at unnecessary risk. He related an example of a male family member who did not look after his health concerns very well. Irwin concluded that this fellow would never go to see a doctor because he was just too stubborn to go. As a consequence, by the time this man finally saw a doctor, it was too late. Irwin thought that even with advertising and education many men still do not go to see a doctor and get themselves checked out for prostate cancer. He noted that the prevalence of prostate cancer within his own community is quite high. He thought that if a lot of men do not seek out proper help one would see the negative health consequences that it could have for so many men. Irwin's view is presented in this next excerpt:

I've talked to lots of guys and not necessarily with prostate . . . but guys . . . never get an appointment and go get a physical . . . my brother-in-law died and he never went to the doctor, either. They checked him out and they found it [cancer] and he was gone in two months . . . the trouble with the damn cancer is if you never get checked it's too far gone before you're ever sick. You don't know you're sick, hey. So, if you don't get these tests and blood tests and things like they tell you should . . . they advertise now on TV . . . lots of guys don't want to do it. Just will not go see a doctor and it could cost their life . . . I don't know . . . [men] stubborn, I guess.

Irwin indicated that this negative attitude towards health care and screening was never a problem for him: "We both [Irwin and his wife] started doing that [checkups] around 50 and we go every

year and get physicals and if I had not been doing that, then I probably wouldn't be sitting here talking to you today." He also indicated that his son has this negative attitude and will not go to see a doctor for anything:

You've pretty near got to carry him [his son] in on a stretcher before he'll go and see a doctor . . . Why? I have no idea. He just doesn't like doctors. I've never ever had that feeling. Yeah, I bet [he's] scared that there'd be something wrong. Well, if you're scared there's something wrong, you'd better get it checked, then . . . you know.

Irwin agreed that men were, perhaps, in a form of denial when it comes to health problems:

I agree with you there [denial] . . . but we're not invincible [men] . . . that's for sure, because I was healthy as could be . . . fat and happy and it [cancer] was still there. So, I couldn't understand why [not getting checked].

Gary stated that although he never had problems with going to a doctor to be examined he thought that many men do have a problem, as he explained:

Well, I'd put it down to the fact that the women have to see doctors frequently . . . in their childbearing years and whatever . . . I went through all this fear of doctors . . . when I was in the Air Force . . . young men, today, they're always healthy as a horse. Why would they bother going to doctors. And you hear these stories, sometimes, that are true. The doctor diagnosed such and such and it didn't happen. Some of them are just looking for an excuse not to go because they, I think they're embarrassed to go to a doctor and you know, if they're embarrassed about seeing a doctor, what about when they're looking at your genitals. I mean, that's about the height of it. That's what I think.

Carl thought that other men in his community would probably talk about having prostate cancer but they would not likely discuss sexual matters or other intimate sexual problems:

So, some of those things they, some people, kind of keep to themselves about. They'll let you know they have prostate cancer, but if you ask for too many details, they kind of keep it to themselves

Carl, however, seemed surprised that men would not want to talk about something with which they may be having a problem.

In summary, the participants in this study implied that masculinity and male behaviours

and the potential conflicts with positive healthcare seeking behaviours were personal concerns. with. The participants deflected deeper examination of their own behaviours in favour of identifying men within their own communities who had suffered or put their own health at risk by exhibiting healthcare seeking behaviours that were more traditional and stereotyped. Although the participants implied that they did not adhere to male stereotyped behaviours it is important to note that when given the opportunity to examine their own behaviours the participants preferred to demonstrate their understanding of masculinity and healthcare seeking behaviours through stories about other men. These participants, however, were aware of the consequences of negative health seeking behaviours. The participants gave examples of men in their communities who ignored health screening practices in general and in some cases, died because of their refusal to do something about a health problem. A few participants also identified that men within their own communities are likely too embarrassed to disclose personal issues with respect to sexual matters. Participants who attended a support group indicated that even within the support group some men were reluctant to be there and reluctant to discuss or disclose intimate sexual matters during the group. For the participants in this study who had a loss of sexual function, there was no evidence that they had a loss of manhood or self identity. As one participant indicated, it was a loss of "manly ambitions" not a loss of manhood.

#### *3.1.2.5 Thoughtfulness and Reflection "Enjoy Today"*

This section presents the participants' reflections in regards to themselves, their family, and friends, and their attempts to find meaning in their prostate cancer experience. These data were derived from the parts of the interviews where the participants revealed a more reflective quality about themselves and their inner thoughts, feelings, and perceptions. This section

describes some of the more internal aspects that may have been going on for these men as they lived and continue to live through the experience of prostate cancer. These moments of reflection and the examples provided by the participants are from a variety of different moments in their experience ranging from the initial diagnosis to where they felt they were at the time of the interview for this study.

Norman indicated that his experience with prostate cancer led him sometimes to wonder about how many days he had left. He knew that his prostate cancer has affected his wife and children. Prior to his treatment his family's wait to see if the cancer had spread to the bones was difficult. Because of his good prognosis, however, it seemed to him to be turning out "all right." He noted that he was diagnosed before Christmas time and acknowledged that the cancer diagnosis was on the minds of the other family members throughout the holidays. He described his family as "very close" and said that "everyone put on a good effort" or a "brave effort" to make their Christmas seem as normal as possible, as reflected in this comment:

We're a very close family and I feel that it bothered them . . . but I also know that they wouldn't want to do anything to make the situation worse . . . I imagine if they were all dull and crying and that type of thing that it would have worse for them . . . and me . . . but we managed [Christmas] very well.

Reflecting on his prostate cancer experience, Norman said he felt "fortunate" that he had been having regular checkups to detect any problems; because of that he was able to get his cancer diagnosed and treated quickly and as a result have a good outcome. He mentioned to me that during his radiation treatment he felt thrilled with the staff at the cancer clinic where he received treatment. He thought that it was wonderful how the people treated him and that he felt they were like family. He made the point that he did not enjoy the cancer but he did enjoy the people

at the cancer centre; his whole experience with prostate cancer had in fact added something new to his life. Therefore, from Norman's perspective, the experience with prostate cancer seemed to be a new experience for him, as illustrated :

I think the cancer people, there, seem to do a good job and that's nice . . . They treated you like you were a member of the family . . . there . . . That was something new in my life [going to the cancer centre] and I enjoyed it too . . . I don't say that I enjoyed the cancer, but I enjoyed the people that were there.

Norman explained that people have to put things into perspective. As people go through life they will know other people with cancer and they must be aware that they may get it as well. He thought that illness is a normal course of events as one gets older. He said that he knew many people (close relatives in his family) who died of cancer and because of this, he tried to be checked by his doctor regularly:

Course you think [cancer is] a normal situation as one gets older . . . I had a brother who died of colon cancer. I had another brother who died of cancer . . . my Dad died of stomach cancer and an uncle the same way . . . So, I was always doing the PSA test for the prostate.

As Andy reflected on his overall experience with prostate cancer he related a story about how he had put things into perspective for himself and how, overall, his cancer experience had been beneficial for him. The next interview excerpt provides an illustrative example of an event that helped Andy view his experience from a new perspective.

Shortly after my second operation, I was fishing up north with my brother-in-law's brother . . . We had to fly in so the pilot came fishing with us. I was grumbling about all the trips to the city and how rotten you feel. He just looked me at me and said, "You're up here fishing aren't you?" . . . Yeah, that put it into perspective.

Andy felt irritated about certain aspects of his treatment and with his doctor. He thought that he had to wait too long while trying organize everything for his treatment for prostate cancer. He

related an incident where one doctor addressed his concerns by telling him that there is "no hurry" in being treated. He thought that while this may be true he had the farm work to do and it was he and not the doctor who had the cancer. Following is Andy's reaction to the doctor's comment:

So, like, if I want to go combining, I've got to make sure that thing [prostate cancer] is fixed up . . . It kind of upsets you when the doctor says, "Well, oh, it's slow down there, don't worry about that there" . . . Yeah, sure, but he hasn't got it.

Andy knew other men in the community with prostate cancer. He stated that these men seemed to have struggled with the experience of prostate cancer more so than he. Andy thought that many aspects of prostate cancer contributed towards a new understanding of his life experience. He explained that because of his experience with prostate cancer he is living his life and making decisions to do things he would not have done before. For example, he and his wife took a trip to Europe which they enjoyed a great deal, although, in terms of the farm, it was a poor time of the year to go. The next interview excerpt illustrates Andy's perspective on the new changes he has experienced as a result of living with prostate cancer:

We took this trip [Europe] last spring. Awful good trip . . . Awful bad timing . . . put the pressure on the boys . . . but go up there fishing for a week . . . There was a time when I wouldn't have thought of that [taking a trip to Europe] . . . too much work to do . . . but I don't think there is as much work to do now as I thought . . . and I think that this is positive . . . but if you can get some pleasure out of something now?

Similarly Fred explained that through his experience with prostate cancer he tried to ensure that he did not have any "negative thinking." He thought that a person should not have negative thinking when dealing with a serious health problem. Fred related an incident where in trying to get reassurance from his doctor in the city yet he felt he got the opposite response. He concluded that the doctor in the city was probably trying not to give him false hope as Fred was not feeling very well, physically, at the time. Fred contrasted this experience with his experience

with his local doctor in the country:

I went to see my doctor out in the country that I seen before . . . In the beginning, when this first started and he said, oh, not to be concerned. He said, "Because you can figure the best part of a year and sometimes even two years before you're [feeling ] back to normal." But he said, "I assure you that you'll be fine." . . . He said, "It's just a little matter of time." . . . Well, whether it worked . . . or whether his reassurance helped or what . . . but I felt better and I got better. This negative thinking that this other doctor tried to implant on me, I didn't take it personally. It's just his way of not leading you down the path of false hope or something. I don't know . . . I don't think a person should have that negative thinking.

Fred often referred to his "positive" attitude during our discussion. As illustrated in the next interview excerpt, however, he also went through a time of "denial" and a "period of temper."

After even the treatment and I seemed to take a positive attitude . . . After the initial shock wore off, I guess, there's some sort of denial, but then there's others . . . a period of temper . . . I guess. I didn't deny . . . deny it because I knew something was wrong.

Fred likened his prostate cancer experience to what it is like growing up. When you are into adulthood and when you get cancer you do not have a choice; "This is just the way that it is." Fred stated, "It seems [cancer] is like a process, like growing up, you know . . . [with] aging. I think . . . as you age you get different ideas." Fred reflected on the changes he made in his life, his work, and his family as a result of prostate cancer:

I think I did . . . this cancer business . . . the thing was, I come to the realization that, maybe, the time [came] I slowed down a bit. You know, all my life I've worked pretty much two jobs and . . . never really fair to the family . . . They never got the holiday or travel or anything . . . So, I guess, I figured it was time that, maybe, we [he and his wife] should take a little time off and I don't regret it at all. No, I regret having the cancer, but I don't regret renting out the farm . . . I've enjoyed being alive the last few years and doing things that I want to do . . . We moved into town for the winter and I have a workshop in there and I play around in there.

For Fred, having prostate cancer gave him new insight into how he had done things before in his life and how he might have done them better or differently. He emphasized that a new perspective

that he gained from having prostate cancer was the subsequent lifestyle changes he had made:

I think I've settled down a little bit . . . slowed up. . . we say, "Stop and smell the roses." Maybe before that [cancer] there wasn't enough hours in the day. Since then, we do take the time. We do take the odd little trip and we take the weekends off work when I feel like it, now. So, I think it's [the cancer] . . . made me realize it's time to slow down . . . and live a little bit.

Fred also indicated that the prostate cancer stimulated him to reflect on his children and how he used to do things when the children were growing up. He thought he could have done some things better for his children, as he explained:

One of my daughters, my oldest daughter, says to me, she says, "You know Dad, we never knew you when we went to school . . . You were out . . . gone to work . . . We'd come home and you'd come in and get a sandwich for out in the field . . . and we went to bed and you were still out in the field." We never went on holidays with the kids. I regret it now because I could have done it, somehow. Maybe I didn't have to . . . didn't have to try and prove anything . . . when my daughter told me . . . "Dad, we never knew you." . . . Well, that kind of really hurt in a way . . . because I realized then that I neglected them. You know, I think that's wrong . . . but fortunately my wife took the girls. We had daughters and so my wife . . . any place the girls went or done anything they done it [was] with their mother. The girls wanted something . . . well, "Go and talk to your mother." Well, it really wasn't fair, you know . . . I mean, since the cancer business, I've become closer with my kids, and whether it's me . . . or part of the kids, 'cause they figure this [cancer] could be bad . . . but you know, we're never were far apart . . . Since then, we've become closer and it seems like the kids have become . . . well, they seen . . . from the kids . . . "Mom and Dad seemed to have got a lot smarter" . . . you know, so I think it [prostate cancer] has changed my life a little bit, maybe . . . Stop and smell the roses.

One negative factor that Fred identified in his prostate cancer experience was the speed with which he had to choose his treatment. He regretted that he did not have more time to think about the choices because he experienced a reoccurrence of the cancer. He wondered if he could have made a wiser or more informed choice of treatment and avoid the reoccurrence, as he stated in this reflection:

Well, you know, you're standing like an ox hit in the head with a hammer from the shock

of being told you've got cancer . . . and you're supposed to make a wise decision . . . I had to make a decision in about 5 minutes . . . too fast . . . I don't say that I would have changed it a lot . . . but, I do believe, now, and sometimes I think about it and I talk to people . . . If I would have had the surgery and everything would have been contained to that tumour . . . to the prostate . . . taken away . . . If everything would work and got rid of it completely . . . then had a couple, two shots or half a dozen shots of radiation in case there was any stray cells or something. But I really don't . . . really dwell on that . . . because I've done what I thought was right at the time. My decision . . . the decision was mine . . . like the doctor says, "You're too young to do nothing."

For Fred, spirituality played an important part during his experience with prostate cancer.

Although he did not participate in any organized religion or church, Fred felt a connection to a higher power as the next interview excerpt shows:

So, I do believe we talked about a higher power and I feel comfortable in it . . . and in the hereafter . . . God and Christ and all that . . . I think it's part of the answer . . . just you believe in who you want to and it seems to give you strength, I think . . . I don't participate in any one particular church . . . I believe in Christ and the hereafter and the belief that you can do it in your own closet and pray . . . I see a bit of church on television and I read my Bible every weekend and I feel comfortable in it . . . I'm not as good living as I should be. I know that [laugh] . . . but I never said I was perfect. So, I really strongly believe . . . in the spiritual side. I really think that is good.

Fred indicated that his prostate cancer experience had strengthened his spiritual beliefs. He thought that this spiritual strengthening had to do with fear as he explained:

I think, maybe, it [cancer] put a bit of fear in a person too. I don't know. Probably . . . be honest about it, probably scared the person, but they don't want to admit it . . . I was brought up in a religious home and I always have had those convictions . . . if I could get more belief . . . more strongly or be more dedicated to my faith, I mean by going to church, I'd go to church, but I don't think it would help me . . . healthy and that. And if you don't preach what's in the Bible as I understand it . . . I don't believe many of these . . . so and it's to each his own. You know, it's what when I stand up before the judge I'm the one that's going to have to atone for my . . . I'm quite strong, spiritually, and I'm quite . . . feel good about it. I would recommend to everybody to have a higher power of some kind.

When Irwin was diagnosed with cancer he was aware of other people in his community with cancer. He used his knowledge of other experiences with prostate cancer to think about his

own situation and to choose his prostate cancer treatment, as illustrated here:

I've had a friend of mine, he died of cancer and my neighbour, down here, died . . . what I don't know . . . something similar and I know lots of them [men with prostate cancer] and they're taking the chemotherapy and radiation and . . . It just seemed to kind of prolong things and they lived in agony and . . . the result was still the same . . . So, I figured if we could get by without having to go through that . . . might as well get the surgery and be done with it.

Irwin's perspective on his situation was shaped in part by comparisons he made between his situation and the situations of other people in his community which he describes in this excerpt:

That neighbour down the road, here, that's just about my age and she, a year ago, had a tumour removed from her brain. And they thought, maybe, they got it all or almost all of it, but she's, it came back again this fall and she's at home and it's just days . . . waiting.

Irwin attended church regularly. He thought that his religion was helpful for him. He felt that his faith did not change in anyway over the course of his cancer experience. He stated that he prayed for himself and he knew the congregation at home prayed for him, as he explained:

Oh yeah . . . I suppose being a church member has helped. I know lots of people were praying for me. I think I did a little praying in the hospital . . . yeah . . . I think so it's probably helped.

In terms of his overall experience with prostate cancer Irwin felt that the best part was that it did not change his lifestyle. When asked, he agreed that in many ways, life seemed more precious than it did before his two episodes of cancer. In addition, his family and grandchildren have taken on a new importance to him, as he relates here:

Well, our lifestyle really hasn't changed at all. Just kept, once I got healed up and got back to work, things kind of kept on going right where they left off so, . . . oh yeah, . . . I think about that a lot [how precious life is] . . . grandchildren and my own kids and . . . Yeah, I've thought of that a lot because of that first surgery.

A very reflective and personal part of Irwin's experience with cancer was revealed in his reflection

on a very significant life event that he felt may have triggered his prostate cancer. His son was killed in an accident. Irwin reflected on what his son's death meant to him and the subsequent problems that he has had with cancer:

It doesn't pick and choose [the cancer]. It just takes anybody it wants . . . and from what I've gathered from the material I've read, we're all full of those cancer cells . . . and what triggers it nobody knows. They kind of thought, maybe, mine got started from stress, because I lost my youngest son when he was 19. He was on his way over to another town one morning and he got killed [accident]. He lived for about 3 days until we took him off life support . . . They thought, maybe, that could have started it [cancer].

Gary, when reflecting on his experience with prostate cancer, felt that because of his age he was living on "borrowed time." Gary explained how his faith was important to him during the diagnosis and treatment phase. He concluded that one of the worst things about his experience with prostate cancer was the stress that it can cause his family, as the next interview excerpt illustrates:

It [cancer] is difficult, but . . . I was 71 years old. The Bible says 3 score and 10, after that it's just borrowed time. I have some faith . . . but not as strong as I wish it was . . . but that helped me through. The worst thing is the anxiety it brings your family . . . They think, "Dad might not be here that long." Oh, yeah, I grew up in a Christian home . . . There isn't much you can't handle if the good Lord's on your side.

Gary identified as a very important period in his experience with prostate cancer, the time he received radiation treatment and stayed at a cancer lodge where people who are receiving cancer treatment can stay at minimal cost. He reflected on this experience during the treatment phase and how it shaped his feelings about prostate cancer. Seeing other people with all kinds of cancer seemed to have a pronounced effect on him. His stay at the cancer lodge gave him the opportunity to see how other people were doing and it allowed him to compare where he fit in terms of treatment and outcomes. He said that during his time at the lodge "everybody, there was like one

big family" and were supportive in many ways to one another he explained:

I tell you, the experience I had during the time I was taking my radiation over here in the Cancer Lodge. I'll tell you. Boy, there's people in there, well, everybody's in there with cancer of some kind or another and that's a real experience. You see people that are on their way out and, uh, just for the grace of God that I went in time [to get a check up], I think. And, incidentally, you know that time in that patient lodge, I was there 4 days a week from early January to early April and, naturally, when I was through, you know, you start in 38 treatments . . . the first week we had 2 . . . I had one on Thursday and Friday the first week, so then . . . you know, it seems like forever . . . but by the time it was all done . . . to be finished this radiation . . . I almost hated to leave that place. Everybody, there, was like one big family . . . Everyone helped each other . . . It's a terrific thing.

Gary's experience with prostate cancer was a "wake-up call." During his time at the cancer lodge he saw people who were younger than he and who did not have much longer to live. Overall, Gary's experience was growth enhancing for him. As he explained, other people who have not had these cancer experiences, who have not been through what he has experienced, also have not had the advantages he gained from his experience. He advised the interviewer to remember that he was not going to live forever either, and "You need to live and be conscious of that fact." The new perspective Gary gained through his experience at the cancer lodge is articulated in the following interview excerpt:

So, I had the advantages of learning a lot of things, then, and then I had all this experience with my own health. A lot of people out on the street haven't had any of those advantages and they don't see things as clearly as I did because they just haven't been involved. Well, I told a lot of people it's [cancer] a real wake-up call . . . it woke me up, that experience, over here, in the Cancer Lodge. It was one of the most impressive things I ever experienced in my life. Some of these people, some of them . . . just could not live much longer . . . you know . . . really a young guy, like you, . . . figured you're going to live forever. Well, you're going to smarten up one day, too . . . because you're not . . . you'll find out you're not. Yeah, I think how I felt during the early stages. Like, uh, I knew, I can't relate truthfully how I felt in the early stages, but I knew I had cancer and I remember thinking, "Well you've got to enjoy. It might be my last year at it." You have to be realistic. You have to have a realistic outlook, I think. But, uh, I don't know. No, I just had a feeling of immense gratitude. The good Lord wanted me to help other people. That's how I feel. It's a dull day when you don't learn something; and we learned something

every single day about people and the reason for their reaction and their rewards. I don't spend a long time pondering over what this one, that one is thinking, but uh, you have to sometimes. I don't know. I don't want to leave the impression that I'm glad I had prostate cancer, but there are . . . it definitely had it's positive things . . . really a young guy, like you, figured you're going to live forever. Well, you're going to smarten up one day, too, because you're not. You'll find out you're not.

Gary also made comparisons within his home community which helped to put into perspective his own experience:

Oh, I just felt so humble, really, to think that I had been more or less spared there just, to just pure accident and I figured well, this is, you would be surprised, you start talking to men 40 and 50 years old. They've heard about prostate cancer, but they don't know anything about it. We had a chap in our town died, and I can't recall his age, but he probably never goes out and gets it checked . . . and I know he had cancer, and he was, I imagine, . . . he was 6 months from death. He was well along with it . . . and he didn't have a clue what it was all about . . . He knew nothing about a walnut sized gland that the urethra goes through.

When Carl was diagnosed with prostate cancer he was scared at first, and worried about what could happen as a result. He hoped the treatment would start right way:

I was just hoping we could get at it as quick as we can. And you don't know what operations, how long you got to wait. But, I was lucky and just that year, just starting . . . right into a perfect [the treatment experience].

In retrospect Carl thought that his children were likely more scared than he but they held back their emotions around him because they did not want to cry in front of him. Carl acknowledged that as a result of having prostate cancer he experienced a change in the way he thought about life and death matters. He felt fortunate that his prognosis is good; however, he has remained "leery" about the cancer returning and thinks about whether they got all the cancer with the surgery. Carl felt a bit uneasy knowing that he will have to be followed up to see if the cancer reappears. He stated that his religion and spiritual beliefs are important to him. He spoke of his minister who came to the city to visit him following treatment and how that was appreciated. He also reflected

on farming and whether he should have slowed down sooner: "Once you get this hit [cancer], you wish that you would have shut down farming maybe a little sooner."

In summary, thoughtfulness and reflection were demonstrated by the participants as they shared their perspectives and appreciation of life, following their treatment for prostate cancer. Most participants indicated that the closeness and support they received from family was appreciated and special. One participant experienced a renewed closeness with his adult children, which was important to him. All the participants were grateful to still be alive. They took into account the need to find new meaning in life and about their experience, and sometimes to take the opportunity to slow down and make the most of each day. In addition, all the participants indicated the importance of their faith in coming to terms and coping with the journey through prostate cancer.

#### *3.1.2.6 Helping Others and Being Helped "A Bit of a Lift"*

The theme of helping others and being helped was evident in the interview data of all men and in some part indicated why they agreed to be interviewed for this study. An important part of the prostate cancer experience for the men was the importance of helping others and being helped themselves. The help came from family members, and it came from friends. Participants used help to get information for themselves and to impart information to others. The theme of helping others and being helped was interwoven with the themes of masculinity, physical and emotional concerns, thoughtfulness and reflection, sexuality, and farming and rural life. Family, friends, and acquaintances played key roles throughout the period of transition and adjustment. "Helping others and being helped" refers to how the participants actively involved themselves with others to solve problems or deal with issues for themselves. The participants also used their knowledge and

experiences to see that they could help others. Because of their experience, they saw the need for help and to help others. This section describes, from the participants' perspectives, how they were helped by others and in what ways they helped others.

Norman attended a cancer support group in the city, which he felt provided him with several personal benefits. He explained that one benefit of the support group was having a physician who came to talk to their group in a more informal manner outside the physician's office. Norman stated, "He just stood there and talked to anybody who wanted to talk to him." For Norman a good outcome of the support group was the information he received which allowed him to help his brother who also had prostate cancer. The following interview excerpt illustrates Norman's perspective on benefits of the cancer support group:

One was just excellent. We had a Chinese doctor that is there now from Hong Kong . . . he was . . . just beautiful . . . I put up my hand up [to ask a question] about my brother . . . He's got cancer of the prostate . . . He's very out of shape and had heart surgery. The guy [brother's doctor] in Vancouver said he wouldn't give him Zolodex. So I asked this doctor, I told him my brother's history and he said, "Tell me one thing, how's your brother's heart now?" I said, "Well . . . he's all over hell and back with his car and van and stuff." He [the doctor] says that his heart's good . . . then he said, "I would give him Zolodex". . . He is getting Zolodex now. . . I think I helped him [his brother].

Norman described how his wife benefited from going to the support group. He felt an important aspect of the group was the men's sharing of their experiences and stories with one another. He explained:

That night when my wife went up and talked to that doctor, she really enjoyed that . . . going up to talk to this fellow on a personal basis . . . This doctor, he was just excellent. Yeah, I enjoyed that, but you, you can talk, you can talk to others, these other people about it if you like. Like, I got up and I talked about, you know, . . . "When do I get rid of these side effects?" . . . One fellow got up and said, "Six months." He says, "I know 'cause I just went through it." . . . if anybody is having trouble this way or that way . . . they answer you . . . Yeah, it's a good crew. You are there with people that have the same problems.

Norman is recognized by other men in his community as someone who is approachable to talk to about prostate cancer. He indicated that other men in the community do come and talk to him about their own concerns. Norman stated that one thing he has done in his own community is send a lot of the men for their own PSA tests. Norman thought that he benefited from his exchanges with the other men because he is helping others. He suggests:

No, I think now that people know that I, I have prostate cancer, they come up to me and they talk about it. And I've done a lot of reading and I think I've sent more people up there to get PSA testing and I tell them, "You've got only 6 months. Well, have the PSA done." . . . and a lot of people are doing that . . . even some people . . . friends or people that I know. I can't call them friends, but a lot of people come and talk to me about their brother had this and that and their brother had that or whatever . . . I enjoy that because there's some sense of a bit of help to them.

Norman reflected on one incident in which he talked with another man. Although he could not help the other man in any way he was able to listen to him, which Norman thought was important, as he explained in the next interview excerpt:

I was sitting there and this fellow came along and said, "Do you mind if I sit down?" and he looked tired and we got talking . . . He has prostate cancer . . . We talked and he's not good . . . They found some in the bone . . . It was nice talking to him. I didn't want to tell him that I was better off than what he was . . . but I think he liked that he had someone to talk to. I love people and can talk to them . . . I think the fact that I'm quite open, it's good for other people when they come and talk. You know they can talk to me about prostate cancer . . . I feel like so many people come up to me now . . . about prostate cancer.

In terms of his family Norman indicated that he is ensuring that his sons recognize that they may be at risk for prostate cancer and that they need to be checked out regularly as well. He stated, "I tell you, I've got the boys and I impress upon them to have their PSA done every 6 months; that's what this fellow [doctor] said."

Andy explained that when he was first diagnosed knowing some friends who were going through prostate cancer at the same time as he, was very important for him. For example, when he

had to choose his treatment, Andy knew that these other men were taking radiation treatment. He thought that if radiation treatment was a good enough for the other men, then it should be good enough for him:

So, he [the doctor] said, "Well you know the three choices is that we leave it alone, surgery, or radiation." Well, at the time I had some friends that were going through this radiation thing and I thought, "What the heck, it's good for them . . . It should be all right for me." . . . So, that's what we did . . . did the radiation.

With the informal support of the other men and his knowledge of what treatment they were receiving, Andy realized that maybe his prostate cancer did not look so bad for him. Because Andy and his friends were receiving radiation treatment at the same time, they decided to travel together for treatment. They were able to make arrangements with the cancer treatment centre to schedule their appointments together. Andy valued being able to share the treatment experience with others who understood. In addition, he made sure that he took the opportunity to enjoy the shared experience with the other men, as he describes in the excerpt below:

When you first start out [treatment], now of course, they tell you it could affect your bowel, it could affect your urinary tract . . . Surely, you can control yourself for that short of distance, but it was a concern for the other two guys as well as me . . . One of the fellows had a van [with a toilet] and he said, "Well . . . we can use the van if we can't, you know . . . if we can't control ourselves." But, we never had to, . . . but with the three of us driving together it, I thought, "What the heck, you might as well be as happy as you can." The one fellow is pretty easy to tease and I used to bother the hell out of him. But what the heck, you're laughing and joking. You forget those things [seriousness of cancer]. Yeah, and then another fellow, he was just starting while, I guess, we were pretty near half-done. He was just starting, so the four of us rode to together. So, you know, you always had something to talk about. We were all farmers, . . . then, of course, this one fellow I'd give him a bad time . . . And he's, at first, . . . he didn't know how to take me . . . and then he found out [laughs] . . . couldn't do a thing about it [laughs].

Andy felt fortunate to have had this informal support group for himself because no support group existed in or near his community during his treatment. Now there is a formal support group in a

smaller city near his farm which he attends. He felt it is important for the men in a support group to know that they are not alone. Andy's views on the importance of the support group are illustrated by the next interview excerpt.

At our meetings we'd have people come that just been diagnosed and they're scared stiff . . . and you know everybody at that given point . . . they say, . . . "Why me?" . . . to start with and "Am I the only one?" And when they come to the meetings, well, "There are lots of us . . . and I am not the only one." . . . Well, I guess going to these meetings is what opens people up . . . Yeah . . . Sure . . . "I'm no different from you or him or you know." . . . to start with you are pretty laid back and you're not . . . you're not a whole lot interested in talking, but once you get to these meetings, everybody's in the same boat. Everybody has different problems and everybody discusses it right there.

For Andy, helping others with prostate cancer is very important to him, as the next interview excerpt shows:

Yeah, well hey, the group has helped me, so why not . . . if I can help somebody else . . . I've spent hours on the phone talking to people that have just been diagnosed. What do you tell them . . . hey? What do you tell them? "Get in there and get it treated." But, okay, they say now, "What kind of cure should I take? What should I do? Radiation? Should I go for this Brachia therapy, or should I have this operation?" Hey, I can't tell them what to do. . . . I can tell them what I did . . . and what my effects are, but I can't tell them what to do. So, all I can do is tell them that, "Hey get in there and do something now, not next year and not a week, even." That's my attitude, anyway, . . . whether I'm right or wrong, I don't know.

The following interview excerpt provides a more personal example of Andy's views on the importance of helping and supporting others:

Like one of the fellows in the group he was just diagnosed and phoned me up. And I went to see him. "What do we do? What do we do?" When he got all the books and everything . . . and he read up about it and he decided on the surgery. Okay, he finished the readings and he's quite proud of the fact that he had the surgery, and he can still drink six beer [laughs] . . . So, okay, that he's happy with his decision. I never worried about six beer but . . . yeah [Laugh] . . . but I spent quite a bit of time with him, you know, trying to help him decide. But anyway, he decided that on his own and he seems quite pleased with it.

Like Andy, Fred thought that he was fortunate during his early experience with prostate

cancer because he was able to share his experience with some of his friends. With Andy and another acquaintance, they travelled together for treatment. Fred's perspective was that they were able to share the experience and make a good time of it for themselves. He explained:

When I started the radiation . . . we went to the city every day except the holidays and . . . the three of us travelled to the city . . . The first while it was pretty bad weather, but then it turned nice and we referred to ourselves as the Three Stooges (laughs) . . . Anyways, it wasn't a bad time. The three of us, together, were company and we never worried about . . . concerned with the fact that it could lead to death or anything . . . That didn't cross our minds. Sometimes we took our wives with us and went for meals and made a good time of it . . . with us it . . . we could well . . . talk to each other . . . and [we] found out we weren't the only one that had this problem and it seemed to lessen the burden [on us men] or something.

Fred also spoke about how important his wife and his friends' wives were during that early experience, as illustrated here:

Our wives, all three of us, . . . Our wives were 100% behind us. They went to the doctors with us. They went every place we went . . . Now, even to this day, we go to a prostate cancer [support group] and our wives go with us every time and they are in there right with us . . .and there's a little bit of support.

Fred commented on how the current prostate cancer support group in his community can help other men, now, as illustrated here:

The hope that our cancer club is providing the opportunity for people that have been diagnosed with cancer. To have the opportunity to talk it over with people, to get tapes and literature . . . and that make really wise decisions themselves . . . I do believe that educating the people is really a important thing . . . I hope that our group, you know, . . . serves some kind of a service.

Reflecting on his own involvement with the support group, Fred felt he would have been okay without it, but he thought that it added a something extra to his experience. The support group was not around when he was initially being treated but he was one founder of the group in his community. He thought that it was important to see if he could use his experience to help others.

He also thought that the support group added to his experience with prostate cancer and it has been good for everyone who has attended, as discussed here:

I guess the companionship was one thing and then the openness . . . I do think the group helped. I don't have any thoughts that I couldn't have made it without, but you think it sort of maybe put the icing on the cake. I think . . . every time you go to a meeting you always come back out feeling a little bit lifted . . . spiritually lifted, maybe, . . . You always feel a little bit better. No, I'm all for meetings . . . if people . . . If they can come and then talk to us and tell us their problems . . . If they want.

Fred emphasized that it is important for men who are just starting out with prostate cancer to talk with others who have been through the experience, themselves, as the next interview excerpt shows:

Lots of time, personal experience means an awful lot, you know, . . . You know it's like a personal recommendation, you know, . . . mind you . . . you can't tell them what they should do . . . but you can tell them what you did . . . there's usually . . . If nothing else, we have a round the table discussion, you know . . . and if somebody's having problems that they'd like to talk about it . . . and sometimes a person gets talking and they unburden themselves . . . ,you know, . . . believe that it's good . . . to have a group.

Fred also discussed the help he received from other people through the ability to compare his experience with that of other people, as illustrated by the following interview excerpt:

Some people really have some really interesting stories like . . . You feel sorry for yourself sometimes. Until you hear somebody else's story . . . I got off pretty lucky. You know, . . . you expect you should feel sorry for yourself . . . go down to the geriatric centre in the city and walk through that and you come out and say, "I'm lucky. I can still walk." You know, . . . "My goodness, it's [cancer] not so bad off after all . . . you know, like people, having one friend of mine out west, he was, he'd go to the city and he'd go and plow in the morning, out in the field, and he'd go to the city and have his treatment and go back and get on the tractor and work for the rest of the day, you know. So, those kind of things . . . you know. "Other people, they'll have good luck. Well, maybe, I'll have good luck . . . maybe this isn't so bad after all."

Irwin talked about the regular checkups he received and how lucky he felt for having such good outcomes. He saw that if he was able to encourage others or teach others, based on his own

experience, then his having cancer would be something worthwhile. He hoped he could influence others to get checkups so that they may "get lucky" as he did. He indicated that being able to help other men who were having similar experiences made him feel happy. Irwin did not attend a formal support group, but when discussing the idea of support, he thought that it would be more beneficial to have that kind of support prior to the treatment, and that talking with others who have been through the prostate cancer treatment would be helpful to them. He observed that some men feel very alone when they are first diagnosed and, maybe, this support would be helpful. He explained:

Well, I just feel (yeah, I do) because they caught mine quick enough because I was getting check-ups, and everything's gone so well up to this point that I figure if I could get somebody else to, maybe, be that lucky. Just it would make me feel good, that's all . . . Once they were diagnosed, I would think maybe even support before . . . they have any treatment . . . would probably be beneficial for just . . . to talk to people that have already been through it [cancer] . . . and had success. I think it would give them a lot of confidence. I had one fellow tell me that he thought when he first heard about this [prostate cancer], he said he felt really alone.

Irwin stated that he has thought a lot about how he could help other people who are in the same position where he once was:

I've often thought of going in and seeing if I could help in at the Cancer Clinic. I don't have time, but I'd make time, I guess. Just to talk to people that are, maybe, waiting for surgery . . . or . . . that had surgery or . . . you know, when I was there just once. I don't know what it was, probably just for assessments, I guess. They did some tests and stuff, but there's sure lots of people sitting around in there.

Irwin indicated that when he was in the hospital during his various treatments he received support from his community:

Oh yeah. You know we had tremendous support out here. In fact, they started to laugh at me in the hospital 'cause so darn many cards came in every day and they wanted to know if I was the Post Office or something. There was just gifts and people dropping in and, in fact, there was days I was almost glad when nobody showed up because it just got to be

too much. There's so many people and all day long and you're kind of pooped anyways. So it's . . . almost you're glad to see them . . . most of them were pretty good . . . they'd stay 10 minutes and then they'd get the heck out of there . . . you know.

In his reflection on helping others, Irwin talked about how he was going to be helping his neighbour. This neighbour had previously helped Irwin and his son on the farm when Irwin was being treated for prostate cancer. Irwin referred to this change in role as a "turn around," because his friend was now having health problems and it was his turn to help his friend:

So this friend of mine that did all the work [when I was sick], I'm going to be helping him [on the farm], now, because he's been diagnosed . . . He's got to have a liver fairly quickly. He's been fighting with . . . Hepatitis C . . . for about the last 10 years and, then, he's had his ups and downs, so he's . . . I may have to turn around and help him out now.

Gary also talked about being around other people with cancer, how that affected him, and what he received from the experience. He talked about how little other people know about cancer and how important it is to educate men, as illustrated in the interview excerpt below.

Incidentally, I have given away since that time [cancer treatment] approximately 300 letters, 300 copies of that same letter urging annual medicals and encourage that a PSA, and I've I always say the same thing. In fact, I write it on these letters and, incidentally, Darren, I intended to bring one for you and I didn't, but I can mail it if you want one. I believe that early detection is the key. Well, there's absolutely nothing you can do except do what the doctors say and hope you're going to get cured and at the start you sure don't know and I've been privileged to help men that are in the early stages of their diagnosis . . . a friend of mine in Saskatoon, here, whose brother-in-law was diagnosed just recently and his brother-in-law lives in Vancouver Island and I phoned out and talked to both he and his wife and I just told them the truth is like I told you and I wished I had a tape recorder to record the gratitude that came from those people. 'Cause they're just at the very early stages and that's all unknown and I didn't tell them what to do or what. I just told them what happened to me. It had to make him feel good. And I firmly believe that attitude has a lot to do with licking these.

Gary also discussed how important it is to him that his sons are getting themselves screened for prostate cancer. He also thought that this ability to help others is extremely important, as he stated:

They're [his sons] going. Oh, I don't relent until they go [see the doctor]. The youngest is, let's see, he's going to be 40 in 2003. I haven't really bothered him much, but he knows and his wife will get him. She'll make him go there. . . . I don't feel that there is anything that's more important in this life than helping people . . . you help them along the right road, you know.

Carl made comparisons with other people he knew with cancer who did not have the same "luck" as him. Being able to make these comparisons was helpful to him and his own situation as he explained:

Like this one guy, he just didn't seem to have the chance to find out quick enough. I don't know why, 'cause I sure did, but if something slips up, you know, and you get, you get the wrong thing the first thing, and then you go another 2, 3 months and still not feeling good, well you know that's 90 days that you had it in your body and if it's real bad, something should have been done . . . like I said, I've been a very lucky man to be done the way I was, as quick as it was, yeah.

Carl explained that he used his experience to help others in his community:

Even my, here I talked to him [another man with cancer]. It was, you know, it's hard for me to talk to him because I feel that I don't know if I can do any good for him. It's, maybe, too late, but he still likes to talk to me and if I can do him . . . give him any good feelings, well, I sure will . . . So, it's younger guys you know, and I say, "Yes, you better do it [prostate screening]. And when you get in the 50's you better start." . . . They feel more freer than a doctor or you know, . . . and, maybe, questions prior to the next time you see the doctor . . . just to see those other guys. I watched their life. They had it before I did and they're coping all right. I guess that helped. Maybe. That helps too. A good understanding wife. She always . . . [your're] down a little bit so she'd try to cheer you up.

In summary, helping others and being helped was an important theme that was identified by all the participants in this study. This helping occurred through the sharing of information and support through support groups or, on a more personal, individual level, within the participants' home communities. The participants were moved to inform other men about their experiences and encouraged other men within their communities and in some cases their own sons, to learn from their experience and take care of their health. For some of the men help was more practical and

tangible when they received physical help on the farm from family or neighbours when the work needed to be done. What emerged from the data was that in some respects what these participants had been through would be for naught if others could not benefit from their experience.

## CHAPTER FOUR - DISCUSSION

### 4.1 Discussion

This study explored six Saskatchewan rural farmers' experiences in living with prostate cancer following diagnosis and treatment. Qualitative data obtained from taped interviews with the study participants were analyzed using methods of Naturalistic Inquiry (Lincoln & Guba, 1985) and Grounded Theory Analysis (Strauss & Corbin, 1998) to identify common themes in the data. The analysis revealed five central themes in the participants' narratives concerning their experience with prostate cancer. The five central themes were: farming and rural life "making adjustments," physical and emotional concerns "wetting myself" and "a bit down," sexuality "manly ambition," masculinity "man like me," and thoughtfulness and reflection "enjoy today." A sixth theme (helping others and being helped "a bit of a lift") emerged as a backdrop theme for all the participants and it flowed through the other themes at different times in interview data. For all the participants, the themes reflected their experience during the transition and adjustment period (see Figure 1). For these farmers many things occurred in their lives to ponder and consider and things to change as a result of being treated for prostate cancer. In this chapter, the common themes in the data are discussed in the context of relevant empirical literature.

#### *4.1.1 Common Themes*

##### *4.1.1.1 Farming and Rural Life*

From the interviews with the six rural farmers in this study, clearly, farm work, farm organization and structure, and farm work responsibilities were ongoing concerns when they were diagnosed and treated for prostate cancer. All the participants indicated that they made temporary or permanent adjustments to the operation of the family farm following their respective treatments

for prostate cancer.

Fatigue following treatment for prostate cancer was identified by most participants in this study as a major post-treatment side effect which they had to take into account in regards to the ongoing operation of the farm. Participants identified the side effect of fatigue, and its impact on the farm work, as one of the most disconcerting side effects that interfered with their ability to farm.

Fatigue for one participant meant that farm safety was occasionally compromised. He stated that the fatigue slowed him down on the farm and he was not able to put in the necessary long hours during critical times of the year; this resulted in his son having to remain working in the field by himself without anybody nearby to help him, should the need arise. This participant thought that his fatigue contributed to increased farm safety risks for his son. For other participants fatigue meant that they relied on increased help from their sons as they adjusted the ongoing operation of the family farm. For two of the participants fatigue meant that their sons made financial commitments and permanent moves out to the farm to operate and maintain the family farm. For one participant fatigue meant that his sons had to pick up the extra work on the farm to finish the work that he was not able to complete himself. In addition, for the one participant who had no sons or daughters involved in the farm operation, his fatigue and diminished ability to perform farm work led to his decision to retire from farming, sell his machinery, and rent out his land. The youngest participant (60 years) indicated that he was not overly affected by fatigue following his surgery treatment for prostate cancer. He indicated that he was able to compensate for the fatigue by taking rest breaks out in the field to keep working longer.

The literature suggests that the fatigue the participants in this study experienced is a normal expectation following treatment for cancer (Barsvik, Whitmer, & Walker, 2001; Harden et al., 2002). Barsvik et al. (2001) indicated that cancer-related fatigue is one of the most common and most disruptive effects for cancer patients. Barsvik et al. (2001) also reported that participants in their study thought that cancer-related fatigue interfered in their ability to participate in usual activities and affected their performance. All the participants in this study indicated that they experienced increased fatigue following their respective treatments for prostate cancer. The significance of fatigue for the rural farmers in this study was that they had to recognize their new physical limits and their capacity to engage in farm work.

There is little research that provides an in-depth look at how prostate cancer disrupts men who are actively employed. Recent research (Fitch, Gray, Franssen, & Johnson, 2000) suggests that most men with prostate cancer are retired and their employment and work concerns are minimal. There are a few reports of previous studies of prostate cancer (Harden et al., 2000; Pinnock, O'Brien, & Marshall, 1998) that have made a brief reference to the impact of prostate cancer on working men. Comparing the findings of this study of farmers with findings of previous research on men in other occupational groups, I suggest that for the rural farmers in this study, there may have been advantages compared with other men who are actively employed during the times of diagnosis and treatment for prostate cancer. Gray et al. (2000) reported that employed men with prostate cancer in their study had to explain work-related absences to the boss and they had to negotiate time away from work for treatment and recovery. The advantage for all the rural farmers in this study was self-employment, and access to assistance from family members or neighbours to help them cover the farm work for short periods of time during the

treatment and recovery phases of their illness. Others received treatment during times of the year when taking time away from the farm was not critical. All six farmers in this study were self-employed which may have been an advantage for them because they did not have to arrange or negotiate sick time away from work. In addition, they could, more easily, make the transition back to work when they were physically able. Being self-employed provides enormous flexibility for farmers when they are only responsible to themselves. The downside of this for some farmers may be that they dislike relying or being too dependent on others, thereby, returning to work too quickly and creating potentially worse health and safety issues for themselves. Being self-employed may also mean that rural farmers with prostate cancer do not have the work-related health benefits that urban men working in other industries may have. It is noted in the literature that rural people tend to delay receiving professional help for health and illness concerns particularly during critical times of the farm year (Wienert & Burman, 1994). On a grain farm the work has to be completed during critical times of the year to remain productive. Farmers with prostate cancer still have to do that work themselves or rely on family and friends to complete the work.

Despite the number of changes that took place in their farm operations, the participants in this study did not indicate that these changes were traumatic or devastating life events. Nor did they indicate that they would have delayed treatment to complete their farm work. Some of the men expressed regret for not being able to work as much as they had before the cancer and frustration when their sons had to pick up the extra work. However, as one participant indicated, it was more of an "annoyance" when he could not finish his work. For most of these farmers, the changes that did take place on their farms (the transfer of the farm to other family members or

renting out the land) as a result of the prostate cancer represented changes that would have occurred, eventually, with their advancing age. As one participant indicated, he was "not going to live forever." Emerging from the data was the fact that the participants' diagnosis and treatment for prostate cancer at worst, sped up decisions to make changes in the operation of their farms and, at best, interrupted farm operations for a short period of time.

Typically, the nature of prostate cancer is that it is slow growing and for these participants seemed to afford them and their families the time needed to make essential adjustments in the operation of the farm. There was no indication in the available data that financial or monetary concerns were important factors during the participants' journey with prostate cancer; this may not be typical for farmers who are financially unstable. What is unknown is whether the participants' experiences were typical of the experiences of all farmers with prostate cancer. Perhaps farmers who are not in a sound financial situation may be reliant on their ability to keep farming and to provide financially for the family. With the recent downturn in the farm economy in western Canada for farmers who are not in a sound financial situation a diagnosis of prostate cancer may create much disruption and stress in the person's life.

In regards to the rural aspect raised by study participants, it seemed that none of the participants viewed their geographical location and the distance from cancer specialists, or the distance to major cancer treatment centres, as major concerns. In fact, in terms of the farm and the rural community at large, some of the participants saw their rural community as an advantage for them. The participants indicated that as farmers in the rural community they knew they could count on their neighbours for help, if needed, and in some circumstances they did not have to ask for help because they knew it would just be there. The perceived advantage of living in a rural

community was not only in regards to farming, but as one participant indicated, they viewed their smaller communities as providing a higher quality of life because of the lifestyle that the farms and small communities offered them. It has been reported that rural people come together and help individuals, families, and neighbours to help and support one another during times of illness (Weinert & Burman, 1994).

Findings of a previous study suggests that Australian rural men may be at a disadvantage because of the financial burden involved in travelling to major treatment centres, which could limit their treatment choices for prostate cancer (Pinnock et al., 1998). The travelling aspect did not seem to be a concern for the participants in this study. Participants in this study used the time and distance of travelling to the city for appointments and treatments as an opportunity for something new and different in their lives. Some participants indicated that it was nice to travel to the city and enjoy the amenities that were available in large cities. Two participants took the opportunity of treatment and travel to do it with friends who were undergoing the same treatments and, subsequently, used that opportunity to share the experience with others and create a new meaning and understanding of their lives.

It is worth noting that major health care restructuring has taken place in the province of Saskatchewan during the last decade. For many of the rural communities health care restructuring meant the loss of local hospital facilities and health care staff. Health care restructuring also meant that with the increasing specialization of medical and treatment procedures much of the complex diagnosis and treatment of human disease and illness now occurs in the larger tertiary centres, particularly in the case of cancer. In addition, rural communities have lost many farm and community-based services and businesses, requiring people in the rural areas to travel to

larger centres for a variety of needs. Perhaps this gradual increase in reliance on the larger cities for services may have dampened the participants' perception that living away from cancer treatment specialists and treatment centres is something negative or a burden. It also may be that the study participants were quick to adapt to new and different situations in their lives and overcame obstacles in life by accepting the realities of their life situation, that is acceptance of what is and what is not available in rural communities.

The particular time of year in which the prostate cancer treatment took place affected the operation of the family farm for two participants. One participant wanted to receive his radiation treatment prior to spring seeding to ensure that he could plant his crops. For the other participant, his surgery reduced his ability to work during spring seeding and he had to rely on his son and a neighbour to get the crop seeded for him that year. A third participant reflected that although he did not have to get outside help to perform his farm work during his surgery treatment or recovery period, he knew that if he was unable to do the work himself, other people in the community would help him complete his farm work if necessary. These data indicate that the time of year in which farmers receive treatment for prostate cancer could be an important consideration for farmers. Depending on the timing of the treatment, farmers may have to make alternate arrangements with family members or neighbours to ensure that necessary farm work gets completed in a timely manner. For farmers in general this may or may not be a considerable problem.

#### *4.1.1.2 Physical and Emotional Concerns*

Palmer (2001) indicated that incontinence affects a man's sense of personhood, manhood, and social integrity. For most participants in this study, the mere idea of incontinence was a troublesome issue. The possibility of becoming incontinent affected the type of prostate cancer treatment that some of the men in this study contemplated. The men highlighted the difficulty involved in these decisions regarding treatment. As one participant indicated he chose surgery so he would avoid the chance of being incontinent. He did however suffer from incontinence after his surgery. Another participant indicated that he chose radiation because he believed that it would afford him the best chance of avoiding incontinence. He, too, had problems with incontinence following treatment.

Butler, Downe-Wambolt, Marsh, Bell, and Jarvi (2001) found that the participants in their study always ensured that they knew the location of bathrooms when involved in social activities. Some participants said that their social activities were restricted because of incontinence. Harden et al. (2002) reported that men in their study who were working had to adjust their schedules to ensure that they could find rest rooms and that this loss of control was very frustrating for the men. In turn, participants in the study by Harden et al. (2002) kept their trips short and well planned. Similarly, the participants in this study reported that issues of incontinence and a sense of urinary urgency had large impact on them. Some participants indicated that adapting to the loss of bladder control involved being aware of their circumstance, at all times, which involved planning road trips for frequent stops to use washrooms so they could avoid urinary accidents. One participant bought a vehicle that had a bathroom on board that he could use to avoid urinary accidents. None of the participants in this study however indicated that urinary problems affected

their social life or prevented them from taking part in any activities that they would have normally participated in before treatment.

In relation to working men, Pinnock et al. (1998) found that men who work in the transportation industry were increasingly disrupted and missed work opportunities because of urinary frequency and urgency. It did not appear that incontinence at work actually developed into a concern for the farmers in the present study. As one participant indicated, incontinence did not interfere with work on the farm as he could relieve himself out in the field if he had to. The necessity of a washroom may not be critical to the operation of the farm and therefore the nature of farm work may be more accommodating for men who suffer from incontinence and urgency issues. The participants in this study who had problems with urinary urgency indicated that it was something that they had adjusted to and accepted.

Kurtz, Kurtz, Stommel, Given, and Given (2001) indicated that symptom distress, when coupled with a decline in physical functioning, is a positive predictor of depression among older persons with cancer. Lavery and Clark (1999) reported that most men with prostate cancer in their study used physical diversions and work to help them cope with their prostate cancer experience. This diversionary strategy helped the men in the current study to avoid negative thinking and, thereby, reduced stress levels. The men's work allowed them to concentrate on other things besides themselves. Lavery and Clark (1999) also reported that working men in their study displayed a more positive attitude during their experience with prostate cancer than men who were not employed.

For most of the participants in this study depression and anxiety appeared not to be overwhelming concerns. Several participants indicated they farmed and there was work to do; so,

they had to do it. They did not have time to think about themselves. Perhaps the practical need to keep busy (i.e., keeping the farm productive) was helpful for the participants, allowing them to cope with the cancer by focussing on the work that needed to be completed. Some participants indicated they were too busy on the farm to worry about prostate cancer because they always had something to do. It appears that having work was helpful for the men and that, in some sense, it helped them to forget about the prostate cancer. Knowing that there is work to be done and that they had to do it is also indicative of self-employment. Perhaps for the participants in this study the nature of the slow growing prostate cancer gave them time to adjust to their new circumstance and adapt the farm operation without precipitating symptoms of depression or anxiety.

Two participants did acknowledge personal changes in their overall mood during their experience with prostate cancer. One participant indicated that his mood and patience level changed while trying to do his work and that it led to frustration, which was observed by the family. The participant indicated that his anxiety was a concern, but having been treated for anxiety in the past he knew how to seek out medical help for the anxiety in a helpful, proactive manner. Neither of these two participants indicated that these personal challenges were extremely detrimental for them.

#### *4.1.1.3 Sexuality*

Prostate cancer and the concerns of impotence are well-documented in the literature (Bertero, 2001; Boehmer & Clark, 2001; Butler et al., 2001; Fergus et al., 2002; Gray et al., 2000; Harden et al., 2002; Monturo, Rodgers, Colman, Robinson, & Pickett, 2001). O'Rourke and Germino (2000) found that some men in their study were willing to forgo treatment to maintain sexual function. Butler, Downe-Wambolt, Marsh, Bell, and Jarvi (2000) found in their study that

the ability to achieve an erection was an important concern for the men; but if the men were older they were less likely to expect any type of resolution to their sexual issues. Bertero (2001) found that men in her qualitative study indicated that sexuality was a major concern for them, but initial concerns related to their ability to survive. The choice was death or impotence. Bertero (2001) also indicated that older men and those in long-term stable relationships were more accepting of the loss of sexual function and were thankful that the prostate cancer occurred later in life when sexual function was not the biggest concern for them. Moynihan (2002) reported that older people who are in stable relationships indicate that their relationships are enhanced as a result of the prostate cancer despite the loss of sexual function. Similarly, Boehmer and Clark (2001) reported that men in their study indicated that the tradeoff for the loss of sexual function was a longer life. Some men however did report that an inability to achieve an erection, their loss of sexual urge, and the lack of sexual function threatened their manhood and for one participant, resulted in depression. Boehmer and Clark (2001) reported that men in their study coped with sexual loss by avoiding the topic, putting it out of their minds, and accepting that sex was something that belonged in the past. Further, Fergus et al. (2002) reported that the men in their study wanted, first, to preserve life and, second, to minimize the sexual effects. Fergus et al. (2002) concluded that the men in their study viewed sexual dysfunction as a limit of medicine and not a personal failing. Gray et al. (2000) reported that in their study men with impotence were concerned with how impotence might be viewed by other people and that they were not looking for help or pity from others. What these men did want was to carry on in life with their normal fashion. In addition, Gray et al. (2002) indicated that impotence can be a "big deal for some and at least a concern for most men" (p.55). Gray et al. (2002) thought that the impact of sexual dysfunction on

men diagnosed with prostate cancer is influenced by the individual's sexual history.

Impotency for most of the men in this study occurred following the treatment. Consistent with the literature the loss of sexual function was less of a concern for some of the participants in this study than their survival. For some of the farmers, impotency involved adjusting their thinking, appreciating other aspects of their lives, and feeling fortunate enough just to be alive. For some the loss of sexual function was a real concern and ultimately they sought medical treatment, which allowed them to adjust and maintain a sexual relationship with their spouse. One participant indicated that he and his wife were so active in other areas of their lives that the loss of sexual function was not a concern. Another participant thought that his other health problems had contributed to his impotence and that impotence just put him out of that "foolishness." A third participant indicated that his wife was more concerned about him being alive than with sexual function. He also stated that he was getting older, so the loss of sexual function was not a concern. The fourth participant indicated that worrying about the loss of sexual function, when you could be dead instead was just "foolish" and that men had to be "sensible." Similar to other research, some of the participants in this study indicated that impotence would have been more of a concern had they been younger men. These men reported very stable married relationships, which were likely important in dealing with the outcome of impotency. The responses of the men in this study in regards to loss of sexual function varied.

#### 4.1.1.4 Masculinity

Masculinity, viewed from the traditional or hegemonic perspective, suggests that when men adhere to the more stringent display of masculinity (e.g. independent, aggressive, stoic, etc.) they may downplay or ignore psychological and emotional distress and they may engage in poor

health practices, delayed treatment, and a refusal to discuss or acknowledge negative health symptoms (Forrester, 1986). The research literature has begun to address the question of masculinity and implications that it may have for men with prostate cancer (Adamsen, Rasmussen & Pedersen 2001; Boehmer & Clark 2001; Butler et al., 2001; Gray et al., 2000; Harden et al., 2002; Lantz, Fullerton, Harshburger, & Sadler, 2001; Lavery & Clark, 1999; Lee & Owens, 2002; Moynihan, 2002). This literature continues to add to the evidence that strong masculine traits demonstrated by men put them at increased risk for physical and emotional problems. Two issues of masculinity from this study, relative to the available literature, will be addressed. One issue is help-seeking behaviour and how it affects men. The other issue is the relationship between masculinity and sexuality.

Lantz et al. (2001) found that the men in their study were less likely than the women to seek medical attention in a timely manner, which could contribute to morbidity and premature mortality. The researchers found that men often needed more overt physical signs (e.g., pain) before they would seek help; by this time the disease may have advanced to a critical stage. The authors concluded that men's delay in help-seeking behaviour was a result of male role behaviours, which are explained by biological and psychosocial theories of masculinity. Lee and Owens (2002) found that, compared to the women in their study, the men were less likely to use preventative health screening behaviours, made less use of health care facilities, were less likely to adopt preventative behaviours, and were reluctant to seek medical and psychological help. Moynihan (2002) found that traditional masculine traits were predictors of poor health practices of men ( i.e., not acknowledging that they have prostate cancer, which could result in the delay of treatment). Moynihan (2002) concluded that most prostate cancer patients are distressed and

largely untreated as a result of men's adherence to traditional masculine traits.

Contrary to the literature on the help-seeking behaviours of men with traditional masculine traits, all the participants in this study indicated that they were not afraid or concerned about seeing their doctor about their health status. All the participants saw their doctors annually or semi-annually to monitor their health status. One participant, who experienced problems with anxiety, sought medical help very quickly and as a result benefited from being proactive about his own health status. In most circumstances the participants in this study thought that the mostly good outcomes they had with prostate cancer were directly related to their active health monitoring and the early diagnosis and treatment for prostate cancer.

Consistent with the literature, the participants in this study provided examples of traditional masculine behaviours of men in their own communities which represented poor health monitoring behaviour and fit the more stereotypical examples of negative male gender behaviour. The participants in this study often discussed how the behaviours of other men they knew reflected the traditional male gender approach to health care. The participants in this study indicated that they knew men who would not disclose intimate knowledge about their health to other men and would maintain a stoic attitude. These participants gave examples of how other men they knew suffered grave consequences because they did not look after their own health or they ignored problems that led to their own early death. The two most important examples were from Andy and Irwin, who presented situations of a family member and a friend who waited too long to receive medical care and, subsequently, died. Some participants in this study, however, talked about how they were able to find some men who would disclose matters to them and how they felt they were able to help them by listening to them. The participants in this study

represented a group of men who were very proactive in the monitoring of their health status.

Boehmer and Clark (2002) suggested that prostate cancer treatment can create physical complications which can threaten a man's self-image and masculinity. In addition, men's traditional roles make it difficult for them to relinquish control and ask for help; this could be intensified when there are issues of urinary problems or erection difficulties. Subsequently, Boehmer and Clarke (2001) reported that men wanted to get on with their lives and move beyond the prostate cancer and that men adjusted to the disease without a loss of identity. However, an inability to achieve an erection and their loss of sexual urge and lack of sexual function threatened their manhood. Lavery and Clark (1999) indicated that the loss of sexuality did affect participants' masculinity. Hardern et al. (2002) agreed that men in their study suffered a loss of self-identity and manliness. Boehmer and Clark (2001) also indicated that if men talked, it was most likely to other men, and the topic of the discussion was limited to the diagnosis and outcome. The conversation was always factual and informative, but never emotional or about experiences. Men did not deal with feelings or fears. Some men in their study also noted a decrease in interactions with friends following diagnosis and treatment.

Participants in this study corroborated the literature on the negative aspects of traditional masculine behaviour with their examples of other men they know who have neglected treatment and who were not forthcoming in regards to sexual function. However none of the participants in this study mentioned a loss of manhood or identity. One participant indicated that the loss of sexual function was a loss of "manly ambitions," but this did not seem to indicate a loss of manhood or self identify. It should be noted that two participants indicated that sex was important to them and on that basis they sought out medical treatment for their impotence. Both participants

reported a satisfactory resumption of their normal sexual activity with the aid of medication. It is interesting to contemplate how these two participants would have felt had medical intervention not been successful in restoring their sexual function.

None of the participants in this study indicated that they, in particular, needed support, but that they did enjoy it and benefited from it when they received that support. Two participants in this study, who travelled together for their prostate cancer treatment, indicated that they benefited from support they gave one another through discussing their shared experience. Neither participant talked about the more emotional aspects of prostate cancer or as one participant stated, they did not talk about "dying or anything." Participants when interviewed were given the opportunity to speak about sexual matters and they felt open to do so. Some participants in this study indicated that they did not have difficulty discussing sexual matters with others.

Gray et al. (2002) identified that there is a wide variation in the display of masculinity and that men in their study adapted to their masculine changes while remaining within the boundaries of traditional male behaviour. The belief is that men display a range of masculinities within men themselves and between men while maintaining their masculine identities (Sabo & Gordon, 1995). The result is that the variation of masculine behaviour demonstrated by men supports the contention that not all men adhere to or make the choice to live up to the tenets of traditional masculine behaviour (Gray et al., 2002). Gray et al. (2002) cautioned researchers to remember that sex is very important to some men and not so much to others. These researchers indicated that it is important not to overemphasize the link between sexuality and masculinity. The impact of impotence would likely depend on each man's sexual history or experience, which is only one aspect of masculinity.

Participants in this study demonstrated the range in masculine behaviour or masculinities with examples given of other men and their more traditional help-seeking behaviour contrasted with the study participants' seemingly more proactive help-seeking behaviour and attitudes. Further, participants' statements in this study support the assertion by Gray et al. (2002) that sex is not always important to all men.

#### *4.1.1.5 Thoughtfulness and Reflection*

This theme includes a variety of ideas that were brought forward by the participants and represents their reflections on a renewed perspective on their lives following their treatment for prostate cancer. This theme reflects the ideas that participants had about their prostate cancer experience and the meaning they gained from having prostate cancer. On a cognitive level they are trying to understand and relate their experience to others and maybe, more importantly, to themselves. These stories within this theme were perhaps the way the participants were trying to re-focus the understanding of their life, following the diagnosis and treatment for prostate cancer. Although participants identified some aspects of the experience as being negative, for the most part, they saw that the prostate cancer experience as a time for learning, making new meaning, and finding new perspective in their lives.

Fitch et al. (2000) reported that families often come together during life-threatening illness and that this illness can bring families together and force a reordering of priorities. These changes are usually seen as something positive by men who have prostate cancer. Other research (Harden et al., 2002) suggests that for some men, families and children grew closer together and enjoyed a renewed family experience.

One common aspect of the prostate cancer experience shared by the participants in this

study was the importance of family and the impact of the prostate cancer on the family. All the participants were in long-term, stable marriages which the literature (Bertero, 2001; Moynihan, 2002) suggests is extremely important for successful adjustment and coping of men living with prostate cancer. All the participants indicated how important their spouses were to them as they went through the various stages of the prostate cancer experience. All six men indicated that the support from all their family was important and that it allowed them to deal with the difficult circumstances of prostate cancer. For one participant his relationship with his children became closer because of his prostate cancer. For another, the importance of his children and grandchildren was renewed and enhanced. Some men reported that they were concerned that their children suffered at times more than they did and that the children were stressed and worried about their father. As one participant indicated, prostate cancer can put enormous stress on the family. Another participant indicated that his children seemed stoic around him because they wanted to be brave for his sake. Some participants developed a renewed closeness with their families particularly when the family realized that the prostate cancer had the potential to be a very serious illness.

This reflective life perspective has been reported by Gray et al. (2000), who concluded that the prostate cancer experience encouraged the men in their study to review their lives and reflect on their past and present priorities and reaffirm how they were now living. In addition, employed individuals in their study thought more about retiring compared to men who were retired and they made deliberate attempts to get the most out of each day. Most of the adjustments for the men in their study involved easing up and enjoying life. In contrast, Harden et al. (2002) found that some men with prostate cancer could not always do the things the way they wanted to

or the way they did them before their illness. In addition men reported that they had less desire for social activities and were more selective in social engagements. Fitch et al. (2000) found that participants in their study reported few lifestyle changes or negative effects of prostate cancer, although participants did report a negative impact when it came to leisure activities. The researchers indicated that many of the participants in their study were retired and problems with treatment side-effects might have affected their ability to engage in leisure activities or the leisurely lifestyle to which they were accustomed.

Participants in the present study reflected on the good outcomes they seemed to have as a result of being treated early, surviving, and being around to enjoy life. Participants indicated that they were both humbled and grateful for early treatment and what survival meant to them. The successful detection and treatment of the prostate cancer led most of the participants to believe, in many respects, that the entire prostate cancer experience renewed their perspective and understanding of their own life, encouraged them to learn something new, and allowed them to meet new people and have new life experiences. For most participants the prostate cancer experience meant gaining a new perspective and using the experience to reflect on their farm work and make the conscious decision to ease back on their work and slow down in life. For a few men, the diagnosis of prostate cancer provided the impetus to enjoy more leisure activities in life and to make different life decisions.

Despite having been diagnosed and treated for prostate cancer and living with the after effects of treatment, for most of the participants, there was an acceptance of having had prostate cancer. The participants understood that as they got older cancer and other illnesses happen to people, and they accepted this was the case for them. As one participant indicated, "Why not

me?" Part of this acceptance of what they had been through was for two participants strengthened by their increased awareness or continuation of their religious faith. This renewed perspective was enhanced when the participants compared themselves with other people whose health outcomes or lifestyles were adversely affected by cancer or other illnesses.

Acceptance of the experience of prostate cancer was also reported by Gray et al. (2000), who found that men in their study downplayed the importance of the prostate cancer diagnosis in their lives and indicated that it is just something that happens as people get older and you cannot worry about that too much. Participants in their study also indicated that their own perception and acceptance was enhanced when they had knowledge of other people who had more difficult life circumstances than they did. Bertero (2001) also reported that survivors of prostate cancer were grateful because their lives had been saved. Participants also identified the need to accept the changes in their lives, in part because they were older to begin with.

An overall impression I received from the men in this study was a pragmatic approach to life and their journey with prostate cancer. The overwhelming aspect that came through in this theme was the men's re-ordering of priorities in respect to family, faith or religion, and a honest look at how they felt, how they compared themselves with others, and how a few of them took the opportunity to slow down at work and enjoy other parts of life. For one participant, it was important that nothing changed for him. The stories that suggest this theme are best understood by Neimeyer's (2000) concept of finding meaning in loss. Neimeyer stated that "the attempt to reconstruct a world of meaning is the central process in the experience of grieving" (p. 83). The participants in this study demonstrated the ability to find new meaning in their life through their prostate cancer experience.

#### *4.1.1.6 Helping Others and Being Helped*

Helping was a cornerstone to all the themes that the men brought forward through the interviews. Three general aspects to the participants' responses led to the development of the theme of helping others and being helped. The three aspects included support group help, individual help, and tangible help. The help involved family members, friends, and acquaintances from their communities.

For some participants in this study it was important to be part of a larger, more formal, prostate cancer support group where they were helped by other men with prostate cancer and by health experts who provided education and information to broaden their understanding of prostate cancer. From the support group the men learned about prostate cancer by listening to the experiences of other men with prostate cancer. The prostate cancer support group for some men was the place where they were able to help other men by telling them about the experiences they had with prostate cancer. Emerging from the data was that the men used the support group as a means to receive or impart education and information to other men about prostate cancer. The groups provided supportive elements for some men by reminding them that they were not alone and that other men with prostate cancer were dealing with the same issues they were. The support group provided a forum where the men could share their experiences with others to benefit other people. It is not clear whether the support group was helpful for participants in an emotional way, because emotional support was not described by the participants. One participant indicated that the support group helped to "lessen the burden" of each individual who participated, which may indicate that emotional support was gained by the men through an internal awareness and deeper

understanding of themselves and what they were living through. Participants in this study who attended a support group also indicated how beneficial it was for their wives to attend the groups with them.

Similar to the findings of the present study, participants in the study by Gray et al. (2000) indicated that the prostate cancer support groups provided them with important opportunities to talk with other men who were going through some of the same experiences. These men found meaning in their prostate cancer experiences by attending the support groups. In addition, participants whose wives attended the support group felt they were better able to manage their lives. In the study by Fitch et al. (2000), participants indicated that the prostate cancer support group was important for those who attended because of the information they received and because they found out that others felt the same way they do. Support groups also were seen as a way or an opportunity to help others. Fitch et al. (2000) found that of those participants who did not attend a support group, some thought that while they needed to talk about the cancer, they already had someone they could discuss the situation with. Others said they wanted to talk with someone, but did not have anyone to talk with. It has been found, in other research involving men with prostate cancer, that few men shared their experiences with others or attended support groups (Butler et al., 2001).

The second aspect to helping others and being helped was that of the participants acting as individuals within their own home communities. Within the community or farm setting, most of the participants in this study were helped by other people and, in turn, helped other people themselves. Responses from most of the participants in this study indicated that they placed much emphasis on educating other men in their communities about the importance of getting screened

medically for prostate cancer. All these participants considered themselves to be the recipients of good outcomes following prostate cancer treatment because they were screened and treated early for their prostate cancer. Another way that the participants helped within their communities was to be available to others who approached them for help. It was very important for these participants to use their experience, to give something back, and to help others. The data suggest that each study participant's own journey with cancer would have been for naught, if he had not been able to use his experience for the benefit of others. All were aware of individual people within their own communities whom they could help and they actively sought out opportunities to help, which they felt added something new to their own life and experience. In addition, all participants thought that it was important to share the experience with their spouse.

From the literature, Butler et al. (2001) indicated that participants in their study preferred one-to-one discussions with other men about prostate cancer. Participants in the previous study stated that they were strong advocates of preventative practices among their circle of friends. Harden et al.(2002) found that men thought it would be important to talk to other men who had gone through the experience of prostate cancer. They reported that some men were more keen to talk about the prostate cancer than were others.

The third aspect of helping others and being helped was the tangible help with the farm work or farm operation that the participants received from family and neighbours. All five participants who had sons indicated that they relied on them for extra help to keep the farm operation going. This meant discussing with their sons the amount of work they were able to do following treatment and having their sons pick up or take over the extra work, or for two participants it meant that their sons made permanent moves back to the farm to provide the extra

help on a permanent basis. For one participant it meant receiving immediate, temporary, physical help on the farm (from his son and a neighbour) with seeding and harvesting until he was able to recover from treatment and once again perform these tasks. This participant indicated that when his treatment and recovery period was over for him in turn he was able to help his neighbour, who was having health problems.

With respect to the tangible help, the literature search failed to reveal any published reports of previous studies of economic and work-related concerns of men with prostate cancer. For the men in the present study, being around others who knew what they are dealing with or going through was important. All six men used knowledge of others' prostate cancer experiences to help put things into perspective, for themselves. To look at their own lives and put prostate cancer into perspective they had to see what others were living like and what was important to or concerned them. Fitch et al. (2000) stated that their study participants did not want to burden other men with their story yet, in this study, one participant indicated that sharing his story with others was not a burden, but a lift.

All the participants in this study, whether they attended a support group or not, indicated that they had people to talk with about their experience with prostate cancer. All six men sought out opportunities to reach out to others and were approached by others in their communities to discuss their experiences with prostate cancer.

#### *4.1.1.7 Summary of the common themes*

In summary, the participants in this study indicated that farming and work is very important to them. After treatment for prostate cancer fatigue affected their ability to continue farming and working as hard as they did prior to treatment. In response to the fatigue participants

reflected on the operation of their family farms and made decisions and adjustments with respect to the future viability of the farm. With the participants diminished capacity to work on the farm after their prostate cancer treatment, other family members, mostly their sons, performed more of the work and took on more responsibility. One participant who had no family members to operate the farm, elected to retire early from active farming. The farmers in this study demonstrated that they benefited from their flexibility as self-employed farmers when they were required to attend doctor appointments and treatment schedules within the cities located away from their own communities. Rural isolation and the distance travelled to the cities for prostate cancer treatment were not viewed negatively. For the most part they saw the travel time as opportunity to enhance the experience by accomplishing other things and enjoying the experience. The participants viewed rural communities as places where people help and support each other through tangible, physical help on the farm, or by providing emotional and supportive help. The idea of being incontinent prior to treatment was a major concern for the participants in this study.

Participants selected treatment options that would, in their belief, afford them the best opportunity to avoid incontinence following treatment. Unfortunately, most of the participants did experience incontinence and/ or urinary urgency following treatment. However, the bladder concerns did not affect the participants' ability to farm, nor did they let the concerns affect their social lives. The participants attended social functions by making road trips that were well planned around rest stops to access washrooms. The participants also familiarized themselves with the location of washrooms while attending community functions.

Depression and anxiety were not self-reported as major concerns. However, one participant sought out help from a psychiatrist for treatment of his anxiety during the more active

phases of his prostate cancer experience.

All the participants in this study suffered impotence. Sexuality and sexual function was important to all of the participants. Some participants sought out alternative treatments to regain sexual function while others adjusted and accepted their new reality and focussed on other aspects of their lives and relationships. Most of the participants reported how spousal support was important in dealing with impotence and sexuality issues and sexual performance was not always important.

It was observed that masculinity and traditional masculine behaviours can be a barrier for men in terms of their health screening behaviours. Participants approached the subject of masculinity not by examining themselves, but relating stories of other men and how stoic, masculine behaviours had negative health consequences for these men.

The participants used thoughtfulness and reflection to find meaning in their experience with prostate cancer. Participants used their experience to engage in the activities of new learning, new meaning, and new perspectives. Families came together for support with the appreciation that prostate cancer has a huge effect on spouses and children. The participants took the opportunity to re-examine and reflect on their own lives. They were grateful to have survived and used their spiritual faith to work through the concerns of their new reality.

Helping others and being helped was a large encompassing theme. Educating others about prostate cancer was important as was encouraging other men to look after themselves. Participants took pleasure in providing tangible help to others in terms of farming and emotional and supportive help including educating others about monitoring their own health and just being with others in their communities. Participants took time to educate, listen to, and support others who

were in similar circumstances.

#### *4.1.2 Implications of the Research*

##### *4.1.2.1 Implications for Practice*

Health professionals have many opportunities to interact with men who have prostate cancer in acute care hospital settings, cancer treatment centres, and within the broader community. It is important for health professionals who interact with this group of men to be aware of the current research and knowledge surrounding the concerns of men with prostate cancer. Although a range of issues may be similar from one man to another, it is important to be attuned to the individual differences and variety of experiences that each man may have. Health professionals need to provide information about resources available for treatment and recovery, and the potential side effects of treatment. It is likely that issues of fatigue, incontinence, and impotence will be encountered by men with prostate cancer. Although these are sensitive issues health professionals, at the very least, have to provide opportunities for men with prostate cancer to explore some of these issues in a safe, judgment-free setting to determine if there are serious concerns of men and their families. Sexuality and sexual expression can be important aspects of health status and perceived well-being. These sensitive issues cannot remain taboo topics if a holistic assessment and intervention is the cornerstone of good health services. In addition, particular attention should be paid to the different circumstances and settings of men with prostate cancer. The men in the present study felt particularly supported in their experience with prostate cancer because they lived in a rural setting where the cultural norm was that people helped each other out and supported each other in difficult times.

Conclusions based on studies of large urban populations may not be transferrable to farm

or rural settings. In particular, travel, work, economic status, community support, and the impact of treatment effects may differ significantly between urban and rural men who suffer from prostate cancer, and may have implications for how men and families cope with prostate cancer. Although not explored in this study, it is well known that the diagnosis of cancer affects not only the individual, but the family as well. Participants in this study often connected aspects of their lives, well-being, and prostate cancer experience with the operation and the function of the family farm. Research conducted, to date, on larger urban populations of men with prostate cancer has not examined whether work or economic factors have had any effect on the study participants and their overall well-being; particular attention should be paid to these factors. Further, gender and gender sensitive care needs to be understood by health professionals so that one delivery model of care is not relied on, which may discriminate or fall short when applied to both men and women. It is important to be aware of emerging trends that can help to act as a guide for intervention and allow for the development of individual care models that are needed for each individual.

#### *4.1.2.2 Implications for Further Research*

This study highlights the need for further research into the health experiences of farmers and rural men. A more in-depth look is required to uncover the variety of masculine and behavioural responses that maybe be evident when men come from a variety of settings, ethnic backgrounds, and geographical locations. The differences between urban and rural populations of men with prostate cancer is an understudied area. Understanding the value of work, community support, travel, and individual coping within different contexts may add to new and dynamic understanding of men's experiences with prostate cancer. This research also highlights the need for an encompassing look at potential regional variations within countries and in contrast with

other countries, which may result in a deeper and broader understanding of men's experiences with prostate cancer. Also, there is a need for more research on the roles, challenges, and concerns that spouses and families have when a man who is close to them is diagnosed with prostate cancer experience. The importance of cultural factors and the experience of younger men are other areas for exploration.

#### *4.1.2.3 Strengths of the Study*

Because of the exploratory nature of this research, inductive qualitative methods were warranted. A convenience sample, comprised of all six men who volunteered for the study, was used. The sample of participants in this study was a homogeneous group of caucasian men and might not have included the variety of types of farmers who live in rural settings in Saskatchewan. The findings of this naturalistic inquiry, however, suggest common themes concerning farmers' experiences with prostate cancer. The themes provide an understanding that can be explored further with other groups of farmers in different settings.

#### *4.1.3 Conclusion*

The aim of this study was to examine a group of Saskatchewan rural farmers' experiences in living with prostate cancer following diagnosis and treatment. Naturalistic Inquiry and methods of Grounded Theory Analysis were used to analyze the data and uncover five common themes in the experiences of six farmers with prostate cancer: farming and rural life, physical and emotional concerns, sexuality, masculinity, and thoughtfulness and reflection. Helping others and being helped, a sixth theme that emerged from the data, served as a background theme interwoven with the five central themes. The information was provided by the men in their own words and represents their prostate cancer story. This study provides valuable information and understanding

of men's experiences in regards to prostate cancer and contributes to the broader understanding of men's psychosocial aspects in relation to health and illness. Developing a deeper contextual understanding of men, how they live, and how they understand the world involves the compilation of information about men from a variety of cultural settings about life and the events that shape men's lives; this study contributes to that quest by describing a group of farmers' experiences in living following the diagnosis and treatment of prostate cancer. The findings of this study suggests common themes concerning farmers' experiences with prostate cancer, which can be explored further with farmers in different settings. In addition, health care workers need to be attuned to the nuances and challenges that men with prostate cancer may have in relation to their educational and psychosocial care needs.

## REFERENCES

- Adamsen, L., Rasmussen, J., & Pedersen, L. (2001). Brothers in arms: How men with cancer experience a sense of comradeship through group intervention which combines physical activity with information relay. *Journal of Clinical Nursing, 10*, 528-537.
- Balderson, N., & Trowell, T. (2003). The prevalence and predictors of psychological distress in men with prostate cancer who are seeking support. *British Journal of Health Psychology, 8*, 125-134.
- Barsevick, A., Whitmer, K., & Walker, L. (2001). In their own words: Using the common sense model to analyze patient descriptions of cancer-related fatigue. *Oncology Nursing Forum, 28*(9), 1363-9.
- Bertero, C. (2001). Altered sexual patterns after treatment for prostate cancer. *Cancer Practice, 9*(5), 245-51.
- Boehmer, U., & Clark, J. (2001). Communication about prostate cancer between men and their wives. *The Journal of Family Practice, 50*(3), 226-231.
- Bottomely, A. (1996). Group cognitive behavioral therapy interventions with cancer patients: A review of the literature. *European Journal of Cancer Care, 5*, 143-146.
- Bottomely, A. (1997). Psychosocial problems in cancer: A brief review of common problems. *Journal of Psychiatric Mental Health Nursing, 4*, 323-331.
- Brink, P., & Wood, M. (1998). *Advanced design in nursing research* (2nd ed.). Thousand Oakes, CA: Sage.
- Burman, M., & Weinert, C. (1997). Concerns of rural men and women experiencing cancer. *Oncology Nursing Forum, 24*(9), 1593-1600.

- Burns, N., & Grove, S. (1997). *The practice of nursing research: Conduct, critique, and utilization* (3<sup>rd</sup> ed.). Philadelphia: W. B. Saunders.
- Butler, L., Downe-Wamboldt, B., Marsh, S., Bell, D., & Jarvi, K. (2000). Behind the scenes: Partners' perception of quality of life post radical prostatectomy. *Urologic-Nursing*, 20(4), 254-258.
- Butler, L., Downe-Wamboldt, B., Marsh, S., Bell, D., & Jarvi, K. (2001). Quality of life post radical prostatectomy: A male perspective. *Urologic-Nursing*, 21(4), 283-288.
- Call for action on prostate cancer. (1997, September). *Report and recommendations from the 1997 national prostate cancer forum* (pp.1-20). Toronto: The Mallard Group.
- Clark, J., Wray, N., Brody, B., Ashton, C., Geisler, B., & Watkins, H. (1997). Dimensions of quality of life expressed by men treated for metastatic prostate cancer. *Social Science and Medicine*, 45(8), 1299-1309.
- Erlandson, D., Harris, E., Skipper, B., & Allen, S. (1993). *Doing naturalistic inquiry*. Newbury Park, CA: Sage.
- Fergus, K., Gray, R., & Fitch, M. (2002). Sexual dysfunction and the preservation of manhood: Experience of men with prostate cancer. *Journal of Health Psychology*, 7(3), 303-316.
- Ferrans, C., Cohen, F., & Smith, K. (1992). The quality of life of persons with narcolepsy. *Loss, Grief, & Care*, 5(3/4), 23-32.
- Fitch, M., Gray, R., Franssen, E., & Johnson, B. (2000). Men's perspective on the impact of prostate cancer: Implications for oncology nurses. *Oncology Nursing Forum*, 27(8), 1255-1263.
- Forrester, D. (1986). Myths of masculinity: Impact on men's health. *Nursing Clinics of North*

*America*, 21(1), 15-23.

Fowler, F., Barry, M., Lu-yao, G., Wassen, J., Roman, A., & Wennberg, J. (1994). Effect of radical prostatectomy for prostate cancer on patient quality of life: Results from medicare survey. *Urology*, 45(6), 1007-1015.

Gillis, A., & Jackson, W. (2002). *Research for nurses: Methods and interpretation*. Philadelphia: F.A. Davis.

Glanze, W. (Ed.). (1990). *Mosby's medical, nursing, and allied health dictionary* (3<sup>rd</sup> ed.). St. Louis, MO: Mosby.

Glaser, B., & Strauss, A. (1967). *The discovery of grounded theory: Strategies for qualitative research*. Hawthorne, N.Y.: Aldine Publishing.

Gray, R., Fitch, M., Fergus, K., Mykhalovskiy, E., & Church, K. (2002). Hegemonic masculinity and the experience of prostate cancer: A narrative approach. *Journal of Aging and Identity*, 1, 43-62.

Gray, R., Fitch, M., Iscoe, N., Johnson, B., Labrecque, M., Klotz, L., & Franssen, E. (1998). Qualitative data from Canadian men with prostate cancer. *Annals of Cancer Control Research*, 8(1), 540-546.

Gray, R., Fitch, M., Phillips, C., Labrecque, M., & Fergus, K. (2000a). Managing the impact of illness: The experiences of men with prostate cancer and their spouses. *Journal of Health Psychology*, 5(4), 531-547.

Gray, R., Fitch, M., Phillips, C., Labrecque, M., & Fergus, K. (2000b) To tell or not to tell: Patterns of disclosure among men with prostate cancer. *Psycho Oncology*, 9(4), 273-282.

Gregoire, I., Kalogeropoulos, D., & Corcos, J. (1997). The effectiveness of a professionally led

- support group for men with prostate cancer. *Urologic Nursing*, 17(2), 58-66.
- Guba, E. (1981). Criteria for judging the trustworthiness of naturalistic inquiries. *ETCJ*, 19, 75-91.
- Gubrium, J., & Sankar, A. (1994). *Qualitative methods in aging research*. Thousand Oakes, Calif: Sage.
- Harden, J., Schafenacker, A., Northouse, L., Mood, D., Smith, D., Pienta, K., et al.(2002). Couples' experiences with prostate cancer: Focus group research. *Oncology Nursing Forum*, 29(4), 701- 9.
- Harris, J. (1997). The prevalence of impotence after radical prostatectomy. *Urologic Nursing*, 17(4), 142-145.
- Held, J., Osborne, D., Volpe, H., & Waldman, A. (1994). Cancer of the prostate: Treatment and nursing implications. *Oncology Nursing Forum*, 21(9), 1517-1529.
- Helgason, A., Fredrikson, M., Adoflsson, J., & Steineck, G. (1995). Decreased sexual capacity after external radiation therapy for prostate cancer impairs quality of life. *International Journal of Radiation Oncology Biology Physics*, 32(1), 33-39.
- Henke-Yarbro, C., & Estwing-Ferrans, C. (1998). Quality of life of patients with prostate cancer treated with surgery or radiation therapy. *Oncology Nursing Forum*, 25(4), 685-693.
- Heyman, E., & Rosner, T. (1996). Prostate cancer : An intimate view from patients and wives. *Urologic Nursing*, 16(2), 37-44.
- Jakobsson, L., Rahm-Hallberg, I., & Loven, L. (1997). Experiences of daily life quality in men with prostate cancer: An explorative study. *European Journal of Cancer Care*, 6, 108-116.
- Jennissen, T. (1992). *Health issues in rural Canada* (Background paper, research branch of library

- of parliament, no. bp-325e). Ottawa: Minister of Supply and Services.
- Karakiewicz, P., & Aprikian, A. (1998). Prostate cancer: 5. Diagnostic tools for early detection. *Canadian Medical Association Journal*, *159*(9), 1139-1146.
- Klotz, L. (2000). *Prostate cancer: A guide for patients*. Toronto: Chapters Inc.
- Klotz, L. (2002). *Expectant management with selective delayed intervention for favorable risk prostate cancer*. *7*(5), 175-179.
- Kornblith, A., Herr, H., Ofman, U., Scher, H., & Holland, J. (1994). Quality of life of patients with prostate cancer and their spouses. *Cancer*, *73*(11), 2791-2802.
- Krongrad, A., Litwin, M., Lai, H., & Lai, S. (1998). Dimensions of quality of life in prostate cancer. *The Journal of Urology*, *160*, 807-810.
- Kurtz, M., Kurtz, J., Stommel, M., Given, C., & Given, B. (2001). Physical functioning and depression among older persons with cancer. *Cancer Practice*, *9*(1), 11-8.
- Labrie, F. (2001). Hormonal therapy in the management of prostate cancer. In K.. Syrigos (Ed.), *Prostate cancer: Biology, diagnosis and management* (pp. 301-315). New York: Oxford University Press.
- Lantz, M., Fullerton, J., Harshburger, R., & Sadler, G., (2001). Promoting screening and early detection of cancer in men. *Nursing-and-Health-Sciences*, *3*(4): 189-96.
- Lavery, J., & Clarke, V. (1999). Prostate cancer: Patients' and spouses' coping and marital adjustments. *Psychology, Health & Medicine*, *4*(30), 289-302.
- Lee, C., & Owens, G. (2002). Issues for a psychology of men's health. *Journal of Health Psychology*, *7*(3), 209-217.
- Levy, I., Iscoe, N., & Klotz, L. (1998). Prostate cancer: 1. The descriptive epidemiology in

- Canada. *Canadian Medical Association Journal*, 159(5), 509-513.
- Lincoln, Y., & Guba, E. (1985). *Naturalistic Inquiry*. Newbury Park, CA: Sage.
- Litwin, M., Hays, R., Fink, A., Ganz, P., Leake, B., Leach, G., & Brook, R. (1995). Quality of life outcomes in men treated for localized prostate cancer. *Journal of the American Medical Association*, 273(2) 129-135.
- Long, K. (1998). The concept of health: Rural perspective. In H. Lee (Ed.), *Conceptual basis for rural nursing* (pp. 211-223). New York: Springer Publishing.
- Montgomery, P., & Santi, G. (1996). The influence of bilateral orchidectomy on self concept: A pilot study. *Journal of Advanced Nursing*, 24, 1249-1256.
- Monturo, C., Rodgers, P., Coleman, M., Robinson, J., & Pickett, M. (2001). Beyond sexual assessment: Lessons learned from couples post radical prostatectomy. *Journal of the American Academy of Nurse Practitioners*, 13(11), 511-515.
- Morrison, H., MacNeil, I., Miller, D., Levy, I., Xie, L., & Mao, Y. (1995). The impending Canadian prostate cancer epidemic. *Canadian Journal of Public Health*, 86, 274-278.
- Morse, J., & Fields, P. (1994). *Qualitative research methods for health professionals* (2<sup>nd</sup> ed.). Thousand Oakes, CA: Sage.
- Moul, J., Anderson, J., Penson, D., Klotz, L., Soloway, M., & Schulman, C. (2003). Early prostate cancer: Prevention, treatment modalities, and quality of life. *European Urology*, 44(3), 283-293.
- Moynihan, C. (2002). Men, women, gender and cancer. *European Journal of Cancer Care*, 11, 166-172.
- National Cancer Institute of Canada: Canadian Cancer Statistics 1999. Retrieved November 15,

- 1999, from <http://www.cancer.ca>
- National Cancer Institute of Canada, 2003: Canadian Cancer Statistics 2003. Retrieved November 20, 2003, from <http://www.cancer.ca>
- Neimeyer, R. (2000). *Lessons of loss: A guide to coping*. New York: McGraw-Hill.
- O'Rourke, M., & Germino, B. (2000). From two perspectives to one choice: Blending couple and individual views of prostate cancer treatment selection. *Journal of Family Nursing*, 6(3), 231-251.
- Palmer, M. (2001). Using epidemiology in patient education for post-prostatectomy urinary incontinence. *OstomyWound Management*, 47(12), 20-25.
- Phillips, C., Gray, R., Fitch, M., Labrecque, M., Fergus, K., & Klotz, L. (2000). Early postsurgery experience of prostate cancer patients and spouses. *Cancer Practice*, 8(4), 165-71.
- Pinnock, C., O'Brien, B., & Marshall, V. (1998). Older men's concerns about their urological health: A qualitative study. *Australian and New Zealand Journal of Public Health*, 22, 368-373.
- Piper, S. (1997). The limitations of well men clinics for health education. *Nursing Standard*, 11(30), 47-49.
- Pitblado, R., Pong, R., Irvine, A., Nagarajan, K., Sahai, V., Zelmer, J., et al., (1999). *Assessing rural health: Toward developing health indicators for rural Canada*. Laurention University, ON, Centre for Rural and Northern Health Research.
- Reiker, P., Clark, J., & Kalisk, L. (1993). Health related quality of life following treatment for early stage prostate cancer. *Proceedings of the American Sociological and Clinical*

*Oncology*, 12, 452.

- Saad, F. (1999). Prostate cancer: Diagnosis and management. *The Canadian Journal of Continuing Medical Education*, July, 49-64.
- Sabo, D. (1996). Caring for men. In J. Cookfair (Ed.), *Nursing care in the community* (2<sup>nd</sup> ed., pp. 347-365). St. Louis, MO: Mosby.
- Sabo, D., & Gordon, F. (1995). Masculinity, health, and illness: Rethinking men's health and illness. In D. Sabo & F. Gordon (Eds.) *Men's health and illness: Gender, power, and the body* (pp. 1-21). Thousand Oaks, Cal: Sage.
- Saskatchewan Institute on Prevention of Handicaps. (1996). *Child injury in Saskatchewan: Injury hospitalizations and deaths 1989-1994*. Saskatoon, SK: University Extension Press, University of Saskatchewan.
- Shepherd, D., Harris, M., & Thompson, I. (2001). Radical prostatectomy in the management of localized prostate cancer. In K.. Syrigos (Ed.), *Prostate cancer: Biology, diagnosis and management* (pp. 227-243). New York: Oxford University Press.
- Statistics Canada: 1996 - Census of Agriculture - Population. Retrieved November 15, 1999, from <http://www.statcan.ca>
- Stoller, M., & Carrol, P. (2003). Urology. In L.Tierney, S. McPhee, & M. Papadakas (Eds.), *Current medical diagnosis and treatment* (42<sup>nd</sup> ed., pp. 993-939). New York: McGraw-Hill.
- Strauss, A., & Corbin, J. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (2nd ed.). Thousand Oakes, CA: Sage.
- Streubert, H., & Carpenter, D. (1995). *Qualitative research in nursing: Advancing the*

*humanistic imperative*. Philadelphia, PA: J.B. Lippincott.

Tester, W., & Brouch, M. (2000). Treatment decision making. In J. Held-warmkessel (Ed.),

*Contemporary issues in prostate cancer* (pp. 81-101). Boston: Jones and Bartlett.

Thurston, W., & Meadows, L. (2003). Rurality and health: Perspectives of mid-life women. *Rural and Remote Health* 3, 219, 1-12. Retrieved November 22, 2003, from

<http://rrh.deakin.edu.au>

Waxman, E. (1993). Sexual dysfunction following treatment for prostate cancer: Nursing assessment and interventions. *Oncology Nursing Forum*, 20(10), 1567-1571.

Weinert, C., & Burman, M., (1994). Rural health and health-seeking behaviours. *Annual Review of Nursing Research*, 12, 65-92.

Zinner, N. (1995). Prostate. In R. Hasselback, (Ed.), *Everyone's guide to cancer therapy*, (pp. 494-504). Toronto: Somerville House Publishing.

## APPENDIX A

## Introduction Letter

Dear Sir

As you may know prostate cancer has become one of the most frequently diagnosed cancers among Canadian men. Despite the high numbers of men who develop prostate cancer very little research has addressed the experience that men have had in being diagnosed and treated for this disease. In particular, no one has addressed the unique experiences that rural farmers may have when battling this disease.

My name is Darren Gronvold and I am a Registered Nurse who is completing a Master of Nursing degree. My research interest is in men's health and men's issues. The purpose of my study is to discuss with men what it has been like for them to live with prostate cancer following diagnosis and treatment. The results of my study will be used to complete my thesis for my master's degree. As well, results of the thesis will be summarised and submitted to a scientific health care journal for publication. Also, a summarization of the results will be used as presentation material at a health care conference. Most importantly, the outcomes of the study will begin to assist health professionals to identify unique needs that men with prostate cancer may have and how those needs could be addressed.

Should you decide to volunteer the requirements that I would need from you involve a tape-recorded interview that would last approximately 1-3 hours. I would travel to your home for the interview or to another suitable location of your choice. I would require a location that is private to others and without interruptions. Also, a second personal or phone interview may be

required at a later date in order to clarify any questions that I may have. Certainly, some of the possible issues and concerns with prostate cancer can involve very personal issues (incontinence and impotence to name a few), therefore, privacy to discuss any of these issues would be beneficial.

Confidentiality and anonymity is a key component of this study and your identity will be known only to the researcher and his supervisor Dr. Karen M. Semchuk. All of the data for the study will be kept in a locked cabinet. At the end of the study all material will be stored in a secure area at the University of Saskatchewan by the thesis supervisor (Dr. Karen M. Semchuk) for a minimum of five years. Your name and location of residence will not be used in any written, presented, published, or public material.

You can withdraw from the study at any point in time should you wish, and without any explanation. Any information that you have supplied will be removed from the study and destroyed.

Should you have any questions or concerns about this invitation, please contact me or my thesis supervisor Dr. Karen M. Semchuk at the phone numbers listed below.

In order to volunteer for this study please phone Mr. Gronvold at 306-966-2274 (Collect calls accepted).

Funding support for this study comes from the Centre for Agriculture Medicine, University of Saskatchewan, through a Founding Chairs Graduate Fellowship awarded to Mr. Gronvold.

Sincerely

Darren Gronvold, R.N., B.S.N.

Karen M. Semchuk, Ph.D.

Master of Nursing Student

College of Nursing / Centre for Agricultural Medicine

University of Saskatchewan

Phone: 306 966 2274 (Answering machine available)

Professor

College of Nursing

University of Saskatchewan

Phone: 306 966 8279

## APPENDIX B

## Change in Recruitment Procedure

June 14, 2000

Dr. Valerie Thompson

Chair,

University Advisory Committee on Ethics

in Behavioural Science Research

University of Saskatchewan

Office of Research Services (Ethics Office)

207 Kirk Hall

117 Science place

Saskatoon, Sk, S7N 5C8

Dear Dr. Thompson:

**RE: Request to include additional participant recruitment procedures for the Thesis Research Project Entitled, "Rural Farmers' Experiences in Living with Prostate Cancer Following Diagnosis and Treatment" by Darren Gronvold, Graduate student, Master of**

**Nursing Program (2024).**

In my original thesis proposal that was approved by the ethics committee I indicated that I would be selecting participants through the snowball sampling method. I also indicated that I had identified three physicians and one nurse from four different Saskatchewan Health Districts who agreed to initiate the process of snowball sampling by forwarding letters of introduction from myself to potential participants. The introduction letter provided a summary of the purpose and goals of the study and provided information on how they could contact the researcher should they wish to participate. Unfortunately this method of initial contact with participants has proven to be very slow and has resulted in the recruitment of only one participant so far.

Therefore, I would like to expand the mode of participant recruitment by adding more strategies.

The additional strategies of recruitment that I would like to utilize include:

- 1) Print advertisement through newspapers, agency newsletters, and community posters for the enlistment of volunteers.
- 2) Widen the distribution of the introduction letter to include additional contacts (co-workers, friends, family members, and others) who may have knowledge of individuals who meet the criteria for my study and are willing to distribute the letter to potential participants on my behalf.

- 3) Distribute the introduction letter to the Chairs of local prostate cancer support groups for general distribution to support group members who might have knowledge of individuals who meet the criteria for my study and are willing to distribute the letter to potential participants on my behalf.

In addition, I would like to expand the inclusion criteria, which currently includes only farmers, to include non-farmers; this would allow me to examine the transferability of the emerging theory concerning the role and importance of gender issues.

The revised sampling strategies would continue to utilize my study's introduction letter in which potential participants would be provided with the introduction letter and have the opportunity to review the letter and the goals of the study. Should they wish to participate in the study at that time then they would have the instructions on how to contact me. With the new strategies for participant recruitment I would continue to have no knowledge of the identity of potential participants until they have contacted me first.

Thank you for your consideration of this request.

Sincerely,

Darren P. Gronvold, RN, BSN

Master of Nursing Program

Telephone: 966-2274

E-mail: [gronvold@sask.usask.ca](mailto:gronvold@sask.usask.ca)

cc. Dr. Karen M. Semchuk, College of Nursing  
Dr. Karen E. Wright, College of Nursing

## APPENDIX C

## Interview Guide

The interview guide allows the interviewer to introduce topic areas should they not occur naturally during the flow of the conversation. The open-ended format of the interview allows the interviewer to delve into the participant's responses to uncover more depth and understanding.

When were you first diagnosed with prostate cancer?

What kind of thoughts and feelings were you having when you were diagnosed?

What kind of treatment did you receive?

How did you decide on what form of treatment to receive?

What thoughts and feelings were you having when you went through the treatment procedure?

What was it like for you in returning home after treatment?

Describe the side effects that you had from the treatment once you returned home after treatment?

What kind of difficult issues came about for you from this disease in terms of your ability to work?

What kind of difficult issues came about for you from this disease in terms of your relationship with your wife/partner?

What kind of support have you received from family and friends in helping you to deal with the cancer?

What kind of support do you think was most beneficial to you?

Were you aware of any supportive services that are available to you within your health district?

Describe some of the most difficult moments for you?

Describe some of the most positive moments for you?

How has living in the rural areas of the province created unique challenges for you in receiving treatment and support?

How has this disease affected your ability to carry out your farming work?

Has this disease changed the way you feel about farming and working?

Has your prostate cancer been something that you can easily discuss with others? If no, why not?

How has being diagnosed and treated for prostate cancer changed your way of living? Or how you feel about your life? How has this been different from before you were diagnosed? What has changed in your life as a result of the diagnosis?

Has this experience been positive for you in any way?

How effective do you think you have been in coping with all the issues that have come up for you as a result of the cancer?

Has prostate cancer affected your ability to participate in any social activities or changed your social relationship in any way?

How has your sexual relationships and function changed since before the diagnosis and treatment?

Has it been difficult for you to participate in this interview? Why? Why not?

## APPENDIX D

## Transcript Release Form

Study Title: Rural farmers' experiences in living with prostate cancer following diagnosis and treatment.

Researcher: Darren Gronvold, R.N., B.S.N.

Master of Nursing Student

Centre for Agricultural Medicine

103 Hospital Drive

University of Saskatchewan, Saskatoon, S7N 0W8

Telephone: 306 966 2274

Supervisor: Karen M. Semchuk, Ph.D.

Professor

College of Nursing

107 Wiggins Road

University of Saskatchewan, Saskatoon, S7N 5E5

Telephone: 306 966 4053

I was given the opportunity to read and to make changes to a written copy of my interview for this study. I acknowledge that the written copy of the interview transcript accurately reflects what I said in my personal interview with Mr. Darren Gronvold.

Further, I understand that all of the data for the study will be kept in a locked cabinet.

Also, at the end of the study all material will be stored in a secure area at the University of Saskatchewan by the thesis supervisor (Dr. Karen M. Semchuk) for a minimum of five years.

I hereby authorize the release of this written transcript to Mr. Darren Gronvold to be used in the manner as described in the consent form.

---

Participants name (Print)

---

Participant's Signature

---

Date

---

Mr. Darren Gronvold

---

Date

## APPENDIX E

## Study Phases

<b>Phase 1</b>	<b>Phase 2</b>	<b>Phase 3</b>
Document audit trail	Document audit trail	Document audit trail
Determine interview questions	Conduct member checking	Conduct member check
Conduct interviews	Continue data analysis	Final analysis
Begin data analysis		Final write up

APPENDIX F

Consent Form

Title of Study: Rural farmers' experiences in living with prostate cancer following diagnosis and treatment for prostate cancer.

Researcher : Darren Gronvold, R.N., B.S.N.

Master of Nursing Student,

Centre for Agricultural Medicine

103 Hospital Drive

University of Saskatchewan, Saskatoon, S7N 0W8

Telephone: 306 966 2274

Thesis

Supervisor : Karen M. Semchuk, Ph.D.

College of Nursing

107 Wiggins Road

University of Saskatchewan, Saskatoon, S7N 5E5

Telephone: 306 966 8279

Office of Research Services

University of Saskatchewan

Telephone: 306 966 4053

I understand that the purpose of this research is to examine rural farmers' experiences in living following diagnosis and treatment for prostate cancer. Outcomes from this study will begin the process of knowledge building about how prostate cancer has affected men's lives. I understand that I will not directly benefit from this study but the information will help health professionals to begin understanding the issues and concerns that men may have when diagnosed with prostate cancer.

I agree to be interviewed by the researcher, Mr. Darren Gronvold, for approximately 1-3 hours. I understand that the interview will be tape-recorded and typed. The interview topics discussed will be about my personal experience in having been diagnosed and treated for prostate cancer. I understand that following the interview I will be provided with a copy of the typed interview. At that time, I will be able to read and revise any part of the interview transcript to ensure that the information I provided has been recorded and presented accurately. After I have reviewed the interview transcript and made any necessary revisions, I will sign a transcript release form authorizing the researcher to use the information as described in this consent form. I understand that the researcher cannot use the transcript in any research activities until I have authorized that use. I also know that the researcher may contact me once in person or by telephone following the interview to further clarify any questions that he may have.

I understand that the information I provide will form a part of the researcher's written thesis. I understand that the information I provide, and possibly specific quotes from the interview, may be used in future reports and presentations. However, my name and identity will

not be disclosed in any written or presented material. I understand that my identity will be known only to the researcher.

I understand that the audiotapes and transcribed information will be safeguarded for confidentiality and anonymity by the researcher at all times. This will include storage in a locked cabinet when not being examined. Also, upon conclusion of the study, all the collected data will be securely stored by the thesis supervisor ( Dr. Karen M. Semchuk) for a minimum of five years.

I may withdraw from this study at any time and without explanation. Should I choose to withdraw, any information that I have already provided will be removed from the study and destroyed. I am aware that the researcher will advise me of any new information that may affect my ability or desire to remain in the study.

I understand that the information that I disclose may be of a very personal and sensitive nature. In discussion, and with assistance from the researcher, I may choose to seek out counseling, supportive, or medical services for issues that may come to light during the interview. Should this occur, my participation in the study would no longer be required.

I understand that I have the right to contact the researcher, thesis supervisor, or the Office of Research Services at the University of Saskatchewan at any time should I have questions about this study, or my participation in this study.

The purpose and procedures of the study have been discussed with me and I understand them. I have had an opportunity to ask questions and receive answers regarding my involvement with this study in a manner that is acceptable to me.

I may obtain the final report of this study by informing the researcher Mr. Darren Gronvold.

I have read and understood this consent form and have received a copy for my own records.

Participant's name: \_\_\_\_\_ Date: \_\_\_\_\_

(Print)

\_\_\_\_\_

(Signature)

Researcher: \_\_\_\_\_ Date: \_\_\_\_\_

Mr. Darren Gronvold

