

University of Alberta

**Exercise Prevalence, Associations with Quality of Life, Determinants and
Preferences in Endometrial and Bladder Cancer Survivors**

by

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Abstract

Background: This dissertation provides an examination of exercise in endometrial and bladder cancer survivors. The purposes were to examine exercise prevalence, determinants of exercise using the Theory of Planned Behaviour (TPB) as a framework, and exercise preferences. The bladder cancer study also examined quality of life (QoL) issues. Secondary purposes were to examine the potential moderating effects of age.

Methods: The endometrial cancer study was a cross-sectional survey ($N = 386$) and the bladder cancer study was a prospective study ($N = 525$).

Results: Exercise Prevalence: Approximately 30% and 22% of endometrial and bladder cancer survivors were meeting public health exercise guidelines.

Determinants and of Exercise Motivation and Behaviour: In the endometrial cancer study, the TPB explained 44.5% of the variance in intention with self-efficacy ($\beta = .29, p < .001$), affective attitude ($\beta = .25, p < .001$) and past exercise ($\beta = .30, p < .001$) being the independent correlates. In the bladder cancer study, intention ($\beta = .25, p < .001$), perceived behavioural control ($\beta = .32, p = .001$), and planning ($\beta = .12, p = .018$) explained 20.9% of the variance in exercise behaviour. Perceived behavioural control ($\beta = .32, p < .001$), affective attitude ($\beta = .18, p = .002$), instrumental attitude ($\beta = .15, p = .025$) and descriptive norm ($\beta = .10, p = .032$) explained 39.1% of the variability in exercise intention. Age was found to moderate associations among the TPB constructs.

Exercise Preferences: The majority of survivors indicated they would be interested (76.9%; 81.1%) and able (81.7%; 84.3%) to participate in an exercise program designed for endometrial and bladder cancer survivors, respectively. Walking was the preferred

activity of endometrial (68.6%) and bladder (81.1%) cancer survivors. Bladder cancer survivors were particularly interested in home-based exercise programming (53.7%).

Exercise and QoL: For the bladder cancer study, analyses of variance indicated that survivors meeting public health exercise guidelines reported more favourable scores on the FACT-BI ($p = .001$) and various fatigue indicators ($ps < .05$).

Conclusions: The results of these studies provide important information on exercise in endometrial and bladder cancer survivors.

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CHAPTER 1 - INTRODUCTION

Overview of the Dissertation

The purpose of this dissertation was to provide an in-depth examination of exercise issues in two previously unstudied cancer survivor groups—endometrial and bladder. The first section of the dissertation provides an overview of cancer statistics, the growing issue of cancer survivorship, and the need for effective interventions for improving quality of life (QoL) in cancer survivors. The next section reviews what is currently known about the role of exercise in cancer survivors and concludes that there are no studies to date of endometrial and bladder cancer survivors. The next section provides a background on the etiology, pathogenesis and treatments for these cancers that leads into a review of the unique QoL issues for each cancer. After that, the literatures on exercise determinants and exercise preferences are reviewed followed by a special focus on exercise in older cancer survivors. The main body of this dissertation is presented in a series of five papers (Figure 1). The first two papers come from a cross-sectional study on endometrial cancer survivors. The first paper is entitled “Correlates of Exercise Motivation in a Population-Based Sample of Endometrial Cancer Survivors: An Application of the Theory of Planned Behaviour” and examines the correlates of exercise motivation and behaviour using the Theory of Planned Behaviour (TPB). The second study examines exercise programming and counselling preferences of endometrial cancer survivors [1] and is titled “Exercise Preferences of Endometrial Cancer Survivors: A Population-Based Study”. The next three papers are based on the results of a study of bladder cancer survivors. This study is similar in design to the endometrial cancer study, but improvements were made by including a prospective study design, sampling more

participants, and adding a QoL assessment. Paper three, "Associations among Exercise and Quality of Life in Bladder Cancer Survivors: A Population Based Study" tests associations among exercise and QoL in bladder cancer survivors. The fourth paper explores medical, demographic, behavioural and social cognitive determinants of exercise in bladder cancer survivors and is titled "A Prospective Study of the Determinants of Exercise in Bladder Cancer Survivors Using the Theory of Planned Behaviour." Paper five, "Exercise Programming and Counselling Preferences of a Population-Based Sample of Bladder Cancer Survivors" documents exercise programming and counselling preferences of bladder cancer survivors. Throughout all five papers, special attention is paid to age and other medical and demographic variables as possible moderators of the main findings. The dissertation ends with a discussion of overall conclusions of this work and practical implications of these findings. Future directions are also discussed.

Cancer Statistics

Cancer is a devastating disease that is increasing in incidence in Canada. In 2006, 153,100 new diagnoses are expected and current estimates suggest that 38% of Canadian women and 44% of Canadian men will be diagnosed with cancer at some point during their lifetimes [2]. On the positive side, because of increasing efficacy in treatments and earlier detection, survival rates are increasing for most cancers with an overall 5-year survival rate of 65%, up from 50% in 1974-1976 [3]. For many survivors, a diagnosis of cancer and the side-effects from treatments have a profound negative impact on many quality of life (QoL) parameters, which can last for years after treatments have ended. As a result, there has been increasing interest in developing means of improving QoL and

survival in cancer survivors. Most QoL interventions in cancer survivors have been primarily psychosocial in nature, and include strategies such as patient education, social support, coping skills training, and psychotherapy [4]. Psychosocial interventions have been found to be effective in reducing depression, anxiety, functional impairment, and perception of symptoms in a number of studies [5] but their utility for addressing physical and functional QoL concerns appears to be more limited. Consequently, psychosocial interventions may not be effective in alleviating all aspects of poor QoL in cancer survivors.

Exercise as a Quality of Life Intervention in Cancer Survivors

A number of studies have indicated that physical exercise may be a useful intervention for improving not only psychological QoL issues, but also physical, functional and emotional complications in some populations of cancer survivors. Recent reviews [6-8] have indicated that exercise may improve a variety of QoL parameters in cancer survivors both on and off treatment, such as aerobic fitness, muscular strength, fatigue, depression, anxiety, self-esteem, body image, functional ability, social function, and overall quality of life.

For example, one recent randomized controlled trial [9] examined the effects of a 6-month long resistance training program on 86 breast cancer survivors (four to 36 months posttreatment) randomly assigned to either an exercise or control group. The exercise group performed nine different resistance exercises twice weekly using weight machines and free weights that targeted the chest, back, shoulders, arms, buttocks, hips and thighs. Results indicated that the exercise group, compared to the control group, indicated significantly higher global QoL scores and psychosocial global scores. Moreover,

increases in upper body strength and lean mass were positively associated with physical and psychosocial global scores. These findings suggest that a resistance training program may improve QoL in breast cancer survivors partially due to changes in strength and body composition.

Another recent randomized controlled trial of 66 localized prostate cancer survivors [10] receiving radiation treatment investigated the effectiveness of a four week long walking program in improving fatigue and physical functioning. Participants assigned to the walking condition were instructed to walk for 30 minutes at least three times per week at a moderate intensity while those assigned to the control condition were told to rest when they felt fatigued. Results indicated a significant increase in fatigue and a slight deterioration in physical functioning in the control condition. The exercise condition however indicated no significant increase in fatigue and a significant improvement in physical functioning. The authors concluded that a walking program during radiation therapy may improve physical functioning and counteract increases in fatigue.

Lesser Studied Cancers

Despite increasing interest in exploring the utility of exercise in rehabilitating cancer survivors, the majority of work to date has primarily focused on breast cancer survivors [11], with only a few studies involving other tumour types such as prostate, colorectal, multiple myeloma, lung, stomach and leukemia [6-8]. To date, many common cancers, such as bladder and endometrial, have not been examined at all in the exercise literature. Recent reviews have concluded that although there are a number of quality studies involving exercise in breast cancer survivors, a substantial gap exists in the literature on exercise in other tumour types [12] and that making generalizations to these

cancer groups may not be wise [6-8, 13, 14]. Because of this, there is a need for research on exercise in tumour types other than breast. For this dissertation, two common, but previously unstudied cancers – endometrial cancer and bladder cancer - were examined in depth in terms of exercise prevalence rates, associations with quality of life, determinants of exercise and exercise preferences in order to gain a preliminary understanding of exercise in survivors of these cancer survivor groups.

Endometrial Cancer

Endometrial cancer (i.e., cancer of the lining layer of the uterus) represents the majority of cancers of the uterine corpus. In Canadian women, endometrial cancer ranks as the fourth most common cancer. An estimated 3,900 new cases of cancer of the body of the uterus are projected to be diagnosed in 2006 in Canada. Furthermore, it is estimated that 720 Canadians will die from endometrial cancer in 2006 [2]. Incidence rates for endometrial cancer peaked in the 1970s with the widespread use of unopposed exogenous estrogen in the form of high potency birth control pills, followed by a decline in the 1980s, and have remained relatively stable since 1988 [3, 15]. The clinical course is favourable, with an overall 5-year survival rate of approximately 84%. For locally contained tumours, the five-year survival rate is 96.1%, but drops to 66.3% for regional tumours and 25.2% when distant metastases are present [3]. The average age of diagnosis is 60 years of age [16], however many cases are diagnosed before menopause [3].

The primary risk factor for developing endometrial cancer is cumulative exposure to unopposed estrogen through means such as estrogen replacement therapy, a history of polycystic ovary syndrome, tamoxifen use, nulliparity, early menarche and late menopause [3]. Lack of physical activity and/or excess body weight may also constitute

major risk factors for endometrial cancer through mechanisms such as compromised insulin sensitivity, elevated insulin-like growth factor (IGF) activity in the endometrium, and increased plasma estrogen levels [17, 18].

Within the group of endometrial carcinomas, 90% are categorized as typical adenocarcinomas [19], which can be further subdivided by percentage of solid tumour growth into three architectural grades. Grade 1 tumours are characterized by cancers with clearly identifiable endometrial glands and are well differentiated, while grade 3 cancers are identifiable by a solid growth and poor differentiation. The remaining 10% of endometrial cancers consist of rare cell types such as mucinous carcinoma, papillary endometrioid carcinoma, clear cell carcinoma, and papillary serous carcinoma [20]. Endometrial cancers are also categorized by surgical staging and clinical staging. Surgical stages range from stage IA (tumour limited to the endometrium) to stage IVB (distant metastases). Stage and grade determine suitability of operative intervention versus primary radiation therapy. In addition stage, subtype, and usually grade are determinants of postoperative adjuvant therapy, which is most commonly radiation but can be chemotherapy or both.

The most common clinical presentation is significant postmenopausal vaginal bleeding [21]. Since bleeding usually occurs at an early stage, approximately 90% of tumours are in operable categories [22]. Other symptoms include pelvic pain and a foul, purulent discharge from the uterine cavity. Endometrial cancer can also, in more advanced cases, resemble ovarian cancer with presenting symptoms of fluid in the abdominal cavity, a pelvic/abdominal mass, and bowel symptoms. Later stages involve local-regional metastases to the lower vagina and suburethral areas and swelling of the

lymph nodes of the groin [15]. Stage IV disease is also associated with vascular metastases to distant organs most commonly the lung – and less commonly bone, liver or brain [22].

Treatment of endometrial cancer depends on the extent of the disease at the time of presentation. Standard treatment for endometrial cancer primarily consists of surgery with or without adjuvant radiation [23].

Once surgical staging is determined, surgical removal of the uterus and fallopian tubes and ovaries are the standard treatment procedures for endometrial cancer. Since most cases of endometrial cancer are diagnosed at an early stage - while the carcinoma is contained within the body of the uterus - surgical removal alone is often curative [24].

An alternative to the traditional total abdominal hysterectomy is laparoscopically assisted vaginal hysterectomy with laparoscopic removal of lymph nodes [25]. This procedure involves the insertion of a tiny scope through a small incision in the abdomen. Through this incision, the peritoneal cavity can be inspected, vaginal hysterectomy assisted, and when necessary, pelvic and aortic lymph nodes sampled [26]. Laparoscopic surgery in early stage endometrial cancer patients has been associated with an excellent surgical outcome, less hospitalization, less need for analgesia, earlier recovery, and improved QoL compared to abdominal hysterectomy [25, 27, 28].

Endometrial cancer tumours are moderately radiosensitive [29]. Adjuvant radiation therapy is often recommended for patients with high risk for extrauterine spread [30]. It can be administered either externally or internally (brachytherapy) and for surgical stage I-III disease either before, or more commonly, after surgery.

External irradiation refers to irradiation from sources at a distance from the body, such as external beam radiation [31]. Internal irradiation, or brachytherapy, involves the insertion of radioactive sources into restricted tissue in close proximity to the tumour. Brachytherapy can consist of two types, (a) interstitial implants, in which hollow needles are used to channel radioactive seeds into the tumour bed, and (b) intracavitary irradiation, which consists of insertion of radioactive sources in close proximity to the tumour within the body cavity [31]. Radiation therapy can act as an effective adjuvant treatment, and can improve local control [15].

In order to preserve childbearing potential, selected cases can be treated with progestational agents as primary therapy as opposed to surgery (hormone therapy). Progestins as primary therapy typically are reserved for young women with grade I tumours without myometrial invasion [32]. Progestational agents have also been used to treat recurrent endometrial cancers with overall objective response rates ranging between 10 and 20 percent. Progestin therapy appears to be most effective for patients presenting with a long disease-free interval and with well-differentiated tumours [33].

Cytotoxic chemotherapy has not been found to be beneficial for the primary management of endometrial cancer, except for the adjuvant treatment of the serous papillary or clear cell subtypes of endometrial carcinoma which behave like and therefore are treated as an epithelial ovarian carcinoma [22]. It has, however, been used for endometrial cancer patients with recurrent, advanced cancer, producing a response rate of approximately 34-60% [34]. Most responses, however, are only partial, with median life expectancy between 4.2 and 15.3 months [35].

Bladder Cancer

Bladder cancer is the sixth most common cancer in Canada with 6400 new cases expected in 2006[2]. Of these cases, 4,700 are expected to be men. Approximately 1,700 deaths from bladder cancer are expected in 2006 [2]. The death/cases ratio is relatively low at 0.27, with a five-year survival rate of 81.8% [3]. Bladder cancer occurs most often in older adults, with the median age of diagnosis being 65 to 70 years [36].

Bladder cancer is highly linked to exposure to carcinogenic substances, such as cigarette smoking and occupational hazards (e.g. dyes and paints) [36]. Cigarette smoking has been estimated to be responsible for approximately 50% of bladder cancer deaths in men, and 37% in women [37]. Bladder cancer incidence has also been associated with chronic or recurrent urinary tract infections [36]. Consumption of some agents, such as artificial sweeteners and caffeine, and exposure to certain viruses, such as HIV and human papillomavirus, have been believed to be linked to bladder, but no evidence to date supports a causal relationship [38].

Participation in regular exercise has also been linked to bladder cancer risk [39, 40]. One large scale survey of 37,459 women aged 55 to 69 years indicated that no regular physical exercise was associated with increased bladder cancer incidence [39]. A previous prospective study of 7,588 middle-aged men, however, indicated that regular participation in vigorous exercise was associated with an increased incidence of bladder cancer [40]. There was no relationship, however, between participation in occasional, light, moderate, or moderately-vigorous exercise and bladder cancer incidence. No explanations were offered for the increased risk of bladder cancer in individuals who regularly partook in vigorous exercise.

Approximately 90% of all bladder cancers are transitional-cell carcinoma (TCC). Other types include squamous cell cancer of the bladder, adenocarcinoma of the bladder, and undifferentiated carcinoma [38, 41]. TCC is further categorized as either superficial or invasive. Superficial bladder cancers are characterized by the tumour being confined to the bladder lining (urothelium) or connective tissue outside the lining (lamina propria). Invasive bladder cancers involve the progression of the tumour beyond these layers to the smooth muscle layer and beyond [42]. Approximately 70% of TCC bladder cancers in developed countries present as superficial [43].

Superficial TCC can be divided into three stages, Ta, T1, and Tis. Ta stage tumours are papillary and confined to the mucosa. T1 tumours are papillary or nodular and invade the lamina propria. Tis stage tumours are confined to the urothelium and are characterized as nonexophytic or 'flat' carcinoma in situ. Stage Ta tumours are the most common of superficial TCC, accounting for approximately 70% of all cases [36, 41]. Muscle-invasive tumours are staged as T2 to T4. Advanced disease refers to the presence of distant metastases and/or involvement of extra-pelvic nodes [44].

TCC can also be divided into grades based on cell differentiation. The World Health Organization grading system consists of three grades, I, II, III, which progressively define less differentiation [45].

The most common clinical presentation in individuals diagnosed with bladder cancer is either hematuria (blood in the urine) or painful urination [46]. Flank or suprapubic pain may be present in individuals with large tumours due to obstruction of the ureteral or bladder outlet [47].

Treatment for bladder cancer varies depending on the extent of the disease at the time of evaluation [48]. The standard initial treatment for both superficial and invasive bladder cancer is surgery, with adjuvant chemotherapy [41, 47].

In superficial bladder cancer, the standard surgical treatment consists of transurethral resection of visible lesions. This can be accomplished with laser treatment, but more commonly electrosurgical resection is used to preserve tissue for pathologic analysis. In cases where tumours may be invasive, or where carcinoma in situ is suspected, prostatic urethral sampling may be required [41, 46, 48].

Invasive bladder cancer, however, involves radical cystectomy (removal of the bladder) and pelvic lymph node dissection [49]. Radical cystectomy typically involves removal of the bladder, peritoneal covering, perivesical fat, and lower portion of the ureters. In men the prostate, seminal vesicles, a portion of the vasa deferentia, and possibly the urethra are also removed. In women, the uterus, ovaries, fallopian tubes, and possibly the anterior vaginal wall and urethra are also excised. The urinary tract is reconstructed with an ileal conduit, continent cutaneous diversion, or neobladder [46].

Surgical treatment of bladder cancer creates a difficult decision for surgeons. On one hand, radical extirpation is the safest from a recurrence perspective since it involves removal of the most tissue. On the other hand, the greater the quantity of tissue removed, the greater the compromise to normal urosexual function and other factors of QoL [50].

External beam radiation alone, preoperative radiotherapy, or brachytherapy alone or with external beam radiation are not commonly used alone to treat bladder cancer in North America [51]. Radiotherapy has been found to be useful as a component of a multimodal approach following transurethral resection of bladder lesions. This technique

has been used successfully in the preservation of the bladder without compromising the survival rate. Radiotherapy also has a role in palliative therapy, either alone or in conjunction with chemotherapy [51].

Systemic chemotherapy is frequently used as a treatment for metastatic and locally advanced disease with a moderate degree of success [52]. This is usually given in the form of adjuvant therapy. In patients at high risk for relapse, chemotherapy may be given as neoadjuvant therapy, perioperatively, or as adjuvant therapy [44].

Intravesical therapy, a form of treatment that involves insertion of therapeutic agents directly into the bladder, is a common treatment modality for superficial bladder cancer [53]. Intravesical therapy can involve cytotoxic agents, such as mitomycin C and epirubicin, or other agents such as non-specific immunotherapy with bacillus Calmette-Guerin (BCG) [54]. Intravesical chemotherapy can be performed pre-, peri-, or post operatively with a moderate degree of improvement in recurrence rates.

Quality of Life

QoL is a subjective concept that captures physical, emotional, and social functioning of individuals [55]. In the area of cancer research, QoL is gaining interest as an important clinical endpoint. This is largely because cancer treatments are improving in terms of increasing overall survival rate, meaning more cancer patients survive the disease, and are left to contend with the QoL issues that follow. In the cancer area, QoL is largely comprised of the patient's own perceptions of his/her own physical, emotional, and social well-being in light of the disease and its treatments [56].

Quality of Life in Endometrial Cancer Survivors

Endometrial cancer survivors have been found to experience a number of QoL issues due to treatment-related side effects and from the cancer experience itself.

Radiotherapy for the treatment of endometrial cancer has been associated with a number of QoL issues. For example, in a sample of stage I and II endometrial cancer patients receiving adjuvant radiotherapy [57], 65% experienced acute toxicities, such as diarrhea, painful urination, genitourinary infection, and fatigue. Furthermore, three months after the end of treatment, 19% of patients reported late toxicities, such as chronic diarrhea, rectal bleeding, chronic cystitis, and vaginal stenosis. Similar results were found in another group of endometrial cancer patients following external irradiation, both during radiation treatment and six months after completion [58].

Some evidence indicates that side effects may continue for months or years after the end of treatment. Li and colleagues [59] found that five to seven years after treatment (surgery, radiotherapy, and/or chemotherapy), younger endometrial cancer survivors (aged 43 to 64 years) reported significantly more gastrointestinal symptoms, such as nausea, constipation, and diarrhea, compared to controls. In a further study, [60], three to four years after radiotherapy, approximately half of endometrial cancer survivors reported their frequency of diarrhea as 'quite a bit' or 'very much'. Urinary incontinence has also been found to be common in endometrial cancer survivors. Herwig et al. [61] found that 53.7% of endometrial cancer survivors, many of them years post treatment, reported being incontinent as a result of radiation therapy. Specifically, those who had received brachytherapy alone most commonly reported having stress incontinence,

whereas survivors who had received both brachytherapy and external beam radiation were more likely to indicate urge incontinence.

Endometrial cancer survivors have also been found to indicate psychological distress as a result of the cancer experience [59]. The main psychological disturbances experienced by gynecological cancer survivors include primarily affective disturbances and sexual dysfunction [62]. Li and colleagues [59] found that younger women (43 to 64 years of age) tended to experience higher than expected levels of depressive symptoms. Some evidence also indicates that endometrial cancer survivors suffer from poor body image and sexual dysfunction [63-65]. As many as 90% of gynecological cancer survivors have reported experiencing sexual difficulties after treatment [63].

We have recently reported the first data to examine the association between exercise, body mass index (BMI), and QoL in endometrial cancer survivors [66]. In that study, we found that meeting public health guidelines for exercise and body weight were associated with higher levels of QoL. Specifically, survivors who reported meeting public health exercise guidelines indicated higher physical, functional and social well-being as well as lower levels of fatigue and anemia compared to survivors not meeting the guidelines. Normal weight survivors indicated significantly higher functional well-being and lower fatigue and anemia compared to severely obese survivors. Differences between the groups were clinically meaningful. Moreover, we also found from multiple regression analyses that exercise and body weight were independently associated with QoL. These findings suggest that exercise and body weight are independent correlates of QoL in endometrial cancer survivors, and that future studies are needed to determine the causal order of these associations.

Quality of Life in Bladder Cancer Survivors

The unique QoL issues of bladder cancer survivors are fairly well documented. A recent review [67] found 35 full-text references dealing with health-related QoL in bladder cancer survivors utilizing a number of generic instruments (e.g. SF-36) [68], cancer-specific instruments (e.g. EORTC) [69], and bladder cancer-specific instruments (e.g. FACT-VCI) [70]. Urinary and sexual issues were a common theme in most investigations [67]. Other QoL issues in bladder cancer survivors also emerged in certain investigations such as poor physical and emotional functioning [71], mental health [72], and mood states [73].

Many bladder cancer survivors experience difficulties with controlling urination, such as urinary leakage, odour, stomal and peristomal problems, and the need for catheterization [74]. One survey [75] found that bladder cancer survivors who had undergone either radical cystectomy or orthotopic bladder substitution reported more urinary leakage (18% vs. 5%) and more urinary tract infections (14% vs. 6%) than healthy matched controls. Additionally, 26% of patients with a neobladder needed to self-catheterize intermittently.

Decreased sexual function is also a common QoL issue among bladder cancer survivors. A longitudinal study of bladder cancer survivors after cystectomy indicated that sexual function decreased significantly from pre-surgery to 1 year post-surgery with the greatest decrease occurring in patients who had received an incontinent diversion [68]. Another recent study found that bladder cancer survivors who had undergone radical cystectomy indicated higher levels of sexual dysfunction compared to survivors who had undergone different treatment options [76]. Sexual dysfunction, along with

bodily disfigurement, urinary leakage, and other treatment related side-effects, may also cause strain on marriage and other relationships, which in turn may negatively influence QoL [74].

For some bladder cancer survivors, body image issues linked to treatments, particularly surgery, may be of concern [77, 78]. For example, Bjerre et al. [77] found that while patients receiving bladder substitution surgery reported fairly good body image scores while those patients receiving ileal conduit diversion indicated decreases in body image scores after surgery.

Some evidence exists to suggest that mood states can also be altered as a result of a bladder cancer diagnosis and its treatments. Henningsohn et al. [75] found, in a sample of 101 bladder cancer survivors, that anxiety and depression were higher in patients with a neobladder who intermittently self-catheterized compared to those who did not need to self-catheterize. A recent study by Kulaksizoglu et al. [73] found that depression rates for a sample of bladder cancer survivors were fairly high pre-operatively (23%), but gradually diminished (1.6%) at 12 months post-surgery. These results suggest that, while depression rates may be relatively high at the initial time of diagnosis, the incidence of depression improves with time, possibly due to a diminishment and/or adjustment to complications.

While several studies have examined the associations between exercise and QoL in survivors of a number of different cancers, such as breast, prostate, and colorectal, no studies to date have specifically targeted bladder cancer survivors. Since bladder cancer survivors experience a number of unique QoL issues such as urinary complications [74] and sexual dysfunction [68], it is unclear whether they would benefit as much from

physical exercise as other cancer survivor groups. Some of the side-effects experienced by bladder cancer survivors, however, have been linked to exercise in non-clinical populations, and may also be applicable to bladder cancer survivors. For example, pelvic floor strengthening exercises have been found to be helpful in controlling stress incontinence (involuntary urinary leakage) in parous women, yet high-impact exercise has been found to increase abdominal pressure and temporarily exacerbate the problem [79]. These findings suggest the potential utility of some types of exercise for controlling urinary leakage in bladder cancer survivors, while other types of exercise may exacerbate the problem.

Exercise Motivation in Cancer Survivors

Despite evidence of the benefits of exercise in cancer survivors, exercise participation rates are low. Recent prevalence studies [80, 81] indicate that cancer survivors report lower levels of physical activity compared to age-matched adults without a history of cancer. Bellizzi et al. [80] found, from a survey of 7,384 cancer survivors and 121,347 noncancer controls, that 70.4% of cancer survivors reported no physical activity compared to 63.4% of noncancer controls. Similarly, Coups and Ostroff [81] found that a significantly higher percentage of noncancer controls compared to cancer survivors between the ages of 40 and 64 years (30.8% vs. 25.2%) reported being physically active, but that no significant differences existed between participants in the 18 to 39 years of age (40.7% vs. 37.3%) and 65 plus years (22.1% vs. 20.6%) groups. In observational studies of cancer survivors, reported exercise participation rates tend to decline after treatment, and remain relatively low post-treatment [82-85]. In most studies, exercise participation rates posttreatment range from 20 to 30% and from 5 to 10% during

treatment [86]. For example, Vallance et al. [87] found that, in a sample of 438 non-Hodgkins's lymphoma survivors, that exercise levels were the highest pre-diagnosis (33.8%), then dropped significantly during treatment (6.5%), and although increased significantly off-treatment (23.7%), never returned to prediagnosis levels.

Research on exercise participation in cancer survivors to date is relatively limited. In the prevalence studies, the participants were mixed samples which included primarily breast and prostate cancer survivors [80, 81]. The observational studies have also been limited to a few tumour types, namely breast [83, 84], multiple myeloma [85], colorectal [82] and non Hodgkin's lymphoma [87]. No study to date has examined the exercise participation rates of endometrial and bladder cancer survivors.

Determinants of Exercise in Cancer Survivors

We recently reviewed studies examining determinants of exercise in cancer survivors and found a growing number of studies in this area [86]. Of these studies, most have used a theoretical framework – most notably the Theory of Planned Behavior (TPB).

The TPB is a social cognitive model of behavior change that postulates that behavior is guided by three concepts: (a) behavioural beliefs (evaluations and expectations of outcomes of the behaviour), (b) normative beliefs (perceived social pressure to perform the behaviour) and (c) control beliefs (perceptions of factors that may facilitate or prevent the performance of the behaviour and their magnitude) [88]. The underlying beliefs form the basis for the three central tenets of the model: (a) *attitude* is formed from behavioural beliefs, (b) *subjective norm* is derived from normative beliefs and (c) *perceived behavioural control* is a result of control beliefs. Each construct

consists of two lower order components. Specifically, attitude consists of an *affective* (evaluation of the enjoyableness of the behaviour) and *instrumental* (expectations of benefit/harm from the behaviour) component, subjective norm is comprised of a *descriptive* (extent to which important others partake in the behaviour) and *injunctive* (degree of social approval for the behaviour) element, and perceived behavioural control consists of a *self-efficacy* (degree of confidence in performing the behaviour) and *perceived control* (perception of control over the behaviour) component. According to the TPB, the more favourable the attitude, subjective norm and perceived behavioural control, the more likely the individual will intend to perform the behaviour. Intention is considered the antecedent to behaviour, and given a person has sufficient perceived control to perform a behaviour, intention should predict the behaviour. Because perceived behavioural control may be distinct from intention, it should be considered as an independent predictor of behaviour.

The cancer populations that have been studied in the exercise domain using the TPB included a number of different tumor sites at various stages of the cancer experience, including breast cancer survivors [89], a mixed sample of recipients of high-dose chemotherapy and bone marrow transplantation [90], post surgical colorectal cancer survivors [91], breast and prostate cancer survivors [92, 93], non-Hodgkin's lymphoma survivors [94], multiple myeloma survivors [95] and brain cancer survivors [96]. The TPB was found to be an effective framework for understanding exercise motivation and behavior in these studies accounting for 14 to 37% of the variability in exercise behaviour and 23 to 68% of the variance in exercise intention. Individual motivational determinants varied considerable from study to study, presumably because each population was

distinct in terms of symptoms, treatment modalities, side-effects, age, and gender. For example, Hunt-Shanks et al. [93] examined exercise determinants in a cross-sectional sample of 315 breast and prostate cancer survivors on active treatment. Results indicated that instrumental attitude and perceived behavioral control were the sole independent correlates of exercise intention in breast cancer survivors whereas in prostate cancer survivors subjective norm and perceived behavioral control made significant unique contributions. In a sample of 100 brain cancer survivors, however, the key correlates of intention were found to be affective attitude and perceived behavioural control [96]. In a study of 399 non-Hodgkin's lymphoma survivors, affective attitude, subjective norm and perceived behavioral control were found to be sole independent correlates of exercise intention [94]. Nonetheless, for all studies, one or more of the TPB constructs significantly predicted intention, which in turn predicted exercise behaviour.

Although a number of different cancer types have been explored, no study to date has examined individual motivational determinants of exercise in endometrial or bladder cancer survivors. Therefore it is unknown which TPB constructs, if any, predict exercise intention and/or behaviour in these tumour types.

Exercise Programming and Counselling Preferences of Cancer Survivors

To date, only five studies have examined exercise preferences in cancer survivors, and of these only three conducted a comprehensive examination of exercise preferences [97-99]. These studies included primarily breast and prostate cancer survivors [97, 100], breast cancer survivors [101], non-Hodgkin's lymphoma survivors [99] and brain cancer survivors [98]. A key finding from these studies is that the majority of participants indicated interest in exercise counselling and/or programming designed for survivors of

their tumour type [97-101]. This finding indicates a need for the availability of exercise programming and counselling to each of these tumour types. From these few studies, several common themes emerged in terms of exercise preferences. For example, walking was found to be the preferred modality of exercise [97, 99, 101], most survivors indicated a preference for moderate intensity activity [97, 99], the majority of survivors preferred home-based exercise programming [97-99] that was done alone [97, 99] and approximately half of survivors wished to start an exercise program after treatment had ended [97, 99]. No studies to date have examined exercise preferences in endometrial and bladder cancer survivors. It is possible that, because of unique side-effects such as urinary leakage in bladder cancer survivors, that these two populations may indicate unique exercise preferences.

Aging and Cancer

At present, the median age of diagnosis of cancer is between 65 and 69 years. With the aging population, and with the increasing numbers of cancer survivors in total, this figure is expected to rise [2]. Despite the large proportion of older people among the cancer survivor population, relatively little is known about cancer in the older adult [102, 103]. This is likely due to under representation of older adults in clinical cancer trials. For example, Hutchins et al. [104] found, in a review of 164 cancer studies, that only 25% of participants were over the age of 65 years, a percentage far lower than the 63% estimated in the general cancer survivor population. The authors speculate that this may be due to a number of reasons, such as age restrictions in the eligibility criteria, misconceptions on behalf of the patients themselves on their ability to participate, logistic barriers, coexisting health conditions, and selection bias due to clinician misconceptions that older

patients may not be as compliant or benefit as much from clinical trials. Because of this gap in knowledge, coupled with the rising number of older people diagnosed with cancer, it is imperative that future research be directed to the concerns of this unique population.

Quality of Life in Older Cancer Survivors

From the limited research available, it is apparent that older cancer survivors often present a number of complex QoL issues unique to their age group. While it appears that older cancer survivors tend to suffer less overall psychological distress than their younger counterparts [105-107], older individuals appear to have different psychosocial QoL issues to contend with [108].

For many older individuals, a cancer diagnosis is often made in the context of other medical conditions. As a result, the combination of pre-existing medical problems and cancer-related side effects may be enough to amplify levels of stress and drastically deteriorate functional and physical QoL [109-111]. For example, Given et al. [111] found, in a sample of breast, colon, lung, and prostate cancer survivors over the age of 65, that patients with three or more co-morbidities had more pain and fatigue compared to those patients reporting less than two co-morbidities.

Older cancer survivors are also often faced with coping with cancer while dealing with age-related disabilities, such as deterioration in mobility, vision, and strength. Consequently, coping may not be as effective as for younger individuals [108]. The inability to cope with a multitude of stressors may lead to deterioration in aspects of psychosocial quality of life, such as symptoms of depression, anxiety, and delirium [108]. Depression and anxiety are fairly common in older cancer survivors. One study found that 25% of a sample of older cancer survivors showed signs of clinical depression [112].

Delirium, which is categorized by disordered attention and cognition, has been found to affect 25% of individuals with advanced cancer, and 85% of those with terminal cancer [113].

Additionally, social and emotional issues such as widowhood, retirement, and declining social support, may also adversely affect older cancer survivors' ability to effectively cope with cancer [109]. A recent study by Ganz et al. [109] found that older breast cancer survivors, 1 year after surgery, had the poorest self-perceived health and psychosocial adjustment if they also reported impaired mental health and lack of emotional support.

Age-related changes in cardiac, renal, pulmonary and gastrointestinal systems have also been found to increase the likelihood of toxicities from cancer treatments. As a result, physical and functional QoL may be impaired more in older cancer survivors compared to younger survivors. For example, age-related declines in gastrointestinal mucosal protective mechanisms make older cancer patients more susceptible to mucositis, a painful condition that can compromise physical and functional QoL [114]. A recent study of rectal cancer survivors found that those over the age of 70 years had significantly lower scores of physical functioning and global health and indicated higher pain and fatigue levels compared to survivors 69 years of age and younger [115].

Exercise Interventions for Improving Quality of Life in Older Cancer Survivors

While exercise has been found to be beneficial in improving a number of QoL variables in cancer survivors, it is unknown what the effects of aging are on these associations. In the non-clinical older adult population, both aerobic and resistance

exercise have been found to improve a number of QoL parameters including the physical and functional domains [116-118] and psychological parameters [119-122].

A number of studies have found that regular exercise can have a role in improving the physical and functional domains of QoL by increasing and maintaining health status in older populations [123-125]. Many of the conditions that physical activity has been found to protect against (e.g. cardiovascular disease, osteoporosis, cancer) have been found to increase in prevalence with age. Consequently, older adults are at particularly high risk for these diseases, and as a result, could benefit the most from the protective effects of physical activity. Additionally, some of the normal declines associated with aging, such as decreased muscle mass [116] and functional capacity [117], can be decelerated with the use of exercise. For example, a recent review [117] indicated that the normal decline of 10% per decade in maximal oxygen consumption (VO_{2max}) can be reduced by 50% in young and middle-aged men through vigorous exercise, and by 10% in young and middle-aged women. All of these changes can have dramatic impacts on QoL through improvements in physical and functional capacities [126].

Psychological and emotional parameters of QoL in older people may also be improved through exercise. Several studies have indicated that exercise can have positive effects on psychological well-being [119, 122, 127, 128], depression [121, 128], tension [121], fatigue [121], anger [121], happiness [119], emotional QoL [129] and global mood [121]. For example, a review by Moore and Blumenthal [120] found that exercise is more effective than a placebo or no treatment for alleviating depression in older adults. This was found to be true for studies that involved an exercise intervention of several weeks or more, or after a single bout of exercise. For example, one study found that just one bout

of aerobic exercise was able to significantly decrease levels of depressive symptoms in a sample of older women [121].

To date, very little is known about the relationship between exercise and QoL in older cancer survivors. Recently, we reviewed the literature on exercise and QoL in older cancer survivors and found that none of the 48 reviewed studies specifically focused on older cancer survivors, or performed a subgroup analyses based on age [130]. Moreover, 10 of the reviewed studies used age as an exclusion criterion. The mean age of the participants of all 48 studies collectively was 48 ± 9 years. Only two studies had samples with a mean age of 60 or above, and only two other studies had used populations with a mean age of 65 or older. Only one study reported including any cancer survivors over the age of 80 years, and only one other included any participants over the age of 75 years. Since the time of our review, there have been two reported studies that examined exercise in older cancer survivors. The first was a cross-sectional survey of 688 older breast and prostate cancer survivors that found that increased physical activity was significantly associated with higher levels of physical function [131]. The authors concluded that physical activity may be beneficial for older cancer survivors. To test this, Demark-Wahnefried et al. [132] recently conducted a 6-month long randomized controlled trial lifestyle intervention for breast and prostate cancer survivors over the age of 65 years. The intervention group received telephone counselling and tailored print materials designed to increase exercise and improve diet. Results indicated that the intervention group significantly improved in diet quality, but not physical activity energy expenditure or physical function over the course of the intervention. The investigators concluded that although trends were in the direction of improved physical activity and physical function

in favour of the intervention group, the study was too underpowered to declare statistically significant differences on these outcomes. Based on the lack of research on exercise in older cancer survivors, very little is known about exercise in this special population. According to research on non-clinical populations of older adults, and research involving exercise and QoL in cancer survivors of all ages, it is likely, however, that older cancer survivors can improve QoL through physical exercise. The associations between exercise and QoL might, however, be different for older cancer survivors compared to younger individuals based on age-related differences in QoL issues.

Exercise Motivation in Older Cancer Survivors

Despite the many documented benefits of exercise, the older adult population remains the most sedentary. In Canada, the percentage of individuals who are physically inactive increases with age, with the lowest levels of physical activity reported among those over the age of 65 [133]. Approximately 56% of individuals over the age of 65, and 63% of those over the age of 75, report no regular physical activity [133]. To date, only two studies have documented exercise participation rates in cancer survivors based on age [80, 81]. Coups and Ostroff [81] found, in a cross-sectional survey of 1646 adult cancer survivors, that only 20.6% of cancer survivors 65 years and older reported being physically active compared to 40.7% of cancer survivors aged 18 to 39 years and 25.2% of survivors aged 40 to 64 years. Similarly, Bellizzi et al. [80] found that only 24.9% of cancer survivors over the age of 65 years reported regular physical activity while 37.6% and 33.0% of survivors 18 to 40 years and 40 to 64 years (respectively) reported being physically active. From these findings, it is likely that declines in physical activity levels that occur with age also happen in cancer survivors, and that possibly the experience of

cancer survivorship coupled with older age may compound to make exercise rates in older cancer survivors particularly low.

Determinants of Exercise in Older Cancer Survivors

Virtually nothing is known about individual motivational determinants of exercise in older cancer survivors [130]. However, a paucity of research has examined the barriers and motivators that influence exercise participation in older adults in the general population. One review of motivational determinants of exercise in older adults found that exercise is determined by a number of psychological, physiological, and socio-environmental components [134]. In older adults, this can involve perceived barriers, social cognitive variables, exercise history, physical condition, and demographics.

A number of barriers to exercising have been reported by older adults, including fatigue, lack of access to facilities, expenses associated with exercise, lack of exercise partners, sensory and mobility impairments, pain, and time restraints [135, 136]. For example, one study [135] found, in a sample of 60 to 80 year olds starting a walking program, that participants identified four prominent problems or barriers to walking – pain, fatigue, mobility, and sensory impairments. The authors noted, however, that these barriers are often not insurmountable, and if approached in this way, older adults may be able to work with their health care workers or fitness specialists to overcome them.

Social-cognitive factors, such as attitudes, norms, and self-efficacy about exercise, may also influence older adults' participation in regular exercise. For example, older adults may not be aware of the health benefits of physical activity, or they may not place value in these benefits [137]. One study found that, generally, older people do not view regular physical activity as a major health determinant [138]. Consequently,

misinformation about the importance of physical activity in maintaining health may discourage some older adults from exercising regularly.

Additionally, prevailing social beliefs about the inappropriateness of exercise for older adults, especially women, may influence physical activity levels [139]. Booth and colleagues [139] found, for example, that many older women remained sedentary because they were influenced by normative beliefs about older women being 'too old' to exercise.

Self-efficacy – an individual's personal judgment on his/her ability to succeed in reaching a particular goal - has also been found to influence exercise participation in older populations [140]. For instance, older adults may feel they are unable to engage in physical activity due to perceptions of sickness, frailty, disability, or advanced age [141, 142]. Older adults with arthritis, for example, often avoid exercise because they feel that it would be painful and/or harmful to their joints, even though evidence indicates the contrary - that exercise may be beneficial in alleviating symptoms [143]. Fear of injury from falling has also been identified as a common reason for not exercising in older adults. One study, for example, found that, in a sample of high-functioning, healthy older adults, fear of falling was independently associated with reduced levels of participation in physical activity [144].

Social factors may also play a role in influencing exercise participation in older adults. A recent cross-sectional study of 3075 older adults aged 70-79 found that married men indicated higher median levels of exercise participation and married women reported higher levels of total activity [145]. Moreover, having an active spouse was positively associated with being physically active. These results suggest that being married may

provide support for exercise and that having an active spouse may further improve activity levels.

Past exercise participation may also determine the likelihood of exercise participation in older adults [146, 147]. Walsh et al. [147] found that past exercise behaviour was positively associated with current walking participation in a large sample of older adults. The strongest correlation between past and current exercise behaviour was past exercise behaviour at the age of 50 years.

Age related complications have also been associated with low physical activity participation in older adults. Of particular note, problems with bowels and bladder control [148] and failing vision and hearing [135] have been found to be potential barriers to physical activity participation in older adults. For example, Brown and Miller [148] found that leaking urine during physical movement was a barrier to physical activity in older women. Results of the study indicated that approximately 25 % of older women reported avoiding physical activity because of leaking urine.

Demographic variables have also been found to be associated with exercise participation in older adults [146, 147]. Higher level of education [146, 147], male gender [149, 150], being unmarried [149], and younger age [149] have been found to be associated with higher levels of physical activity. Socioeconomic status, although a significant predictor of exercise behaviour in younger and middle-aged adults, appears to be weakly related with exercise in older adults [151].

Several studies have successfully used the Theory of Planned Behavior (TPB) as a theoretical framework to examine motivational determinants of exercise in older adults [152-155]. For example, one study found [153], in a sample of 225 women aged 65 and

older, that behavioral beliefs and perceived control beliefs predicted exercise. These constructs accounted for 23% of the variance in exercise. Behavioral beliefs, perceived control beliefs, and normative beliefs significantly predicted exercise intention, although each of the odds ratios were of modest magnitude. The authors concluded that perceived control beliefs were particularly important barriers to exercise.

To date, no known study has specifically examined individual motivational determinants of exercise in older cancer survivors [130]. Based on the variability in motivational determinants in previous studies of cancer survivors, and the unique factors that influence exercise behaviour in older adults, it is presumable that individual motivational determinants of exercise in older cancer survivors are quite different from those of younger individuals.

Exercise Programming and Counselling Preferences of Older Cancer Survivors

No study thus far has specifically examined exercise programming and counselling preferences in older cancer survivors. Several investigations to date, however, have documented exercise preferences in non-clinical populations of older adults [139, 156-158]. The results of this research indicate that age affects exercise preferences [157, 158]. For example, participation in vigorous physical activity has been found to decline with age, with greater preferences for walking as a form of activity in older compared to younger individuals [139, 157]. Preference for exercising alone, and the desire for professional advice on exercise, has also been found to increase with age [139, 156]. For example, one study found that 67 % of older adults (65 years of age and older) in a randomly selected sample preferred to exercise alone compared to in an

exercise class [159]. Older men, as a group, had the greatest preference for exercising alone (75%) compared to older women (62%).

PURPOSES

The primary purposes of this dissertation were to: (a) document the exercise prevalence rates of endometrial and bladder cancer survivors, (b) examine the determinants and correlates of exercise behaviour and/or intention in these populations using the TPB as a theoretical framework, and (c) document the exercise preferences of survivors of these tumour types. An additional purpose of the bladder cancer study was to (d) examine the association between exercise and QoL. Secondary purposes were to examine the moderating effects of age and other demographic and medical factors (i.e., body mass index, sex, adjuvant therapy, stage, months since diagnosis, invasiveness) on the main findings.

HYPOTHESES

Exercise Prevalence Rates

Based on previous literature, it was expected that exercise participation rates would be lower for endometrial and bladder cancer survivors than would be expected in the general population, and would be even lower during treatment [86]. Since exercise rates have been found to decrease with age in cancer survivors [80, 81], it was expected that exercise rates would be lower for older compared to younger survivors.

Determinants of Exercise

Endometrial and bladder cancer survivors were expected to display unique motives and barriers for exercise and exercise intention due to treatment-related side-effects and other factors specific to the demographics of these populations. Perceived

behavioural control was expected to be a strong predictor of exercise intentions and/or behaviour in both bladder and endometrial cancer survivors due to major barriers to exercise in the form of obesity-related co-morbidities in endometrial cancer survivors and urinary leakage in bladder cancer survivors. In healthy populations of older adults, perceptions of sickness or frailty [141, 142] and urinary leakage have been found to be prominent reasons for avoiding physical activity [148]. It was expected that subjective norm would be an important correlate of exercise intention in endometrial cancer survivors but less important in bladder cancer survivors since previous studies suggest that subjective norm may be a more important correlate of exercise intention in women compared to men [92]. Individual motivational determinants were also expected to be moderated by age. Based on previous research of older, non-clinical populations, self-efficacy, or perceived behavioural control, was expected to be a more important predictor of exercise intention in older than younger individuals in these populations [141, 142].

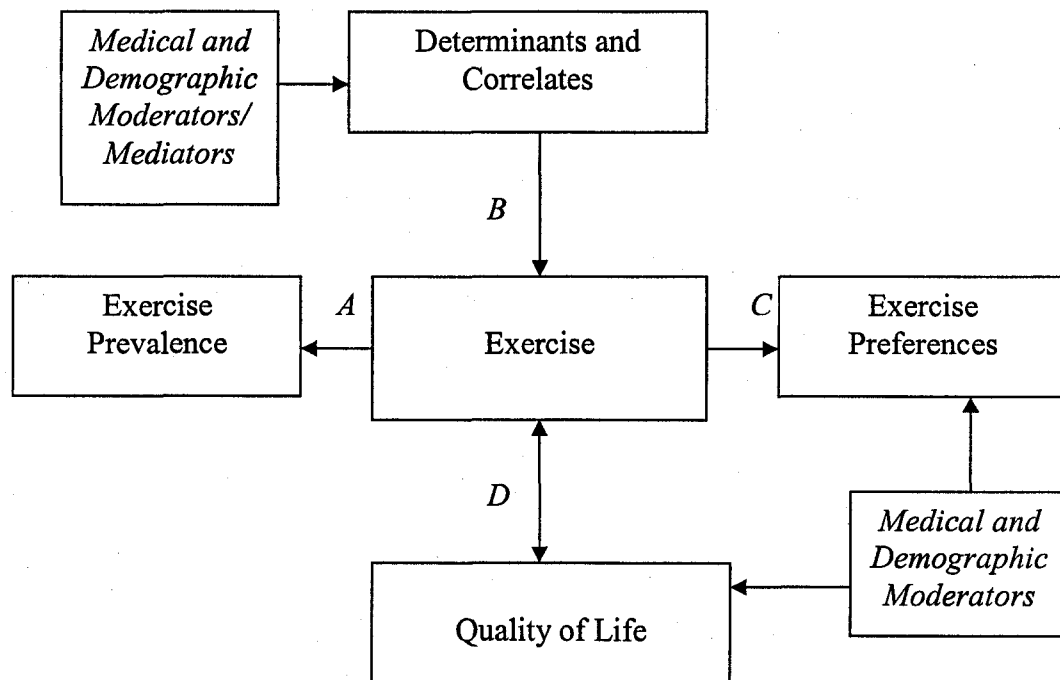
Exercise Preferences

Exercise programming and counselling preferences were also expected to be unique for endometrial and bladder cancer survivors. Based on previous research of survivors of some other cancer groups [86], it was expected that both endometrial and bladder cancer survivors would indicate interest in having exercise counselling at some point during the cancer experience. Older survivors were expected to have different exercise preferences compared to younger survivors. For example, older participants were expected to be more interested in walking programs and exercising at home [139, 157] compared to younger individuals.

Exercise and Quality of Life

Although previous research involving survivors of several types of cancers have indicated a positive association between exercise and QoL [7], it was uncertain if the same held true for bladder cancer survivors. QoL issues that are not specific to bladder cancer but common in cancer survivors in general, such as fatigue and functional well-being, were expected to be associated with exercise. Testing of the association between exercise and some of the unique QoL issues of bladder cancer survivors, such as urinary and sexual dysfunction, was primarily exploratory. These findings were expected to be moderated by age. Previous research has indicated that, with age, QoL issues in cancer become increasingly important in the physical and functional domain [109-111]. Consequently, it was expected that, if an association was found between QoL and exercise in this sample, particularly in the physical and functional domains, the association would be even stronger for older participants.

Figure 1-1 Schematic diagram of overview of dissertation studies.*



* Paper one assessed path A & B
Paper two assessed path C
Paper three assessed paths A & D
Paper four assessed path B
Paper five assessed path C

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CHAPTER 2:

Endometrial Cancer and Exercise Study

Paper 1:

Correlates of Exercise Motivation and Behavior in a Population-Based Sample of Endometrial Cancer Survivors: An Application of the Theory of Planned Behavior

Introduction

Exercise has received attention as a means of ameliorating physical, functional, and emotional quality of life issues in cancer survivors [1]. Despite the many documented benefits of exercise in cancer survivors, exercise participation rates are relatively low in cancer survivors [2, 3] suggesting the importance of identifying the determinants of exercise in this group.

Several studies have explored exercise motivation in cancer survivors [4-12]. Almost all, however, have focused on survivors of only a few different cancers such as breast [4, 6, 8], prostate [4], colorectal [9], non Hodgkins lymphoma [10], multiple myeloma [11] and brain cancer [12]. Moreover, the results have indicated that the determinants of exercise motivation may vary depending on the cancer survivor group. Consequently, different cancer survivor groups may present unique determinants of exercise motivation, and generalizations among cancer survivor groups may not be warranted. Furthermore, the determinants of exercise motivation in cancer survivors may be moderated by a number of medical and demographic variables. For example, age has been found to influence exercise determinants [13], and it may be an important moderator in endometrial cancer survivors given their typical age range of 50 to 70 years. Body weight has also been found to influence exercise determinants in the general population [14] and may be important for endometrial cancer survivors because high obesity rates [15]. Finally, months since diagnosis may moderate exercise determinants given that the effects of treatments tend to dissipate over time [16].

The majority of studies to date that have examined exercise motivation in cancer survivors have used the Theory of Planned Behavior (TPB) [17]. The TPB, compared to

other models, has become one of the most widely used frameworks for understanding exercise behavior [18, 19]. The TPB postulates that intention (motivation and plans) is the antecedent of behavior. Intention, in turn, is determined by subjective norm (perceived social pressure to perform the behavior), attitude (positive or negative evaluation of the behavior), and perceived behavioral control (PBC; confidence and control over performing the behavior). Moreover, subjective norm is based upon normative beliefs (specific individuals that may approve or disapprove of the behavior), attitude is based upon behavioral beliefs (specific perceived advantages and disadvantages of participating in the behavior), and PBC is based upon control beliefs (specific barriers and opportunities the individual has for performing the behavior). Each TPB construct (i.e., attitude, subjective norm, PBC) is considered to be a higher order structure that is each composed of two lower order components [20]. Attitude consists of affective (enjoyableness of exercise) and instrumental (perceived benefits of exercise) components, subjective norm is comprised of descriptive (perception that important others exercise) and injunctive (perception that social system supports exercise) components and PBC consists of self-efficacy (confidence in ability to exercise) and perceived control (perceived control over exercise). Some theorists have recently proposed that the multidimensional testing of the lower order structures (i.e., affective and instrumental attitudes, descriptive and injunctive norms, self-efficacy and perceived control) directly in the model instead of the aggregated higher order structures results in better model fit and higher explained variance [21-23]. For this study, we tested the multidimensional components of attitude and PBC, but on the recommendations of Ajzen

[20], tested the aggregate subjective norm construct rather than the lower order components (i.e., descriptive and injunctive norms).

To date, no study has examined correlates of exercise motivation in endometrial cancer survivors, even though endometrial cancer ranks as the fourth most common cancer in women and has a five-year relative survival rate of 84% [24, 25]. In the present paper, we report data on correlates of exercise intention in endometrial cancer survivors using the TPB as our model. Our primary purpose was to examine the utility of the TPB as a theoretical framework for understanding exercise intention in endometrial cancer survivors. We hypothesized that attitude, subjective norm, and perceived behavioral control would each be independent correlates of exercise intention. Our secondary purpose was to explore potential moderators of these associations. Based on previous research with other cancer survivors, we expected some of the demographic and medical variables, such as age, body mass index (BMI), months since diagnosis, disease stage, and treatment type to moderate the associations in the TPB [10].

Methods

Sample and Procedures

Details of the methods of our study have been reported elsewhere [26]. The Alberta Cancer Board and the University of Alberta provided ethical approval for the study. All contact information was obtained through the Alberta Cancer Registry and involved a list of all endometrial cancer survivors diagnosed in Alberta, Canada between November, 1994 and June, 2003. Participants were eligible for the study if they were: (a) over the age of 18 years, (b) could provide written consent in English, (c) approved for contact by a family physician or primary oncologist (as required by our ethics boards),

and (d) had a histologically confirmed diagnosis of endometrial cancer. Once physician/oncologist approval to contact was obtained, endometrial cancer survivors were mailed a questionnaire package and asked to return the questionnaire plus one copy of the consent form. All participants gave consent for the researchers to utilize their medical data. The study was conducted between March and May of 2004.

Measures

Marital status, annual income, employment status, education level, height, and weight were all obtained exclusively by self-report. Age, time since diagnosis, tumor grade, disease stage, and treatment type were collected by both self-report and the registry records. Registry data were used, and if unavailable, self-report data were used as a supplement.

A modified version of the Leisure Score Index (LSI) from the Godin Leisure Time Exercise Questionnaire (GLTEQ) [18] was used to assess past exercise. The GLTEQ assesses average frequency and duration of exercise at three levels of intensity: mild (minimal effort, no perspiration), moderate (not exhausting, light perspiration), and strenuous (heart beats rapidly, sweating). We did not use the mild minutes for our calculations, but included the category in the questionnaire to ensure that participants did not report mild exercise minutes in the moderate intensity category [27]. We calculated average weekly exercise minutes in the past month separately for moderate and strenuous exercise as well as a combined score for moderate plus strenuous exercise. We then categorized participants as either (a) meeting public health exercise guidelines (≥ 60 minutes of strenuous or ≥ 150 minutes of moderate plus strenuous exercise per week), (b) not meeting public health exercise guidelines but accumulating some moderate-to-

strenuous exercise minutes or (c) not reporting any exercise in the past month [28]. This ordinal variable was used as our past exercise variable. An independent evaluation of the GLTEQ reported its reliability and validity to compare favourably to nine other self-report measures of exercise based on test-retest scores, an objective activity monitor (i.e., accelerometer), and fitness indices. The LSI showed a one-month test-retest reliability of .62 and concurrent validity coefficients of .32 with the accelerometer, .56 with VO_{2max} , and -.43 with % body fat [29].

The Theory of Planned Behaviour (TPB) constructs were assessed based on Ajzen's recommendations [17, 20]. At the beginning of the TPB scales, we provided the following definition of regular exercise as: "vigorous physical activity (e.g., sweating, heart beats fast) performed for at least 3 times per week for 20 minutes or more, or moderate physical activity performed at least 5 times per week for 30 minutes or more".

Intention was measured by two items on 7-point Likert scales ranging from 1 (strongly disagree) to 7 (strongly agree). The first item was "I intend to exercise for at least 30 minutes, 5 days per week at a moderate intensity" and the second item was "I intend to exercise for at least 20 minutes, 3 days per week at a vigorous intensity". Internal consistency (α) for these two items was .70. The intention variable was the mean of the two items.

Attitude was assessed by seven items measured on 7-point bipolar adjective scales. These items assessed both instrumental (harmful-beneficial, foolish-wise, useless-useful, good-bad) and affective (unenjoyable-enjoyable, boring-fun, unpleasant-pleasant) components of attitude [20]. Verbal descriptors were extremely (points 1 and 7), quite (points 2 and 6), and slightly (points 3 and 5). The stem that preceded the items was "For

me, exercising regularly over the next month would be”. Internal consistencies (α) for the instrumental and affective subscales were .92 and .89, respectively. We scored instrumental and affective attitude separately.

Subjective norm was determined using three items on a 7-point Likert scale ranging from 1 (strongly disagree) to 7 (strongly agree). The three items were “Most people who are important to me (1) think I should, (2) would encourage me to, and (3) would support me, exercising regularly over the next month”. Internal consistency (α) for this scale was .91.

Perceived behavioral control was assessed by four items on a 7-point Likert scale that tapped self-efficacy and controllability [20]. The three items that comprised self-efficacy were: “If you were really motivated, (1) exercising over the next month would be....” (1 = extremely hard to 7 = extremely easy), (2) “how confident are you that you could exercise regularly over the next month” (1 = not at all confident to 7 = extremely confident), and (3) “I could easily exercise regularly over the next month” (1 = strongly disagree to 7 = strongly agree). The item that comprised the controllability component was “If you were really motivated, how much control do you feel you would have over exercising regularly over the next month” (1 = very little control to 7 = complete control). Internal consistency (α) of the self-efficacy scale was .86. Self-efficacy and perceived control were scored separately.

Underlying beliefs were assessed using open ended questions. Participants were asked to list: (1) “...the main advantages of participating in regular exercise” (behavioural beliefs), (2) factors that “...make it difficult for you to exercise regularly”

(control beliefs), and (3) “...people or groups who would approve or disapprove of you exercising” (normative beliefs).

Analysis

Data were analyzed using SPSS 13 (SPSS Inc., Chicago, Ill). Descriptive statistics were calculated to determine the distribution of the variables. Pearson correlation coefficients were calculated to determine the bivariate associations between the TPB constructs.

A forced entry multiple regression procedure was used to test the primary hypothesis by determining which of the TPB constructs (i.e., affective attitude, instrumental attitude, subjective norm, perceived control, self-efficacy, past exercise) independently correlated with exercise intention.

Subsequent regression analyses were conducted in order to test for the potential moderating effects of several medical and demographic variables (i.e., age, BMI, months since diagnosis, disease stage, adjuvant treatment) on the associations among the TPB. For these analyses, age was divided into < 60 years ($n = 119$), 60 – 69 years ($n = 133$), and ≥ 70 years ($n = 102$) and BMI was divided into healthy weight (< 25; $n = 102$), overweight (25 - 29.9; $n = 113$), and obese (≥ 30 ; $n = 139$). Months since diagnosis was divided into < 60 months ($n = 221$), and ≥ 60 months ($n = 133$) based on the approximate median of the number of months since diagnosis as well as a commonly accepted cut-point for a “long term survivor” (i.e., five-year survivor) [30]. Disease stage was categorized as I ($n = 170$), II ($n = 60$), or III ($n = 33$). Treatment was categorized as having received any adjuvant treatment (i.e., chemotherapy, radiation therapy or hormone therapy; $n = 183$) versus no adjuvant treatment ($n = 164$). Interaction terms were created

by multiplying the potential moderator (e.g., age) by each of the TPB constructs (e.g., intention by age, instrumental attitude by age, etc.).

For the moderator analyses, hierarchical forced entry multiple regression procedures were again conducted using the procedures outlined by Baron and Kenny [31]. We regressed exercise intention on affective attitude, instrumental attitude, subjective norm, self-efficacy, perceived control and past behaviour followed by the particular moderator (e.g., age), and then the six interaction terms (e.g., age by affective attitude) [32]. We also repeated the analyses with each of the independent variables mean centered (i.e., the individual score subtracted from the group mean) to reduce any potential effects of multicollinearity [32] but did not find any meaningful differences. We present the results of the uncentered analyses.

Results

Flow of participants through the study has been presented elsewhere [26]. Of the 769 eligible endometrial cancer survivors to whom we mailed questionnaire packages, 386 returned the completed questionnaire (response rate = 50.2%). For the present analyses, we had 354 individuals provide evaluable data since 32 of the original participants were missing data on one or more of the TPB variables. We compared responders, non-responders, and non-approvals (by their physicians) in terms of medical and demographic variables and found that the only significant difference ($p < .001$) was that fewer non-approvals had received radiation therapy (24.6%) compared to responders (49.3%) and non-responders (48.7%).

Details of demographic and medical variables are reported elsewhere [26]. We found that 44% ($n = 156$) of participants did not exercise at all in the past month, 23% (n

= 80) did not meet public health exercise guidelines in the past month but accumulated some moderate-to-strenuous exercise minutes and 33% ($n = 118$) met public health exercise guidelines in the past month. The mean age of the sample was 64.5 years ($SD = 10.6$), 69% were married, 38% had completed university/college, and 63% were retired. The mean number of months since diagnosis was 52 ($SD = 32$), 54% had disease stage I², 18% had stage II, 9% had stage III, and 18% were ambiguous. For treatment, 99% had undergone surgery, 48% had received radiation therapy, 8% had received chemotherapy, and 7% had received hormone therapy. Mean BMI was 29 ($SD = 6.6$).

Descriptive statistics indicated that participants, on average, had neutral intentions to exercise regularly over the next month. Participants indicated quite positive instrumental attitudes and slightly positive affective attitudes. On average, participants moderately agreed that important others in their life would encourage and support their exercise efforts. They also believed exercising regularly would be slightly easy, and felt they had moderate control over exercise (Table 1).

Correlations among Theory of Planned Behaviour Constructs

Bivariate correlations among the TPB constructs were positive and significant (Table 1). Intention had the strongest correlation with self-efficacy ($r = .56, p < .001$), affective attitude ($r = .53, p < .001$) and past exercise ($r = .53, p < .001$).

Multivariate Tests of the Theory of Planned Behaviour

Results of the multiple regression procedures (Table 2) indicated that the TPB explained 44.5% of the variance in intention with self-efficacy ($\beta = .29, p < .001$),

² The true percentage is likely considerably higher since the 18% of participants who were listed as "ambiguous" for stage were most likely stage I. Data that contain ambiguous information are typically from reports that come from physicians outside of the cancer hospitals and thus concern early stage cases (i.e. stage I).

affective attitude ($\beta = .25, p < .001$) and past exercise ($\beta = .30, p < .001$) being the independent correlates.

Medical and Demographic Moderators of the TPB

We found significant moderating effects for age and BMI but not for months since diagnosis, stage, or treatment. For age we found a significant interaction with past behaviour ($p = .013$; Table 3). Subsequent separate regression analyses of the three age categories revealed that past exercise was independently associated with exercise intention in survivors under the age of 60 years ($\beta = .41, p < .001$) and between the ages of 60 and 70 ($\beta = .38, p < .001$) but not in the oldest age category ($\beta = .08, p = .450$).

We also found a significant interaction for BMI with instrumental attitude ($p = .001$) and self-efficacy ($p = .009$; Table 4). Follow up regression analyses for each of the three separate BMI categories indicated that instrumental attitude was independently associated with intention in healthy weight survivors ($\beta = .61, p < .001$), but not in overweight ($\beta = .04, p = .718$) or obese survivors ($\beta = -.06, p = .538$). Conversely, self-efficacy was independently associated with exercise intention in obese survivors ($\beta = .40, p = .001$), but not in healthy weight ($\beta = -.14, p = .415$) or overweight survivors ($\beta = .26, p = .076$).

Most Common Accessible Beliefs

The five most commonly reported beliefs for each belief category were as follows. Behavioural beliefs: (1) lose weight, (2) feel better about one's self, (3) keep in shape, (4) improve strength/tone muscles, and (5) improve cardiovascular health. Control beliefs: (1) poor health, (2) lack of time, (3) poor weather conditions, (4) injury, and (5)

fatigue/lack of energy. Normative beliefs: (1) doctor, (2) spouse, (3) family, (4) children, and (5) friends (Table 5).

Discussion

The present study examined the utility of the TPB as a theoretical framework for understanding exercise motivation in endometrial cancer survivors and explored potential demographic and medical moderators. We also documented the most common exercise beliefs.

Our results support the primary hypothesis that the TPB is a useful framework for understanding exercise motivation in endometrial cancer survivors. According to our analyses, the TPB accounted for 45% of the variance in exercise intention. These findings are comparable to a meta-analysis that found, in exercise studies of the general population, that the TPB accounted for 44.5% of the variance in intention [33]. In the literature on cancer survivors, the TPB has generally explained 23% to 49% of the variance in exercise intention [4-12].

An examination of the correlates of exercise motivation from the present study suggests endometrial cancer survivors show some similarities to other cancer survivor groups but also several important differences. Specifically, we found that affective attitude, self-efficacy and past exercise were the independent correlates of intention. These results are similar to other studies of non-clinical populations and cancer survivors that suggest attitude and PBC are the key correlates of intention [4, 5, 33]. Other research has also specifically indicated affective attitude to be a significant correlate of intention in cancer survivors [10]. The finding that subjective norm was not an independent correlate of intention in the present study, however, is different from other research [10]. This may

be because the majority of participants in the present study were overweight or obese and therefore may be accustomed to hearing advice from others to exercise more. For example, physicians are more likely to offer advice on exercising and weight loss to obese patients than to those who are non-obese [34]. These women may, as a result, not be very responsive to advice from others to exercise since they have heard it so much in the past.

From our secondary analyses, we also found that two medical and demographic variables moderated the associations of the TPB. Specifically, for survivors under the age of 70 years, past exercise was an independent correlate of exercise behaviour, but not for survivors over the age of 70 years. From these findings, it appears that endometrial cancer survivors under the age of 70 years are more likely to intend to exercise if they had exercised in the past month compared to those over the age of 70 years. This difference may be due to the number of co-morbidities in older compared to younger survivors which may make it more difficult to exercise (e.g., health problems, injuries, pain) on a regular basis.

We also found that for survivors that were healthy weight, instrumental attitude was the only independent correlate of exercise intention. For obese survivors, however, self-efficacy was the only independent correlate of exercise intentions. In other words, for healthy weight survivors, those who perceived that exercise was beneficial were most likely to intend to exercise, whereas for obese survivors, those who had confidence in their ability to exercise regularly were the most likely to intend to exercise. Self-confidence for exercise may be particularly important to obese survivors because of excess body weight and other health conditions that make exercising more difficult.

This study also documented the underlying beliefs that endometrial cancer survivors have about exercise. These findings are important since they: (a) can be used to design TPB questionnaires that include belief-based measures for endometrial cancer survivors and (b) provide an understanding of attitudes, subjective norms, and perceived behavioural control in this population that can be targeted in interventions. The finding that weight loss is the most commonly reported behavioural belief is consistent with the obesity rate in this population (72%), as well as previous research which suggests weight loss is a key motivator for exercise in women [35]. Additionally, the key behavioural beliefs appear to be primarily about physical health benefits. These findings are in line with previous research that has found health to be the most common motivator for physical activity [36].

The control beliefs reported in the present study are similar to those of other research with cancer survivors, which also cite lack of time, fatigue, and various health related problems as important barriers [37]. Poor health was, however, a novel control belief reported in the present study. This barrier may be paramount for this population because of the high obesity rate, and the greater rate of co-morbidities attached to obesity, such as diabetes, hypertension, cardiovascular disease, and other cancers [38]. Moreover, poor health has been found to be a major barrier to exercise adoption in older adults in general [39].

The present study has a number of strengths and limitations. The main strengths of this study include being the first study to examine exercise motivation in endometrial cancer survivors, testing a validated theoretical framework, using validated TPB and exercise measures, and obtaining a large and representative sample of endometrial cancer

survivors in the Alberta population. The main weaknesses of our study are the self-report measure of exercise and not having a prospective design so that we could also examine determinants of exercise.

Conclusions

The findings from this study have a number of practical implications that may be useful for guiding future interventions. Exercise intentions in endometrial cancer survivors may be optimally promoted by developing programs that are enjoyable and fun, but also by strategies to improve self-efficacy for exercise. Moreover, interventions aimed at healthy weight survivors would be most effective if they focused on the potential benefits of exercise. In obese survivors, the most effective interventions should target improving exercise self-efficacy. Future research will be able to determine the relative importance of the underlying beliefs that we identified in the present study and these should be the primary targets for interventions.

Table 2-1-1.

Descriptive Statistics and Correlations for the Theory of Planned Behaviour (N = 354).

Variable	2.	3.	4.	5.	6.	7.	<i>M</i>	<i>SD</i>
1. Past Exercise	.53*	.42*	.41*	.38*	.49*	.44*	0.89	0.87
2. Intention		.46*	.53*	.34*	.56*	.47*	4.14	1.86
3. Instrumental Attitude			.53*	.65*	.66*	.64*	6.17	1.02
4. Affective Attitude				.33*	.54*	.47*	5.25	1.29
5. Subjective Norm					.53*	.52*	5.95	1.17
6. Self-efficacy						.84*	5.40	1.42
7. Perceived Control							5.27	1.67

* $p < .001$

M = mean

SD = standard deviation

Table 2-1-2.

Hierarchical Forced Entry Multiple Regression Analysis of Exercise Intention on the Theory of Planned Behaviour.

	<i>F</i> _{change}	<i>df</i>	<i>R</i> ² _{change}	β^1	β^2
(Block #1)	43.1	5,348	.38		
Instrument Attitude				.06	.06
Affective Attitude				.30*	.25*
Subjective Norm				.02	-.03
Self-Efficacy				.36*	.29*
Perceived Control				-.02	-.04
(Block #2)	4.0	1,347	.06		
Past Exercise					.30*
Total Model	39.1	6,347	.45		

* $p < .05$

F = F ratio

df = degrees of freedom

*R*² = coefficient of determination

β^{1-2} = standardized regression coefficients for equations #1 and #2

Table 2-1-3.

Hierarchical Forced Entry Multiple Regression of Exercise Intention on the Theory of Planned Behaviour, Age, and Interactions with Age.

	F_{change}	df	R^2_{change}	β^1	β^2	β^3
(Block #1)	46.4	6,347	.45			
Instrumental Attitude				.06	.07	-.25
Affective Attitude				.25*	.23*	.22
Subjective Norm				-.03	-.02	.10
Self-efficacy				.29*	.29*	.10
Perceived Control				-.04	-.04	.18
Past Exercise				.30*	.30*	.60*
(Block #2)	2.0	1,346	.00		.06	-.16
Age						
(Block #3)	2.1	6,340	.04			
Age*Instrumental Attitude						.78
Age*Affective Attitude						-.02
Age*Subjective Norm						-.23
Age*Self-efficacy						.15
Age*Perceived Control						-.39
Age*Past Exercise						-.33 [†]
Total Model	23.0	13,340	.47			

* $p < .001$

[†] $p < .05$

F = F ratio

df = degrees of freedom

R^2 = coefficient of determination

β^{1-3} = standardized regression coefficients for equations #1 to #3

Table 2-1-4.

Hierarchical Forced Entry Multiple Regression of Exercise Intention on the Theory of Planned Behaviour, BMI, and Interactions with BMI .

	F_{change}	df	R^2_{change}	β^1	β^2	β^3
(Block #1)	46.4	6,347	.45			
Instrumental Attitude				.06	.05	.75*
Affective Attitude				.25*	.26*	.03
Subjective Norm				-.03	-.05	-.10
Self-efficacy				.29*	.30*	-.30
Perceived Control				-.04	-.04	.08
Past Exercise				.30*	.31*	.22
(Block #2)	2.7	1,346	.00		.07	.40
BMI						
(Block #3)	3.2	6,340	.03			
BMI*Instrumental Attitude						-1.60 [†]
BMI*Affective Attitude						.32
BMI*Subjective Norm						.12
BMI*Self-efficacy						.90 [†]
BMI*Perceived Control						-.11
BMI*Past Exercise						.08
Total Model	24.0	13,340	.48			

* $p < .001$

[†] $p < .01$

F = F ratio

df = degrees of freedom

R^2 = coefficient of determination

β^{1-3} = standardized regression coefficients for equations #1 to #3

Table 2-1-5.

Most Common Behavioural, Control, and Normative Beliefs of Endometrial Cancer Survivors Concerning Regular Exercise (N = 354).

	n	% survivors*	% respondents†
Most Common Behavioural Beliefs (Advantages)			
Lose weight	127	35.9	45.8
Feel better about self	99	28.0	35.7
Keep in shape	92	26.0	33.2
Improves strength/tones muscles	62	17.5	22.4
Improve cardiovascular health	51	14.4	18.4
Improves mental health	41	11.6	14.8
Improves flexibility	17	4.8	6.1
Improves breathing	16	4.5	5.8
Aids in recovery from injuries	10	2.8	3.6
Most Common Control Beliefs (Barriers)			
Poor health	56	15.8	25.9
Lack of time	52	14.7	24.1
Poor weather conditions	47	13.3	21.8
Injury	39	11.0	18.1
Fatigue/lack of energy	24	6.8	11.1
Lack of access to facilities	23	6.5	10.6
Lack of motivation	17	4.8	7.9
Frequent disruptions to schedule	12	3.4	5.6
Family demands	11	3.1	5.1
Most Common Normative Beliefs (Approve)			
Doctor	152	42.9	52.1
Spouse	132	37.3	45.2
Family	111	31.4	38.0
Children	110	31.1	37.7
Friends	79	22.3	27.1
Everyone	44	12.4	15.1

* Percentage of responses from all participants (N=354).

† Percentage of responses from participants who answered the question.

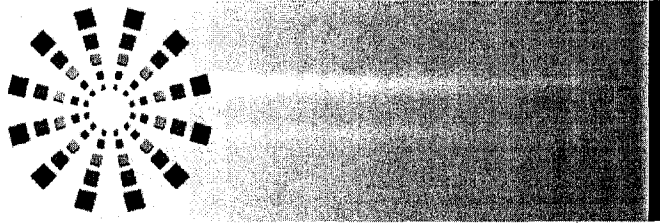
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Paper 2:
**Exercise Preferences of Endometrial Cancer Survivors:
A Population-Based Study**



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Exercise Preferences of Endometrial Cancer Survivors

A Population-Based Study

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Preferences
Survivors

Exercise has gained recognition as an effective supportive care intervention for cancer survivors, yet participation rates are low. Knowledge of the specific exercise counseling and programming preferences of cancer survivors may be useful for designing effective interventions. In this study, we examined the exercise preferences of 386 endometrial cancer survivors. Participants completed a questionnaire that included measures of past exercise behavior, exercise preferences, and medical and demographic information. Some key findings were as follows: (a) 76.9% of participants said they were interested or might be interested in doing an exercise program and (b) 81.7% felt they were able or likely able to actually do an exercise program. Participants also indicated that walking was their preferred activity (68.6%) and moderate exercise was their preferred intensity (61.1%). Logistic regression analyses showed that meeting public health guidelines for exercise, being overweight or obese, receiving adjuvant treatment, months since diagnosis, income, marital status, and level of education all influenced exercise preferences. These results suggest that endometrial cancer survivors have unique exercise preferences that are moderated by a number of demographic and medical variables. These findings may have implications for the design and implementation of clinical and population-based exercise interventions for endometrial cancer survivors.

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Physical exercise has received considerable attention in recent years as a means of alleviating some of the physical, psychological, functional, and emotional quality of life issues that present in cancer survivors.¹⁻⁴ To date, the positive effects of exercise on these parameters have been demonstrated in a number of different cancer survivor populations including breast, prostate, colorectal, multiple myeloma, and non-Hodgkin lymphoma.^{2,4} Although support for the potential benefits of exercise is increasing, relatively few cancer survivors exercise regularly, with exercise rates dropping drastically during treatment, and remaining low even posttreatment.⁵⁻¹⁰

Because of the potential benefits of exercise and the low exercise participation rates, researchers are beginning to explore methods for promoting exercise in cancer survivors.¹¹⁻¹⁴ Although a number of studies have successfully explored social cognitive correlates of exercise motivation, relatively little is known about the exercise programming and counseling preferences of cancer survivors—factors that would also presumably influence exercise participation. Only 4 studies to date have examined exercise preferences in cancer survivors, and all have been restricted to survivors of only a few tumor types.¹⁵⁻¹⁸

We recently conducted a population-based survey of endometrial cancer survivors to obtain a better understanding of the exercise behavior, motivation, and quality of life issues in this relatively understudied cancer survivor population. We have previously reported that endometrial cancer survivors meeting public health guidelines for exercise and body weight reported significantly and meaningfully higher quality of life than those not meeting guidelines.⁵ We also reported that only 30% of the sample were meeting public health exercise guidelines and 72% were overweight or obese. These findings highlight the importance of exploring exercise programming and counseling preferences for this population to guide behavior change interventions.

The primary purpose of the present study was to report the exercise programming and counseling preferences of a population-based sample of endometrial cancer survivors. A secondary purpose was to explore any moderating effects of demographic and medical variables on exercise preferences. Based on previous research involving exercise preferences in cancer survivors,¹⁵⁻¹⁸ we expected that endometrial cancer survivors would indicate a strong interest in an exercise program, as well as indicate a number of unique preferences for type, location, and structure of exercise counseling and programming.

■ Patients and Methods

A detailed description of study methods has been reported elsewhere.⁵ The study was approved by the Alberta Cancer Board Research Ethics Board and the University of Alberta Health Research Ethics Board. The Alberta Cancer Registry provided information on all endometrial cancer survivors diagnosed between November 1994 and June 2003 in

Alberta, Canada. Data collection was conducted between March 2004 and May 2004. Endometrial cancer survivors were deemed eligible for the study if they (a) were 18 years or older, (b) were able to provide written consent in English, (c) had family physician or primary oncologist approval to contact (as required by our ethics boards), and (d) have had a confirmed diagnosis of endometrial cancer.

Participants

Eligible participants were mailed a questionnaire package consisting of a cover letter, 2 copies of the consent form, the questionnaire, and a postage paid business reply envelope. Participants were asked to complete and return the questionnaire and 1 copy of the consent form. A modified version of the Total Design Method¹⁹ was used for the mail protocol. This included (a) an initial mailout of the questionnaire package, (b) a mailout of the postcard reminder 2 weeks later, and (c) a second mailout 4 weeks later of the questionnaire package to those who had not yet responded. Methods of improving survey participation were used, such as postage paid envelopes, personalized cover letters, colored paper questionnaires, confidentiality assurance, and institution sponsorship.

Measures

Demographic and medical information was collected from the Alberta Cancer Registry and from the questionnaire. The registry data were used first for medical information and supplemented with self-report data in cases of missing information. Demographic information was gathered exclusively by self-report.

Exercise behavior was assessed using a modified version of the Leisure Score Index from the Godin Leisure Time Exercise Questionnaire.^{20,21} The Godin Leisure Time Exercise Questionnaire was developed to measure average weekly frequency and duration of mild (minimal effort and no perspiration), moderate (not exhausting and light perspiration), and strenuous (heart beats rapidly and sweating) exercise in the past month. We classified participants as *meeting* (accumulating an average of either 60 minutes of strenuous activity, or 150 minutes of moderate plus strenuous activity per week) or *not meeting* public health guidelines for exercise as recommended by the Centers for Disease Control and Prevention and the American College of Sports Medicine.¹¹ The Leisure Score Index has been found to be a valid and reliable instrument.²²

Exercise preferences were assessed using questions derived from previous studies on exercise preferences.^{15,16,23} Three closed-ended items tapped exercise counseling preferences, whereas 10 closed-ended items asked about exercise programming preferences. Three items were open-ended and asked participants to list exercises they were most interested in doing as well as favorite exercises during the summer and winter. Two items asked about any personal exercise equipment and current fitness center memberships. Details of these items are listed in Tables 2 and 3.

Statistical Analysis

Statistical analyses were conducted using SPSS 13.0 (SPSS Inc, Chicago, Ill). Demographic and medical variables were dichotomized by making cut-points, such as "under 65 years" and "over 65 years" for age, "less than \$60,000 annual family income" and "\$60,000 and more of annual family income" for income level, and "high school or less education" and "post secondary school education" for education level. Frequencies and percentages of each response option were calculated for each variable. Details of the cut-points for the demographic, medical, and exercise variables are displayed in Table 1.

Descriptive statistics were used to calculate frequencies and percentages of responses for each of the exercise preference items. We also calculated frequencies and percentages for dichotomized exercise preference items. For our logistical regression analyses, multiple response options were combined to create a dichotomy. In cases where the response options were "yes," "no," and "maybe," "yes" and "maybe" were combined. The 5 options for starting exercise counseling or programming were split into "before/during treatment" and "posttreatment." Modality of counseling was dichotomized as "face-to-face" and "other." Response options for the preference of exercise partners were split into "alone" and "with others." Preferred location of exercise was grouped into "at home" or "not at home." Preference of intensity was

dichotomized as "light" and "moderate-to-vigorous." Responses for "no preferences" were not coded for our logistic regression analyses.

To test for potential moderating effects of demographic and medical variables, a series of logistic regression equations were conducted. Specifically, we tested the moderating effects of (a) past month exercise participation (ie, meeting public health guidelines for exercise or not), (b) body mass index (normal weight vs over weight/obese), (c) receiving adjuvant therapy or not, (d) age (under 65 years vs 65 years and older), (e) months since diagnosis (under 60 months vs 60 months or older), (f) income (less than \$60,000 per year vs \$60,000 per year or more), (g) employment status (employed full or part time vs not employed), and (h) level of education (completed high school or less vs completed post secondary school). In these analyses, we used the dichotomized exercise preference items.

Results

Flow of participants through the study is reported elsewhere.⁵ In brief, a total of 769 endometrial cancer survivors were approved for contact by their family physicians or oncologists. Of these survivors, 386 returned the completed questionnaire, making the response rate 50.2%. Details of demographic and medical variables are reported elsewhere.⁵ In brief, the mean age of the sample was 64.5 years (SD = 10.6), 69% were married, 38% had completed university/college, and 63% were retired. The mean number of months since diagnosis was 52 (SD = 32), 72% had disease stage I or II (although we suspect this percentage is actually higher due to missing data), almost all had undergone surgery, and 54% had received some form of adjuvant therapy. Table 1 displays frequencies and percentages of demographic, medical, and exercise variables in terms of the cut-points we created for the moderator analyses. Table 2 displays details of the exercise counseling preferences of participants.

Participants most commonly reported an exercise specialist at a cancer center as their preferred source of exercise counseling (40.9%), a cancer center as the preferred location for counseling (41.0%), and face-to-face counseling as their preferred mode of counseling (82.8%).

Details of exercise programming preferences of participants are displayed in Table 3. Nearly 80% of survivors indicated that they were interested or might be interested in an exercise program, and 82% felt they were able or might be able to participate. From the possible response choices, the most commonly indicated preference was to begin an exercise program either immediately after treatment (27%) or 3 to 6 months after treatment (40%). Participants were equally distributed in their wishes to exercise alone (23.8%), with friends (22.6%), or had no preference (32.7%). The most commonly indicated preference for location of exercise was at home (32.7%), at a community fitness center (24.3%), or no preference (32.7%). More than half of the participants indicated that they preferred to exercise in the morning.

Table 1* Descriptive Statistics for Medical, Demographic, and Exercise Variables

Variable	Frequency	Percent
Meeting ACSM guidelines (n = 386)		
Yes	118	30.6
No	268	69.4
Body mass index (n = 386)		
Normal weight	108	28.0
Overweight	278	72.0
Adjuvant treatment (n = 378)		
Yes	174	46.0
No	204	54.0
Age (n = 386)		
Under 65 years	200	51.8
65 years and older	186	48.2
Months since diagnosis (n = 386)		
Under 60 months	146	37.8
60 months and older	240	62.2
Income (n = 306)		
Less than \$60,000/y	231	75.5
\$60,000/y or more	75	24.5
Employment (n = 368)		
Not currently employed	258	70.1
Currently employed	110	29.9
Education (n = 370)		
Completed high school or less	176	47.6
Completed post secondary school	194	52.4

ACSM indicates American College of Sports Medicine.

*Numbers may not equal 386 due to missing data.

Table 2* Descriptive Statistics for Exercise Counseling Preferences of Study Participants*

Preference Variable	n	%
Who would you have preferred exercise counseling from?	347	
Oncologist		18.7
Nurse		12.7
Cancer patient/survivor		10.4
Exercise specialist from community		17.3
Exercise specialist from cancer center		40.9
Where would you have preferred counseling to take place?	346	
Cancer center		41.0
Community center		22.0
My home		28.6
Other		8.4
How would you have preferred to be counseled?	348	
Face to face		82.8
Telephone		3.4
Brochure		11.8
Other		2.0

*Numbers may not equal 386 due to missing data.

More than half of the survivors also indicated that they had at least 1 piece of exercise equipment at home (57.0%). The most commonly reported home exercise equipment was a stationary bike (31.1%) or a treadmill (26.4%). Nearly 80% of participants did not have a current membership at a fitness center.

Results of the logistic regression analyses indicated that meeting public health exercise guidelines in the past month was associated with preferring other modalities of counseling other than face-to-face [odds ratio (OR) = 4.89, 95% confidence interval (CI) = 1.77–13.52, $P < .01$], starting an exercise program posttreatment (OR = 2.69, 95% CI = 1.38–5.25, $P < .01$), exercising at home (OR = 2.17, 95% CI = 1.06–4.46, $P < .05$), doing moderate-to-vigorous intensity activities (OR = 8.01, 95% CI = 3.24–19.79, $P < .001$), and having a current fitness center membership (OR = 3.31, 95% CI = 1.75–6.26, $P < .001$). Being overweight or obese was positively associated with preferring exercise counseling that was face-to-face (OR = 3.43, 95% CI = 1.54–7.63, $P < .01$) and starting an exercise program before or during treatment (OR = 2.41, 95% CI = 1.21–4.80, $P < .05$). Participants who received adjuvant treatment were also more likely to prefer to start an exercise program before or during treatment (OR = 2.83, 95% CI = 1.45–5.53, $P < .01$). Survivors less than 60 months since diagnosis were more likely to have a current fitness center membership than those 60 months or older postdiagnosis (OR = 2.64, 95% CI = 1.36–5.13, $P < .01$). Participants with higher income were more likely to prefer counseling other than face-to-face (OR = 10.96, 95% CI = 2.33–51.57, $P < .01$), be interested in an exercise program for endometrial cancer survivors (OR =

2.28, 95% CI = 1.09–4.81, $P < .05$), and prefer spontaneous/flexible exercise sessions (OR = 2.35, 95% CI = 1.16–4.79, $P < .05$). Participants who were married or common law were more likely to prefer face-to-face counseling (OR = 3.39, 95% CI = 1.37–8.36, $P < .01$). Those with a high school education or less were more likely to prefer exercising away from home (OR = 2.20, 95% CI = 1.13–4.26, $P < .05$) than those with higher education. Age and employment status did not influence exercise preferences in this sample. Medical and demographic variables did not influence any of the other exercise preferences.

Discussion

This study explored the exercise programming and counseling preferences of a population-based sample of endometrial cancer survivors. A secondary purpose was to examine the influence of a number of demographic and medical variables on exercise preferences. Results indicated that most participants were interested in an exercise program designed for endometrial cancer survivors (76.9%). Most participants also indicated that they felt they would be able (yes/maybe) to participate in an exercise program designed for endometrial cancer survivors (81.7%). These findings are slightly lower, but similar, to those of other studies that also indicated that participants expressed an interest in exercise programming at some point after their cancer diagnosis.^{15–18} These findings support the desire for the availability of exercise programming services for endometrial cancer survivors.

Participants also most frequently, from the choices available, indicated a preference for exercise counseling from an exercise specialist affiliated with a cancer center (40.9%), preferred the location to be a cancer center (41.0%), and preferred to have face-to-face counseling (82.8%). These findings are partially in line with those of Jones and Courneya,¹⁶ who found that 77% of their study participants indicated a preference for exercise counseling from an exercise specialist at a cancer center and that 85% wished to have face-to-face delivery of that counseling. The lower percentage of participants reporting a preference for cancer center-affiliated counseling in the present study may be because of differences in the time elapsed since diagnosis; participants were within 1.5 years of their diagnosis date in the Jones and Courneya¹⁶ study, whereas in the present study, participants were up to 10 years postdiagnosis. Presumably, those closer to their diagnosis date would feel more of a connection with their cancer center than those many years past their diagnosis date.

The preference for face-to-face counseling is consistent with Jones and Courneya,¹⁶ highlighting the importance of this counseling modality for cancer survivors. The study of Demark-Wahnefried et al,¹⁵ however, reported mailed literature as the most commonly reported preference for counseling modality. It does not appear, however, that participants were given the option to choose face-to-face counseling in that study. Interestingly, our logistic regression analyses indicated many significant moderators of this

Table 3 • Descriptive Statistics for Exercise Programming Preferences of Study Participants*

Preference Variable	n	%
Would you be interested in an exercise program?	359	
Yes		41.5
No		23.1
Maybe		35.4
Able to participate in an exercise program?	360	
Yes		46.4
No		18.3
Maybe		35.3
Types of exercise most interested in	290	
Walking		68.6
Weight training		26.9
Swimming		16.2
Aerobics		14.8
Yoga		13.4
When would you have preferred to start an exercise program?	298	
Before treatment		18.1
During treatment		6.0
Immediately after treatment		26.8
3-6 months after treatment		39.3
At least 1 year after treatment		9.7
Who would you prefer to exercise with?	349	
Alone		23.8
With other cancer survivors		11.7
With friends		22.6
With family		9.2
No preference		32.7
Where would you prefer to exercise?	342	
At home		32.7
At a community fitness center		24.3
At a cancer fitness center		10.2
No preference		32.7
What time of day would you prefer to exercise?	349	
Morning		51.3
Afternoon		12.3
Evening		12.9
No preference		23.2
What is your favorite exercise in the summer?	347	
Walking		76.9
Gardening		23.6
Swimming		14.7
Golf		13.8
Bicycling		12.7
What is your favorite exercise in the winter?	308	
Walking		68.5
Weight training		9.7
Skiing		9.1
Swimming		8.1
Stationary bike		7.5
What intensity would you prefer to exercise at?	350	
Light intensity		26.3
Moderate intensity		61.1
Vigorous intensity		7.7
No preference		4.9

Table 3 • continued

Preference Variable	n	%
Same or different activities for each exercise session?	320	
Same activity each exercise session		40.9
Different activity each exercise session		59.1
Supervised or not supervised exercise sessions?	335	
Supervised		53.1
Unsupervised		46.9
Spontaneous/flexible or scheduled exercise sessions?	321	
Spontaneous/flexible		35.5
Scheduled		64.5
Do you have any of the following exercise equipment at home?	386	
Treadmill		26.4
Stationary bike		31.1
Stair stepper		7.3
Rowing machine		4.9
Skiing machine		3.9
Abdominal machine		4.7
Other		11.9
Do you have a current membership at any fitness center?	370	
No		79.7
Yes		20.3

*Numbers may not equal 386 due to missing data.

preference. Participants who preferred face-to-face counseling were most likely not currently meeting public health guidelines for exercise, were overweight or obese, were making less than \$60,000 per year, and were married. This may be the case because perhaps participants who are not regular exercisers, or who have the additional obstacle of being overweight/obese, may feel the need for more direct support and encouragement that comes from face-to-face counseling. In addition, having lower income may be associated with a preference for face-to-face counseling because they may have less resources available to them, and consequently, may be eager to have a face-to-face counseling service available to them that they otherwise may not be able to afford.

Most participants indicated that they would have preferred to start an exercise program posttreatment (75.8%). Specifically, most participants indicated they would have preferred to start an exercise program immediately after treatment (26.8%) or 3 to 6 months after treatment (39.3%). These results are similar to those of Vallance et al,¹⁸ who found that more than half of the participants wished to start an exercise program at least 3 months posttreatment, and Jones and Courneya,¹⁶ who found that 51% of participants preferred to start an exercise program after treatment.

Participants not currently meeting public health exercise guidelines, who were overweight or obese, and having received adjuvant treatment were more likely to have preferred to start an exercise program before or during treatment. This may be because those survivors who were currently not exercising may have a long history of being

sedentary, and therefore, may have been more in need of an exercise program compared with those who were already exercising. Obese and overweight participants may also be interested in initiating an exercise program early during the cancer experience as they may feel, because of the potential benefits of weight loss, that they should also begin exercising as soon as possible. Those individuals who received adjuvant treatment may have felt that exercise may have eased some of the treatment-related side effects, and therefore, they indicated the preference for the initiation of an exercise program early in the cancer experience.

Most participants reported that they had no preference for exercise partners (23.8%), or that they preferred to exercise alone (23.8%) or with friends (22.6%). At home (32.7%) and no preference (32.7%) were the most commonly listed places for preference for exercise. These results are somewhat similar to those of Jones and Courneya¹⁶ and Vallance et al,¹⁸ who found that the most common preference for exercise partners was alone (43.6%, 30.8%) or no preference (18.9%, 34.0%), and that home (39.8%, 42.6%) was the most commonly listed preference for place of exercise. The greater preference for "alone" and "at home" in the Jones and Courneya¹⁶ and Vallance et al¹⁸ studies may be because nearly half of the 2 samples were men, and men may have very different preferences for exercise partners and location than women due to various social factors. These findings are, nonetheless, in line with past research on older adults who have been found to prefer to exercise at home and alone.²⁴⁻²⁶

Moderate-intensity exercise was found to be the preference for exercise intensity in this population (61.1%). This figure is comparable to that of Jones and Courneya¹⁶ and Vallance et al,¹⁸ who found that 56% and 62%, respectively, of their samples preferred moderate-intensity exercise. These findings suggest that exercise interventions for endometrial cancer survivors should be directed towards moderate-intensity activities. Not surprisingly, in the present study, participants who reported meeting the public health guidelines for exercise were more likely to prefer moderate-to-vigorous exercise compared with those individuals who were not exercising regularly. This suggests that nonexercisers would likely prefer lower-intensity exercise, at least to begin.

Nearly 60% of participants indicated they preferred different activities at each exercise session, whereas the other 40% preferred activities to be the same. A fairly even number of participants preferred supervised (53.1%) to unsupervised (46.9%) exercise, and most participants indicated they wanted scheduled exercise sessions (64.5%) compared with spontaneous/flexible sessions (35.5%). Jones and Courneya¹⁶ and Vallance et al¹⁸ reported similar findings, with an almost even number of participants preferring each of the 2 options for each item. The implications of these findings are that exercise interventions aimed at endometrial cancer survivors should be flexible enough that participants can make choices about the degree of supervision they desire, the kinds of activities they do, and whether or not the sessions are scheduled.

Walking was found to be the type of exercise participants were most interested in during the summer (76.9%) and

winter (68.5%). These findings were similar to that of Jones and Courneya,¹⁶ who found that 80.6% of participants preferred walking to other types of exercise; however, a lower percentage indicated this preference in the present study. Rogers et al¹⁷ and Vallance et al¹⁸ also found that walking was the preferred activity of breast cancer survivors and non-Hodgkin lymphoma survivors. The findings of the present study are also consistent with literature on older adults in the general population that has found that preference for walking as a form of exercise increases with age.^{24,27}

More than half of the participants reported having at least 1 piece of exercise equipment at home. The most common equipment reported was a stationary bike (31.1%) and a treadmill (26.4%). Only 20.3% of participants reported having a current membership at a fitness center. These findings suggest that many endometrial cancer survivors could potentially exercise at home given the large percentage that own home exercise equipment and indicate that exercise interventions for this population should at least contain a home-based option.

Our study has a number of strengths and limitations that should be noted. Firstly, this study is the first to examine exercise preferences in endometrial cancer survivors and one of the few to examine exercise preferences in cancer survivors in general. In addition, the sample size was sufficiently large to examine the moderating effects of various demographic and medical variables. Limitations include the potential overrepresentation of proponents of exercise in this sample; presumably, those survivors who were the most interested in exercise were the most likely to respond to the survey.

Practical Implications for Nursing

The results of this study have a number of practical implications for nursing. These findings suggest that endometrial cancer survivors are interested in having an exercise program available to them. Specifically, endometrial cancer survivors may prefer face-to-face exercise counseling that is conducted at a cancer center by an exercise specialist associated with the cancer center. Exercise programming may be best received if initiated posttreatment, is moderate in intensity, and contains a walking component. Sufficient variation was found within this sample in terms of many of the preferences to warrant caution when making generalizations and to consider the unique preferences of individual endometrial cancer survivors.

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CHAPTER 3:

Bladder Cancer and Exercise Study

Paper 3:

**Associations among Exercise and Quality of Life in Bladder Cancer Survivors:
A Population Based Study**

Introduction

Over 61,000 new cases of bladder cancer are expected in the United States in 2006, making it the sixth most common cancer (1). The five, 10, and 15-year survival rates are 82%, 76%, and 70.3%, respectively, indicating that most bladder cancer survivors can expect to live for many years after their diagnosis and treatments (2). About 500,000 Americans are currently bladder cancer survivors (3).

Bladder cancer survivors undergo various treatments that improve survival. Surgery is the most common treatment for bladder cancer (4). For superficial tumours, adjuvant therapy commonly involves the insertion of cytotoxic agents directly into the bladder (5). For metastatic and locally advanced disease, systemic chemotherapy is frequently used as an adjuvant treatment. Radiation therapy is less commonly used alone as a treatment in North America (6).

Bladder cancer survivors experience a number of side-effects that may affect quality of life (QoL) (7). Urinary dysfunction and sexual difficulties are the primary side effects from treatment and may have acute and long-lasting effects (8). As a result, poor physical and emotional functioning, body image disturbance and mood state disturbances are common QoL issues faced by bladder cancer survivors (7).

Recent reviews (9, 10) have indicated that exercise improves a variety of quality of life outcomes in various cancer survivor groups both during and after adjuvant therapies including aerobic fitness, muscular strength, fatigue, depression, anxiety, self-esteem, body image, functional ability, and overall QoL. These findings have been based on the results of randomized controlled trials of primarily breast and prostate cancers (11, 12) and observational studies in other cancer groups such as endometrial (13), non-

Hodgkins lymphoma (NHL) (14), and multiple myeloma (15). No studies to date have examined exercise and QoL in bladder cancer survivors. Bladder cancer survivors experience a number of unique QoL issues such as urinary complications (8) and sexual dysfunction (7) that may be less amenable to an exercise intervention and may also make it more difficult to exercise.

The primary purpose of the present study was to examine the association between exercise and QoL in bladder cancer survivors and, in the process, document the prevalence rate of exercise in this population. The secondary purpose was to explore the moderating effects of several demographic/medical variables on these potential associations. We hypothesized that exercise prevalence rates would be lower in bladder cancer survivors than in the general population or in other cancer survivor groups. We also hypothesized that exercise would be positively associated with QoL, particularly the physical and functional domains.

Methods

Protocol and Research Participants

The Alberta Cancer Board and the University of Alberta provided ethical approval for this study. Participants were eligible if they were: (a) at least 18 years old, (b) provided written informed consent in English, (c) approved for contact by their primary oncologist or family physician (as required by our ethics boards), and (d) diagnosed with bladder cancer within the past 15 years. Contact information was obtained from the Alberta Cancer Registry for all bladder cancer survivors diagnosed between January, 1989 and December, 2003 residing in Alberta, Canada. After the names were obtained, we sought approval from oncologists/physicians to contact the survivors. Survivors who

were approved for contact were mailed a questionnaire package consisting of a cover letter, two copies of the consent form, a questionnaire, and a postage paid return envelope. Survivors were asked in the cover letter to mail back the completed questionnaire and one copy of the consent form. Those survivors who chose to participate in the study were mailed a follow-up questionnaire three months later for the purposes of collecting prospective data on the determinants of exercise (data not reported here). For the mail protocol, a modified version of the Total Design Method (16) was used. This method consists of mailing: (a) the initial questionnaire package, (b) a post card reminder 2 weeks later to those who did not respond, and (c) a second questionnaire package 4 weeks later to those who had still not responded. In order to enhance the response rate, we also utilized coloured paper questionnaires, personalized cover letter and signatures from the investigators, provision of postage paid business reply envelopes, assurances of confidentiality, and institution sponsorship (17).

Measures

Demographic and Medical Information

Demographic and medical information were collected from the registry and by self-administered questionnaire. Specifically, marital status, annual income, employment status, education level, ethnicity, height, weight, presence of an ostomy appliance, cystectomy, recurrence and current cancer status were collected exclusively by self-report. Age, sex, time since diagnosis, tumour grade, degree of invasion (i.e., superficial or invasive), and treatment(s) received were collected from both the registry and self-report. For the medical variables, we first used information from the registry and supplemented it with self-report in the case of missing data.

Exercise Behaviour

A modified version of the Leisure Score Index (LSI) from the Godin Leisure Time Exercise Questionnaire (GLTEQ) (18) was used to assess exercise behaviour. Participants were asked to recall average frequency and duration of mild (minimal effort, no perspiration), moderate (not exhausting, light perspiration), and strenuous (heart beats rapidly, sweating) exercise behaviour for three separate time periods: (a) in the months before diagnosis, (b) during adjuvant therapy (if applicable), and (c) in the past month. We calculated weekly exercise minutes for mild, moderate, and strenuous activities plus combined scores for moderate plus strenuous exercise minutes. Participants were categorized as meeting or not meeting public health exercise guidelines (≥ 60 minutes of strenuous exercise per week or 150 minutes of moderate plus strenuous exercise per week) as recommended by the American College of Sports Medicine and the Centers for Disease Control (19). The LSI has been found to be valid and reliable in comparison to nine other self-report measures of exercise (20). The LSI has a one-month test-retest reliability of .62 and concurrent validity coefficients of .32 with an accelerometer and .56 with maximal oxygen consumption.

Quality of Life

Quality of life was assessed by the Functional Assessment of Cancer Therapy-Bladder (FACT-BI) scale (21). The FACT-BI consists of five subscales: physical well-being (PWB; 7 items), functional well-being (FWB; 7 items), emotional well-being (EWB; 6 items), social well-being (SWB; 7 items), and an additional concerns scale specific to bladder cancer (13 items). The additional concerns scale assesses urinary functioning (3 items), bowel functioning (2 items), sexual functioning (2 items), body

image (1 item), weight loss/appetite (2 items), and issues concerning an ostomy appliance (2 items). The PWB, FWB, EWB, and SWB subscales can be summed to form the FACT-General (FACT-G) score. The PWB, FWB, and additional concerns subscale can be summed to form the Trial Outcome Index (TOI). A 5-point Likert scale ranging from 0 (“not at all”) to 4 (“very much”) was used to rate all FACT items. Higher scores indicate higher QoL. The FACT-G has been found to have acceptable internal consistency, test-retest reliability, convergent and discriminant validity and to be easy to administer and brief (22).

Fatigue

Fatigue was assessed using the Fatigue Symptom Inventory (FSI) (23). The FSI is a 13-item scale designed to capture multidimensional aspects of fatigue in cancer survivors. The FSI consists of four ratings of intensity of fatigue over the past week (most fatigue, least fatigue, average fatigue, current fatigue), two ratings of duration of fatigue in the past week (number of days fatigued, time spent per day fatigued), and a fatigue interference subscale (7 items). The FSI has been found to be reliable and valid in a sample of women with breast cancer (23) and in a sample of men and women with mixed cancers (24).

Statistical Analyses

Changes in exercise behaviour across the three cancer-related time periods were analyzed by repeated measures ANOVAs followed by dependent t-tests.

Differences in QoL between bladder cancer survivors meeting and not meeting public health exercise guidelines in the past month were analyzed using analysis of variance (ANOVA). Our analytical strategy was to first test for differences in the largest

aggregate scale (i.e., FACT-BI) and, if significant, continue with tests of the smaller aggregate scales (i.e., FACT-G and the TOI) followed by the subscales (i.e., PWB, FWB, SWB, EWB, and additional concerns). We also had an interest in several aspects of the additional concerns subscale that were analyzed separately (i.e., urinary functioning, bowel functioning, sexual functioning, and body image). For fatigue, we used similar analyses for each of the 7 fatigue parameters (i.e., most, least, average, current, interference, days spent fatigued, and time fatigued). We repeated these analyses using analysis of covariance (ANCOVA) to control for demographic and medical variables that had statistically significant associations with the FACT-BI in our data set.

We tested several demographic/medical variables that may be potential moderators of the associations between exercise and QoL/fatigue. For these analyses, we conducted 2 X 2 ANOVAs with demographic and medical variables that have been found to be associated with exercise (25-27), namely age (< 65 years versus \geq 65 years), sex, BMI (non-obese versus obese), presence of an ostomy appliance, degree of invasiveness (superficial versus invasive), adjuvant therapy (yes versus no), and current cancer status as potential moderators. We used a strategy similar to the main effects analysis by first testing the FACT-BI as the dependent measure, followed by the FACT-G and the TOI, and finally the subscales. For fatigue, all 7 fatigue dimensions were tested. These analyses were repeated using ANCOVA using the same covariates as the main effects analyses.

Results

We contacted 605 oncologists/physicians asking permission to contact the 1999 bladder cancer survivors under their care. A total of 513 oncologists/physicians

responded (84.8%) and approved 1287 (64.4%) survivors for contact. The two main reasons for non-approval were failure of the oncologist/physician to respond after multiple attempts ($n = 348$) and the patient was no longer under the care of that oncologist/physician ($n = 133$). We mailed questionnaires to 1287 survivors and received 525 completed questionnaires, 457 non-responses, 200 unopened questionnaires (return to sender), and 105 contacts (by phone or returned survey) indicating the person would not be participating. Of the 105 contacts to decline, 32 were not interested, 30 were too sick or disabled, 14 said they had never had bladder cancer, 13 provided no reason, 11 were deceased, 3 did not speak English, and 2 had moved. Based on the subtraction of the 200 returned surveys and the 60 that were ineligible or could not respond, we calculated the response rate to be 51% (525/1027). We compared responders ($n = 525$), non-responders ($n = 762$), and non-approvals ($n = 712$) on age, sex, months since diagnosis, grade, and degree of invasiveness. The only differences we found were: (a) responders were younger (mean = 70.2 years) than non-approvals (mean = 72.6 years; $p = .001$) and (b) responders were closer to their diagnosis date (mean = 72.3 months) than non-responders (mean = 80.6 months; $p = .004$) and non-approvals (mean = 90.0 months; $p < .001$). Demographic and medical variables of the participants are displayed in Tables 1 and 2.

Exercise Behaviour Across the Three Cancer-Related Time Periods

Based on the entire sample ($n = 525$), we found that exercise levels for moderate and strenuous activity were significantly higher prediagnosis (mean = 89.6 minutes/week) compared to the past month (mean = 74.5; $p < .001$). For those who had received adjuvant treatment ($n = 340$), exercise levels dropped significantly ($p < .001$)

from pre-diagnosis (mean = 80.3 minutes/week) to during treatment (mean = 42.2 minutes/week) and then increased significantly ($p < .001$) from during treatment to the past month (mean = 68.5), but did not return to prediagnosis levels ($p < .001$).

Exercise Patterns Across the Cancer Experience

We categorized participants into eight exercise patterns based on their exercise participation during each of the time points of the cancer trajectory (i.e., prediagnosis, treatment, and past month) (Table 4). At each time point, participants were identified as “active” or “inactive” based on public health exercise guidelines. Based on this criterion, we found that 93% of participants fell into four exercise patterns: (a) Maintainers (active at all three time points; 12%), (b) Temporary Relapsers (active at prediagnosis, inactive during treatment, active in the past month; 4%), (c) Permanent Relapsers (active at prediagnosis, inactive during treatment and during the past month; 9%), and (d) Nonexercisers (inactive at all three time points; 68%).

Quality of Life Differences Based on Exercise Behaviour

We found significantly higher scores for the exercise group on the FACT-BI ($p = .001$), the FACT-G ($p = .007$), the TOI ($p = .001$), the FWB ($p = .002$), additional concerns ($p = .002$), the PWB ($p = .06$), sexual interest ($p < .001$), erectile function ($p < .001$), and body image ($p = .001$) but not SWB ($p = .072$), EWB ($p = .284$), urinary functioning ($p = .211$), or bowel functioning ($p = .586$) (Table 5). Cohen’s (28) effect sizes (d) for these scales ranged from .28 to .43. After covarying for prognostic factors for QoL (i.e., income, current cancer status, presence of an ostomy appliance, and degree of invasiveness) we found no substantive differences.

Differences in Fatigue Based on Exercise Level

We found that the exercise group reported significantly lower scores for least fatigue ($p = .007$), average fatigue ($p = .012$), current fatigue ($p = .008$), average amount of time fatigued ($p = .029$) and fatigue interference ($p = .052$) but not most fatigue ($p = .139$) or number of days fatigued ($p = .196$) (Table 6). Cohen's (28) effect sizes (d) ranged from .24 to .29. After controlling for prognostic factors for fatigue (i.e., income, current cancer status, presence of an ostomy appliance, degree of invasiveness, and age) we found only one substantive change, time fatigued per day was no longer significant ($p = .064$).

Moderators of the Associations among Exercise and Quality of Life

We found a significant interaction between BMI and exercise group with the FACT-BI as the dependent variable ($p = .027$). Specifically, we found that non-obese survivors meeting the public health exercise guidelines reported significantly higher scores on the FACT-BI compared to those not meeting the guidelines ($p < .001$) but the association did not hold for obese survivors ($p = .419$) (Figure 1). Further testing found significant interactions between BMI and exercise group for the FACT-G ($p = .022$), the FWB subscale ($p = .023$), and the bowel functioning subscale ($p = .036$). No other significant interactions were found with any of the other demographic/medical variables. Covarying for income, current cancer status, presence of an ostomy appliance, and degree of invasiveness did not alter these results.

Discussion

As hypothesized, the exercise prevalence rate in bladder cancer survivors was lower (22%) than the general population (45%) (29) but was similar to other cancer survivor groups (20-30%) (13-15, 30). Exercise levels also decreased from prediagnosis

to active treatment, and then increased from active treatment to the past month, but not back to prediagnosis levels. When we examined the exercise patterns of bladder cancer survivors, we found that over 90% could be categorized into one of four groups (i.e., maintainers, temporary relapsers, permanent relapsers, and nonexercisers). These results are consistent with previous studies of colorectal and breast cancer survivors (31, 32). In the present study, the majority of participants (68%) were nonexercisers, indicating that many participants had a long history of inactivity. Since physical inactivity is related to other poor lifestyle choices, such as smoking and unhealthy dietary habits (33), these factors may have contributed to the onset of bladder cancer in some of these cases. The finding that the majority of bladder cancer survivors are long-time non-exercisers suggests that exercise behaviour change interventions are needed in this population but may be challenging.

Also consistent with our primary hypotheses was that exercise was positively associated with QoL in bladder cancer survivors. Specifically, exercise was positively associated with the FACT-BI, the FACT-G, the TOI, the FWB subscale, the PWB subscale, the additional concerns subscale, sexual interest, erectile function, and body image. Differences between the two exercise groups appear to be meaningful. The difference in FACT-G scores was 4.1, which exceeds the proposed minimally important difference (MID) of 4.0 for this scale (34). Although there are no published MIDs for the FACT-BI, the MIDs for other FACT scales, such as the FACT-B (35) and the FACT-C (36) are typically around 7 points. In the present study, the difference between groups on scores on the FACT-BI was 6.4, suggesting that this difference may be enough for survivors to perceive a meaningful difference in their QoL based on exercise.

Results of our study are consistent with those of other studies of other cancer survivors that have found exercise to be positively associated with QoL (11-15). Specifically, data from the present study suggest that exercise is associated primarily with the physical and functional aspects of QoL, rather than the social and emotional dimensions. This result is also consistent with other studies of cancer survivors, suggesting that exercise may have the most benefits for cancer survivors in the physical and functional domains of QoL (11, 12). Mechanisms through which exercise may influence physical and functional QoL in bladder cancer survivors include improved aerobic fitness, muscular strength, range of motion, balance, body composition, and comorbidity profile. This finding is important because it suggests that exercise may have similar associations with QoL in bladder cancer survivors as it does in other cancer groups.

The present study also indicated that exercise was positively associated with sexual interest in men and women, and erectile functioning in men. This result is of particular interest because sexual dysfunction is one of the main QoL issues surrounding bladder cancer (7). The results of the present study are consistent with one recent study that reported a positive association between exercise and sexual functioning in prostate cancer survivors (37). Moreover, in the general population, exercise has been found to improve sexual functioning in both men and women (38, 39). Explanations for this association may include physiological mechanisms, such as increased blood flow and circulating testosterone levels, and social-cognitive factors, such as improved self-efficacy, mood states and better self-esteem.

Exercise was also positively associated with body image in the present study. This finding is consistent with studies of breast cancer survivors and healthy populations of men (40) and women (41). The mechanisms for this effect may be through improvements in stamina, strength, agility and body composition (42, 43). Unique to bladder cancer, urinary and sexual dysfunction may also mediate body image disturbance by causing negative changes in sexual body image, identity, and body dissatisfaction from treatment related side-effects like scarring and urinary diversion. By improving sexual function, exercise may also improve body image.

Exercise was also negatively associated with several aspects of fatigue, a finding that is consistent with other studies of cancer survivors (9, 10). Previous studies, however, have used only unidimensional fatigue measures, such as the FACT-F(13), EORTC-QLQ (44), and POMS (45), which precludes any determination of what aspects of fatigue might be most related to exercise. To our knowledge, our study is the first in cancer survivors to examine exercise and multidimensional fatigue. Interestingly, exercise was also significantly associated with decreased levels of least, average, and current fatigue, average amount of time per day spent fatigued, and interference but not most fatigue or number of days spent fatigued. In terms of intensity of fatigue, these results suggest that exercise may be beneficial for improving lower to moderate levels of fatigue, but may not have utility for improving the most intense fatigue. In terms of duration, exercise may reduce the amount of fatigue experienced in a given day but not the number of days fatigued. Further studies are needed to verify these observations.

As a secondary purpose, we also explored some potential moderators of the associations between exercise and QoL. The only variable that moderated the exercise

and QoL association was BMI. Specifically, exercise was positively associated with QoL for normal and overweight bladder cancer survivors but not for obese survivors. This differs from the results of a previous study of endometrial cancer survivors that indicated that exercise is beneficial for QoL for survivors of all ranges of BMI (13). There is evidence that obese bladder cancer survivors suffer from greater post-operative side-effects (46), and thus these factors may reduce the possible benefits of exercise. It is important to note, however, that there were small numbers of obese survivors who reported exercising regularly ($n = 17$). The finding that other demographic and medical variables did not moderate the associations between exercise and QoL is also meaningful since this suggests that exercise is associated with QoL in bladder cancer survivors regardless of sex, age, presence of an ostomy appliance, degree of invasiveness, adjuvant therapy, or current cancer status.

Our study has important strengths and limitations. To the best of our knowledge, our study is the first to examine exercise issues in bladder cancer survivors and the first exercise study to utilize a multidimensional measure of fatigue in cancer survivors. Moreover, we obtained a large sample of bladder cancer survivors that were representative of the population of bladder cancer survivors in Alberta, Canada. The main limitation of our study is the observational design that does not allow us to conclude the causal role of exercise in QoL. From this study, we cannot know with certainty if exercise improves QoL or if participants with higher levels of QoL are more likely to exercise. Another important limitation is the self-report exercise measure, which may have resulted in an over-reporting of exercise. Nevertheless, our study provides important preliminary

data suggesting that further studies of exercise and QoL in bladder cancer survivors are warranted.

In conclusion, the present study examined exercise prevalence rates and the associations between exercise and QoL in a population-based sample of 525 bladder cancer survivors. We found that only 22% of bladder cancer survivors reported meeting public health exercise guidelines, a percentage considerably lower than the general population. We also found significant associations between exercise and multiple QoL indicators that are important to bladder cancer survivors. The associations held for men and women, and young and old regardless of presence of an ostomy appliance, degree of invasiveness, adjuvant therapy, or current cancer status. Only BMI moderated some of the associations but the sample of obese bladder cancer survivors that met public health exercise guidelines was small. Findings from our study provide a rationale for further studies of exercise in bladder cancer survivors to determine the causal effects of exercise on QoL in this population. These results, if validated, may warrant efforts to promote exercise for this cancer survivor group.

Table 3-3-1.

Demographic profile of bladder cancer survivors (N=525).

Demographic Variable	Mean±SD or %
Age (n=525)	70.2±11.2
< 65 years	30.9%
≥ 65 years	69.1%
Sex (n=525)	
Male	74.7%
Female	25.3%
Marital Status (n=525)	
Married/Common Law	79.8%
Divorced/Separated	6.1%
Widowed	11.8%
Never Married	2.3%
Education (n=525)	
Some Elementary School	5.5%
Completed Elementary School	8.2%
Some High School	27.8%
Completed High School	24.0%
Some University/College	14.3%
Completed University/College	16.2%
Some Graduate School	1.1%
Completed Graduate School	2.9%
Annual Family Income (n=525)	
<\$20,000	11.0%
\$20,000-\$39,000	48.6%
\$40,000-\$59,000	17.5%
\$60,000-\$79,999	10.1%
\$80,000-\$99,999	4.8%
>\$100,000	8.0%
Annual Family Income (Data missing: n=424)	
<\$20,000	13.7%
\$20,000-\$39,000	36.3%
\$40,000-\$59,000	21.7%
\$60,000-\$79,999	12.5%
\$80,000-\$99,999	5.9%
>\$100,000	9.9%
Employment Status (n=525)	
Retired	70.9%
Disability	4.4%
Employed Full/Part-Time	23.2%
Temporarily Unemployed	1.5%

Ethnicity (n=525)	
Caucasian	98.1%
Native/Metis	1.3%
Asian	0.6%
Smoking Status (n=525)	
Never Smoked	23.4%
Ex-Smoker	59.2%
Occasional Smoker	6.8%
Regular Smoker	10.6%

Table 3-3-2. Medical profile of bladder cancer survivors (N=525).

Medical Variable	Mean±SD or %
Body Mass Index (n=525)	27.3±4.1
<25.0	24.6%
25.0-29.9	56.2%
30.0-34.9	14.5%
≥35.0	4.8%
Months Since Diagnosis (n=525)	72.4±42.2
< 60 months	48.6%
≥ 60 months	51.4%
Tumor Grade (n=525)	
1	22.3%
2	38.5%
3	14.9%
4	11.0%
Unknown	13.3%
Degree of Invasiveness (n=525)	
Superficial	65.0%
Invasive	35.0%
Surgery (n=525)	
Yes	97.9%
No	2.1%
Cystectomy (n=525)	
Yes	20.2%
No	79.8%
Immunotherapy (n=525)	
Yes	57.7%
No	42.3%
Chemotherapy (n=525)	
Yes	11.8%
No	88.2%
Radiation (n=525)	
Yes	6.7%
No	93.3%
Any Adjuvant Therapy (n=525)	
Yes	64.8%
No	35.2%
Ostomy Appliance (n=525)	
Yes	11.8%
No	88.2%
Recurrence (n=525)	
Yes	37.9%
No	62.1%
Current Status (n=525)	
Cancer Free	89.5%
Still has Bladder Cancer	10.5%

Table 3-3-3. Exercise behaviour and quality of life in bladder cancer survivors (525).

Variable	Mean±SD
Weekly Exercise Prediagnosis (n=525)	
Mild Minutes	165.5±288.5
Moderate Minutes	64.5±110.2
Strenuous Minutes	25.1±77.7
Strenuous plus Moderate Minutes	89.6±145.7
% Meeting Public Health Guidelines	27.8%
Weekly Exercise During Adjuvant Treatment (n=340)	
Mild Minutes	122.2±221.3
Moderate Minutes	32.7±83.6
Strenuous Minutes	9.4±51.3
Strenuous plus Moderate Minutes	42.2±101.8
% Meeting Public Health Guidelines	17.4%
Weekly Exercise in the Past Month (n=525)	
Mild Minutes	162.7±282.3
Moderate Minutes	56.1±108.6
Strenuous Minutes	18.5±68.4
Strenuous plus Moderate Minutes	74.5±133.4
% Meeting Public Health Guidelines	22.3%
Quality of Life (n=525)	
FACT-BI (0-152)	123.6±19.2
FACT-G (0-108)	88.2±14.5
TOI (0-104)	82.9±14.2
Physical Well-Being (0-28)	25.4±4.1
Functional Well-Being (0-28)	22.0±5.9
Emotional Well-Being (0-24)	21.0±3.6
Social Well-Being (0-28)	19.7±5.2
Additional Concerns (0-48)	35.5±7.1
Urinary Functioning (0-12)	9.7±2.8
Bowel Functioning (0-8)	6.9±1.6
Sexual Interest (0-4)	1.8±1.4
Erectile Dysfunction (n = 392) (0-4)	1.4±1.4
Body Image (0-4)	2.5±1.2
Fatigue (n=525)	
Most Fatigue (0-10)	4.0±2.8
Least Fatigue (0-10)	2.0±2.1
Average Fatigue (0-10)	2.9±2.4
Fatigue Now (0-10)	2.4±2.6
Number of Days (0-7)	2.8±2.4
Time Fatigued per Day (0-10)	2.6±2.5
Interference Scale (0-10)	1.7±2.0

Table 3-3-4.

Exercise patterns of bladder cancer survivors across the cancer experience (N=340).

Major Cancer-Related Time Points

Exercise Pattern	Before	During	After	N	%
1. Maintainers	Active	Active	Active	42	12%
2.	Active	Active	Inactive	7	2%
3. Temporary Relapsers	Active	Inactive	Active	15	4%
4. Permanent Relapsers	Active	Inactive	Inactive	30	9%
5.	Inactive	Active	Active	10	3%
6.	Inactive	Active	Inactive	0	0%
7.	Inactive	Inactive	Active	6	2%
8. Nonexercisers	Inactive	Inactive	Inactive	230	68%
Total				340	100%

Table 3-3-5.

Quality of life differences between bladder cancer survivors meeting (n=117) and not meeting (n=408) public health exercise guidelines during the past month (n=525).

QoL Variable	Meeting Guidelines	Not Meeting Guidelines	Between Group Difference	<i>F</i>	<i>d</i> *	<i>p</i>
	<i>M</i> ± <i>SD</i>	<i>M</i> ± <i>SD</i>	<i>M</i> [95% CI]			
FACT-B1 (0-152)	128.6±17.6	122.2±19.5	6.4 [2.5-10.4]	10.3	.33	.001
FACT-G (0-108)	91.4±13.7	87.3±14.6	4.1 [1.2-7.1]	7.4	.28	.007
Trial Outcome Index (0-104)	86.9±12.4	81.8±14.6	5.1 [2.1-8.0]	11.7	.36	.001
Physical Well-Being (0-28)	26.1±3.8	25.3±4.2	0.8 [-0.03-1.7]	3.6	.20	.06
Functional Well-Being (0-28)	23.5±5.0	21.6±6.1	1.9 [0.7-3.1]	9.7	.32	.002
Emotional Well-Being (0-24)	21.3±3.3	20.9±3.7	0.4 [-0.3-1.1]	1.2	.11	.284
Social Well-Being (0-28)	20.4±4.9	19.5±5.3	1.0 [-0.1-2.0]	3.3	.19	.072
Additional Concerns (0-48)	37.3±6.9	34.9±7.1	2.3 [0.9-3.8]	9.7	.32	.002
Urinary Issues (0-12)	10.0±2.3	9.6±2.9	0.4 [-0.2-0.9]	1.6	.14	.211
Bowel Issues (0-8)	6.9±1.6	6.9±1.6	0.1 [-0.2-0.4]	0.3	.06	.586
Sexual Interest (0-4)	2.3±1.3	1.6±1.3	0.6 [0.3-0.9]	19.3	.43	<.001
Erectile Dysfunction (0-4)	1.8±1.5	1.2±1.3	0.6 [0.3-0.9]	13.8	.43	<.001
Body Image (0-4)	2.8±0.9	2.4±1.2	0.4 [0.2-0.7]	12.1	.33	.001

* *d* = mean difference / pooled SD

Table 3-3-6.

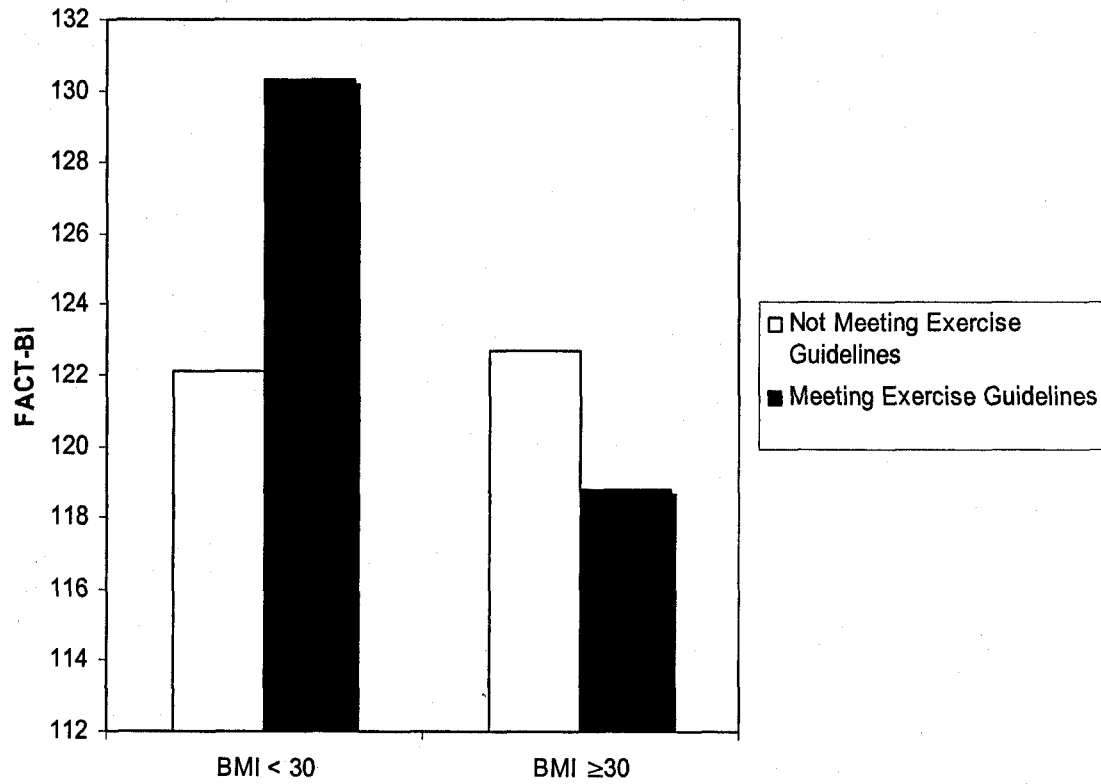
Differences in fatigue between bladder cancer survivors meeting (n=117) and not meeting (n=408) public health exercise guidelines during the past month (n=525).

Fatigue Variable	Meeting Guidelines	Not Meeting Guidelines	Between Group Difference	<i>F</i>	<i>d</i> *	<i>p</i>
	<i>M</i> ± <i>SD</i>	<i>M</i> ± <i>SD</i>	<i>M</i> [95% CI]			
Most Fatigue (0-10)	3.7±2.7	4.1±2.8	0.4 [-0.1-1.0]	2.2	.14	.139
Least Fatigue (0-10)	1.6±1.8	2.2±2.1	0.6 [0.2-1.0]	7.3	.29	.007
Average Fatigue (0-10)	2.4±2.1	3.1±2.4	0.6 [0.1-1.1]	6.3	.25	.012
Fatigue Now (0-10)	1.9±2.3	2.6±2.7	0.7 [0.2-1.2]	7.0	.27	.008
Number of Days Fatigued (0-7)	2.5±2.3	2.8±2.4	0.3 [-0.2-0.8]	1.7	.13	.196
Time Fatigued /Day (0-10)	2.1±2.0	2.7±2.6	0.6 [0.06-1.1]	4.8	.24	.029
Interference (0-10)	1.3±1.7	1.7±2.1	0.4 [-0.004-0.8]	3.8	.20	.052

* *d* = mean difference / pooled SD

Figure 3-3-1.

Significant interaction between exercise behaviour and body mass index on quality of life in bladder cancer survivors.



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Paper 4:

**A Prospective Study of the Determinants of Exercise in Bladder Cancer Survivors
Using the Theory of Planned Behaviour**

Introduction

Exercise has gained recognition as a potential supportive care intervention for cancer survivors by improving a number of quality of life parameters in the physical, functional and emotional domains (1). Despite evidence of these benefits, exercise participation rates decline sharply after a diagnosis of cancer, and remain relatively low years into survivorship (2, 3). Recent studies indicate that approximately 70% to 80% of cancer survivors off-treatment do not exercise sufficiently (3-5). Thus, it is important to identify determinants of exercise among cancer survivors to gain a better understanding of exercise motivation and, ultimately, for the design of exercise interventions.

No studies to date have specifically examined the determinants of exercise in bladder cancer survivors even though bladder cancer ranks as the 6th most common cancer in both men and women and approximately 499,000 people are currently bladder cancer survivors in the United States (6, 7). We recently reported that meeting public health exercise guidelines was positively associated with quality of life in bladder cancer survivors, yet we also found that 78% of our sample was not meeting public health guidelines (8). Moreover, because of the prevalence of unique quality of life issues, such as urinary incontinence and possibly the presence of an ostomy appliance that may act as barriers to exercise (9), we expect that bladder cancer survivors experience unique motives and barriers to exercise. Because of these factors, a careful examination of exercise motivation in bladder cancer survivors is warranted.

A number of different theories and models of behaviour change have been applied to understanding exercise determinants in different populations (10), some of the most common being social cognitive models (11, 12). Research to date on social cognitive

determinants of exercise in cancer survivors has primarily applied Ajzen's (13) Theory of Planned Behaviour (TPB) (14-17). According to the TPB, intention to perform a behaviour is the central determinant of that behaviour since it reflects motivation and planning. Intention, in turn, is determined by three independent constructs: attitude (positive or negative evaluation of the behaviour), subjective norm (perceived social pressure to perform the behaviour), and perceived behavioural control (confidence and control over performing the behaviour). Since control over performing the behaviour may be separate from intention, it is best to test perceived behavioural control as an independent predictor of behaviour. Ajzen (18) has hypothesized that TPB constructs (i.e., attitude, subjective norm, perceived behavioural control) are higher order structures composed of lower order components. Specific lower order components are (a) affective (enjoyableness of exercise) and instrumental (perceived benefits) components of attitude, (b) descriptive (perception that important others exercise) and injunctive (support from others for exercise) components of subjective norm and (c) self-efficacy (confidence in ones own ability to exercise regularly) and perceived control components (control over exercising) of perceived behavioural control. Recently, some theorists (19-21) have argued that multidimensional modeling of the TPB constructs by directly testing the lower order structures as distinct constructs (i.e., affective attitude, instrumental attitude, injunctive norm, descriptive norm, self-efficacy, perceived control) yields a better model fit and explained variance compared to testing of the aggregated model of higher order structures (i.e., attitude, subjective norm, perceived behavioural control). For the present study, the multidimensional model of the TPB was utilized.

In addition to examining the traditional constructs of the TPB, we were also interested in exploring how selected demographic (i.e. age, sex), medical (i.e. invasiveness, adjuvant treatment, body mass index, months since diagnosis), and behavioural (i.e., smoking) variables predict exercise behaviour and/or moderate the associations between the TPB constructs and exercise. Past studies have shown that some of these variables, like age (22), body mass index (23), sex (24) and smoking (25), have been found to be associated with exercise participation.

The primary purpose of the present study was to examine the determinants of exercise intention and behaviour in bladder cancer survivors. Based on previous research (14-17, 26), we hypothesized that intention, planning, and PBC would predict exercise behaviour, and that attitudes, subjective norms, and PBC would correlate with exercise intention. We also expected that the TPB constructs would mediate any associations between the demographic, medical, or behavioural variables and exercise. Our secondary purpose was to explore the major demographic and medical variables as possible moderators of the associations between the TPB and exercise behaviour. Based on previous research (15), we expected that age would moderate some of these associations.

Methods

Sample and Procedures

Details of the study methods have been reported elsewhere (8). Ethical approval for the study was provided by the Alberta Cancer Board and the University of Alberta. We obtained a list of contact information for all bladder cancer survivors diagnosed in Alberta, Canada between January, 1989 and December, 2003 through the Alberta Cancer Registry. Survivors were deemed eligible for the study if they met the following criteria:

(a) 18 years of age or older, (b) were able to provide written consent in English, (c) family physician or oncologist approval to contact (required by our ethics boards), and (d) diagnosis of bladder cancer within the last 15 years. After physician/oncologist approval was obtained, eligible bladder cancer survivors were mailed the baseline questionnaire package and were asked to return the questionnaire and one copy of the consent form in a business reply envelope to the investigators. Three months later, participants were mailed a follow-up questionnaire package and again were asked to return the completed questionnaire. The study was conducted between October, 2005 and February, 2006.

Measures

All demographic, medical, behavioural, and social cognitive variables used in subsequent analyses were from the baseline questionnaire. Exercise behaviour was assessed with the 3-month questionnaire. Marital status, annual income, employment status, education level, height, weight, smoking status and recurrence were collected from the baseline questionnaire. Age, sex, months since diagnosis, degree of cancer invasion (i.e., superficial or invasive), and cancer treatment(s) received were collected from both the registry and the baseline questionnaire. We relied on the registry data but supplemented it with self-report when the registry data was missing. There were few missing values for each scale on the baseline questionnaire [i.e., instrumental attitude (0.8%), affective attitude (1.8%), injunctive norm (1.5%), descriptive norm (2.0%), perceived behavioural control (0.8%), planning (10.6%)] and each was substituted with the variable mean.

Theory of Planned Behaviour (TPB) constructs were assessed based on the recommendations of Ajzen (13, 18) and previous studies with cancer survivors (15). On the questionnaire, regular exercise was defined consistent with public health exercise guidelines as “vigorous physical activity (e.g. sweating, heart beats fast) performed for at least 3 times per week for 20 minutes or more, or moderate physical activity performed at least 5 times per week for 30 minutes or more”.

Exercise intention was assessed by two items on 7-point Likert scales ranging from 1 (strongly disagree) to 7 (strongly agree). These items were “I intend to exercise at least 30 minutes, 5 days per week at a moderate intensity” and “I intend to exercise for at least 20 minutes, 3 days per week at a vigorous intensity”. We used the higher value of these two items to measure the degree to which the participant intended to meet public health exercise guidelines. Planning was measured by four items on a 7-point Likert scale designed to tap into multidimensional aspects of planning. Specifically, participants were asked if they have “...made a detailed plan regarding...” (a) “when...”, (b) “where...”, (c) “how...”, and (d) “how often...” “...to exercise over the next week” (1=not at all true to 7=exactly true). These items were averaged, and then dichotomized (intending to make a plan versus not intending to make a plan). Internal consistency (α) for the planning scale was .98.

Attitude was measured by seven items on 7-point bipolar adjective scales. Four of these items tapped into the instrumental component (harmful-beneficial, foolish-wise, useless-useful, good-bad) and three items measured the affective component (unenjoyable-enjoyable, boring-fun, unpleasant-pleasant). Written descriptors were extremely (points 1 and 7), quite (points 2 and 6), and slightly (points 3 and 5). “For me,

exercising regularly over the next three months would be..." was the stem that preceded the items. The internal consistencies (α) for the instrumental and affective subscales were .91 and .89, respectively. Affective and instrumental attitude were applied as separate variables for the analyses.

Subjective norm was assessed using six items on a 7-point Likert scale. The three items that measured injunctive norm were "Most people who are important to me (a) think I should, (b) would encourage me to, and (c) would support me, exercising regularly over the next three months" (1 = strongly disagree to 7 = strongly agree). The three items that tapped into descriptive norm were (a) "Most people who are important to me will be doing an exercise program themselves over the next three months" (1 = strongly disagree to 7 = strongly agree), (b) "In the next three months, most people who are important to me will be" (1 = extremely inactive to 7 = extremely active), and (c) "in the next three months, exercise levels of most people who are important to me will be" (1 = extremely low to 7 = extremely high). Internal consistencies (α) for the injunctive and descriptive subscales were .93 and .84, respectively. Descriptive and injunctive norm were scored as separate variables for the analyses.

Perceived behavioural control was determined by four items on 7-point Likert. These items were: "If you were really motivated, (a) "exercising over the next three months would be..."(1 = extremely hard to 7 = extremely easy), (b) "how confident are you that you could exercise regularly over the next three months" (1 = not at all confident to 7 = extremely confident), (c) "I could easily exercise regularly over the next three months" (1 = strongly disagree to 7 = strongly agree) and "If you were really motivated, how much control do you feel you would have over exercising regularly over the next

three months” (1 = very little control to 7 = complete control). Internal consistency (α) was .93. Because perceived control and self-efficacy were highly correlated ($r = .88, p < .001$), we measured the aggregate perceived behavioural control variable rather than the multidimensional components of perceived control and self-efficacy.

We used a modified version of the Leisure Score Index (LSI) (15, 16) from the Godin Leisure Time Exercise Questionnaire (GLTEQ) (27) to assess exercise behaviour over the past three months. The GLTEQ measures average exercise frequency and duration at three levels of intensity: mild (minimal effort, no perspiration), moderate (moderate effort and elevated heart rate, light perspiration) and strenuous (rapid heart rate, sweating). The mild exercise minutes were not utilized for the present study, but were included in the questionnaire to ensure participants did not report these exercise minutes in the moderate or strenuous categories (28). Average weekly moderate and strenuous exercise minutes were calculated as well as a combined score for moderate plus strenuous exercise minutes. Participants were then categorized into three categories based on exercise behaviour: (a) meeting public health exercise guidelines (≥ 60 minutes of strenuous or 150 minutes of moderate-to-strenuous exercise per week), (b) some moderate-to-vigorous exercise but not sufficient to meet public health exercise guidelines and (c) no reported exercise (29). We used this ordinal variable as our dependent variable. The GLTEQ has been found to be reliable and valid compared to nine other self-report exercise measures based on test-retest scores, compared to an objective activity monitor (i.e., accelerometer), and fitness indices. The LSI has been shown to have a one-month test-retest reliability of .62 and concurrent validity coefficients of .56 with VO_{2max} , .32 with the accelerometer, and -.43 with % body fat (30).

Analysis

All analyses were conducted using SPSS 14 (SPSS Inc., Chicago, Ill). Bivariate correlations using Pearson correlation coefficients were used to determine associations between (a) exercise and the relevant demographic (i.e., age, sex), medical (i.e., invasiveness, adjuvant treatment, body mass index, months since diagnosis) and behavioural variables (i.e., smoking), and (b) exercise behaviour and the TPB constructs.

To test our primary hypothesis, we used hierarchical multiple regression analyses to examine the associations between demographic, medical, behavioural, and social cognitive variables and exercise intention and behaviour. Only demographic/medical/behavioural variables that were found to be significantly associated with exercise behaviour were entered into the multiple regression analyses. Additional regression procedures were used to test our secondary hypothesis - for the potential moderating effects of relevant demographic and medical variables and planning on the relationships among the TPB constructs. For the purposes of these analyses, each demographic, medical and behavioural variable was dichotomized. Demographic variables were age (< 65 years vs. ≥ 65 years), sex, marital status, education (high school or less vs. more than high school), income (< \$40,000/year vs. \geq \$40,000/year) and employment (working vs. not working). Medical variables were body mass index (BMI; < 30 vs. ≥ 30), months since diagnosis (< 60 months vs. ≥ 60 months), invasiveness (superficial vs. invasive), adjuvant therapy (yes vs. no) and recurrence (yes vs. no). The behavioural variable was smoking (smoker vs. non smoker).

We conducted two analyses to test our hypotheses, the first to test predictors of exercise behaviour and the second to test correlates of exercise intention. For the first

analysis, when behaviour was the criterion variable, we entered the predictor variables into a hierarchical multiple regression analysis in three blocks: (1) intention, perceived behavioural control, and planning (2) medical/demographic/behavioural variable, and (3) the interaction terms. For the second analysis, when intention was the criterion variable, we consecutively entered the following blocks into a hierarchical regression analysis: (1) the TPB constructs, (2) medical/demographic/behavioural variable, and (3) the interaction terms. For each medical/demographic/behavioural variable found to be a significant moderator, we ran further regression analyses at each level of the moderator to determine the nature of the interaction.

In order to minimize the effects of multicollinearity, each of the analyses was repeated with each of the independent variables mean centered (i.e., the individual score subtracted from the group mean) (31). We found that there were no meaningful differences between the mean centered and uncentered results, so we present the latter results.

Results

Flow of Participants through the Study

Details of the flow of participants through the study are presented elsewhere (8). In brief, 1287 bladder cancer survivors were mailed the questionnaire package. A total of 525 bladder cancer survivors responded to the baseline questionnaire. Because 16 survivors requested no further participation, the three-month questionnaire was mailed to 509 survivors. Of these, 10 were returned to sender, 13 indicated that they were too sick or disabled, 1 was deceased, 20 indicated that they no longer wished to participate, and 68 did not response. Therefore we received 397 completed three-month questionnaires

making the response rate for those who were eligible and able to respond 81.9% (397/485). Independent t-tests revealed no significant differences in age, sex, BMI, adjuvant therapy and degree of invasiveness between those who responded to the three-month questionnaire ($n = 397$) and those who only completed the baseline questionnaire ($n = 128$). However, the group that completed the three-month questionnaire were significantly further past their diagnosis date ($t = 1.6, df = 523, p = .022$) and more were meeting public health exercise guidelines ($t = 1.6, df = 523, p = .001$) compared to the group that only completed the baseline questionnaire. Medical and demographic information are reported in detail elsewhere (8). For participants who completed the three-month questionnaire, the average age of participants was 70 years ($SD = 10.9$), 74% were men, average BMI was 27 ($SD = 4.3$), the average time since diagnosis was 74 months ($SD = 43.4$), 35% had invasive disease and 65% has received adjuvant therapy. For the exercise categories, 58.2 % ($n = 231$) reported no moderate-to-strenuous activity, 20.9% ($n = 83$) reported some moderate-to-strenuous activity but not enough to meet public health exercise guidelines and 20.9% ($n = 83$) reported meeting public health exercise guidelines.

Test of the Primary Hypothesis

Differences in Exercise Levels Based on Demographic, Medical and Behavioural Variables

Results of the bivariate correlations indicated that of the medical, demographic, and behavioural variables, only adjuvant therapy ($r = -.10, p = .039$), invasiveness ($r = -.098, p = .051$) and age ($r = -.11, p = .037$) were significantly associated with exercise.

For the TPB, descriptive statistics indicated that, on average, participants had neutral intentions to exercise regularly, quite positive instrumental attitudes, slightly positive affective attitudes, moderately high injunctive norms, slightly high descriptive norms, and slightly high perceived behavioural control. Table 1 displays bivariate correlations among the TPB constructs. Results indicated that all associations were positive. Exercise behaviour correlated the strongest with exercise intention ($r = .41, p < .001$). Exercise intention had the strongest correlations with perceived behavioural control ($r = .56, p < .001$), instrumental attitude ($r = .52, p < .001$) and affective attitude ($r = .51, p < .001$).

Exercise Behaviour on the Theory of Planned Behaviour and Other Significant Predictors

Results of the first primary hierarchical multiple regression analysis indicated that intention ($\beta = .25, p < .001$), perceived behavioural control ($\beta = .18, p = .001$) and planning ($\beta = .12, p = .018$) explained 20.9% of the variance in exercise behaviour (Table 2). The demographic/medical variables (i.e., adjuvant therapy, invasiveness, age) were not found to independently predict exercise behaviour, but rather were found to be mediated by the TPB; evident by the demographic/medical variables no longer being significant after controlling for the TPB constructs in the model. Subsequent independent t-tests comparing the demographic/medical subgroups on scores on the TPB variables indicated which TPB construct mediated that particular demographic/medical variable. Specifically, those who had received adjuvant therapy reported significantly lower scores on affective attitude compared to those survivors who had not received adjuvant therapy ($t = 2.6, df = 395, p = .009$), those who had invasive disease reported significantly lower

instrumental attitudes ($t = 2.3, df = 395, p = .021$), affective attitudes ($t = 2.7, df = 395, p = .006$), and descriptive norms ($t = 2.6, df = 395, p = .011$), and those who were over the age of 65 years reported significantly lower instrumental attitudes ($t = 2.7, df = 395, p = .008$) and perceived behavioural control ($t = 2.8, df = 395, p = .005$) and higher descriptive norms ($t = 3.2, df = 395, p = .002$) compared to younger survivors.

Exercise Intention on the Theory of Planned Behaviour

Results of the second regression analysis indicated that instrumental attitude ($\beta = .15, p = .025$), affective attitude ($\beta = .18, p = .002$), descriptive norm ($\beta = .10, p = .032$), and perceived behavioural control ($\beta = .32, p < .001$) explained 39.1% of the variability in exercise intention (Table 3).

Test of the Secondary Hypothesis

Moderators of the Theory of Planned Behaviour

Age and adjuvant therapy moderated some of the associations of the TPB (Table 4). For exercise behaviour, age was found to have a significant interaction with intention ($p < .001$) and perceived behavioural control ($p < .001$). Subsequent separate regression analyses of each of the age categories indicated that for survivors 65 years and older, intention ($\beta = .14, p = .041$) and perceived behavioural control ($\beta = .30, p < .001$) independently predicted exercise behaviour, but for survivors under the age of 65 years, intention ($\beta = .57, p < .001$) was the only independent predictor of exercise behaviour. Adjuvant therapy was found to have a significant interaction with perceived behavioural control ($p = .041$). Further regression analyses found that, for those survivors who had received adjuvant therapy, intention ($\beta = .36, p < .001$) was the only independent predictor of exercise behaviour, whereas for participants who had not received adjuvant

therapy, perceived behavioural control ($\beta = .28, p = .002$) was the only independent predictor.

For intention, we found a significant age by affective attitude interaction ($p = .041$). Further regression analyses indicated that affective attitude was an independent correlate of intention for survivors under the age of 65 years ($\beta = .32, p < .001$), but not for survivors over the age of 65 years. No other demographic/medical/behavioural variables moderated the associations within the TPB. Planning did not moderate the association between intention and behaviour.

Discussion

In support of our primary hypothesis, we found that the TPB constructs mediated the associations that several medical (i.e., adjuvant therapy, invasiveness) and demographic (i.e., age) variables had with exercise. Specifically, results indicated significantly lower exercise participation rates for survivors who had received adjuvant therapy, had invasive disease, and were over the age of 65 years. Survivors who had received adjuvant therapy reported less positive affective attitudes, suggesting that exercise is less enjoyable for survivors that have had adjuvant therapy. It is possible that the side-effects from adjuvant treatments, such as fatigue and urinary complications, may cause exercise to be less enjoyable. We also found a similar finding for invasiveness, with those who had been diagnosed with invasive disease also indicating lower affective attitudes compared to those with superficial disease. In addition, survivors with invasive disease indicated lower instrumental attitudes and descriptive norms, suggesting they anticipated fewer benefits of exercise and believed that others important to them were less active. These survivors may feel that exercise may not be helpful for them, or even

detrimental, because they have been seriously and life-threateningly ill. These findings are important because they suggest that receiving adjuvant therapy and having more advanced disease may significantly impact exercise beliefs and behaviour well into survivorship. Previous research has documented that cancer treatments have detrimental effects on exercise participation (2, 3), but none to date have indicated that adjuvant treatments and invasiveness may have long lasting effects on exercise participation and exercise beliefs.

Survivors over the age of 65 years reported significantly lower instrumental attitudes and perceived behavioural control, indicating they find exercise to be not as beneficial and have lower perceived control over exercise compared to younger survivors. This may be because older survivors may not be as aware of health benefits associated with exercise. Past research in the general population has suggested that older adults may not view exercise as a health determinant or may not place value in the benefits of regular exercise (32, 33). Additionally, older survivors may not feel as though they have as much control over exercising because of perceptions of frailty, illness, disability or advanced age (34, 35). Interestingly, participants over the age of 65 years also indicated significantly higher descriptive norms compared to younger participants, indicating they perceive that more people important to them are exercising regularly.

Specifically, bladder cancer survivors who have received adjuvant therapy, have invasive disease, and are over the age of 65 years may benefit the most from exercise interventions, and that these interventions would be most effective if the specific TPB constructs that mediate exercise behaviour were targeted (36).

We also found the TPB predicted exercise behaviour and exercise intentions in this sample of bladder cancer survivors. Specifically, 21% of the variability in exercise behaviour and 39% of the variance in exercise intention in this sample were accounted for by the TPB constructs. These results are in line with previous studies of cancer survivors that found the TPB explained 14% to 35% of the variance in exercise behaviour and 23% to 66% of the variance in exercise intention (2, 14-16, 26, 37). Specifically, results showed that exercise intention, planning, and perceived behavioural control were significant independent predictors of exercise. The majority of other studies, however, have found intention to be the only important correlate of exercise (14, 37-39). This discrepancy may be because bladder cancer survivors tend to be older than survivors of the other tumour types studied, and therefore may have more age-related barriers to exercise, such as poorer health and more disabilities. Moreover, previous studies of older adults in the general population have indicated that constructs that tap into control and self-efficacy are important predictors of exercise behaviour (40, 41). Additionally, the high prevalence of urinary complications, such as presence of an ostomy appliance or urinary leakage, may create additional important barriers for exercise in bladder cancer survivors. The fact that planning was also found to be an independent predictor of exercise behaviour is somewhat novel, since other studies have found support for either a moderating or mediating role with intention for planning (42, 43). This discrepancy may be because of differences in study populations, with the present study being the first to examine planning in cancer survivors. Taken together, these results suggest that exercise interventions aimed at bladder cancer survivors should attempt to improve perceived behavioural control and target planning strategies.

Our second regression analysis indicated that affective attitude, instrumental attitude, descriptive norm, and perceived behavioural control were the key correlates of exercise intention, with perceived behavioural control and affective attitude being the strongest correlates. These findings are in line with previous exercise research on cancer survivors that indicate that attitudes and perceived behavioural control are the most important correlates of exercise intention (2, 14, 16, 37, 38). Unique to the present study is the relatively large independent contribution of instrumental attitude possibly due to differences in health and age. Bladder cancer survivors potentially suffer poorer health because of lifestyle factors (e.g. smoking), greater number of recurrences, and older age compared to many other tumour groups. Participants in the present study consequently may have had the most to gain from exercise, and were therefore more willing to intend to exercise if they felt it would be beneficial. The present study also was the first in cancer survivors to examine subjective norm from a multidimensional perspective. Thus, the finding that descriptive norm was an independent correlate of exercise intention while injunctive norm was not is of particular interest since it suggests that descriptive norm is the more important subcomponent. Thus the exercise behaviour of important others may be more influential in determining exercise intention than support for exercise from these same people. Taken together, these results have important implications for future exercise interventions with bladder cancer survivors. The most effective interventions would likely be those that targeted all constructs of the TPB, with particular emphasis on perceived behavioural control and affective attitude.

In support of our secondary hypothesis, we found that two demographic/medical/behavioural variables (i.e., age and adjuvant therapy) moderated

some of the relationships between exercise and the TPB. Specifically, for older survivors (65 years and older), intention and perceived behavioural control independently predicted exercise behaviour, but for survivors under the age of 65 intention was the only independent predictor. Previous research on older adults in the general population supports these findings by suggesting that control over exercising regularly may play a substantial role in influencing exercise participation in older people (40, 44, 45), possibly because barriers faced by older adults (e.g. disabilities, health problems) are more difficult to overcome than those of younger adults (e.g. time restraints, family commitments). Additionally, for older survivors, instrumental attitude and perceived behavioural control were the most important correlates of exercise intention, whereas for younger survivors, affective attitude and perceived behavioural control were the key correlates. Older survivors may be more influenced by whether or not they feel exercise is beneficial for them because they may have the most to gain in terms of improvements in health and disability. For younger survivors, who may not be as concerned about improving their health, enjoyableness of exercise may be more influential in determining exercise intention.

We also found that intention was the sole independent predictor of exercise for survivors who had received adjuvant therapy, whereas perceived behavioural control was the only independent predictor for survivors who had not received adjuvant therapy. This is counterintuitive, since we would have expected that perceived behavioural control would have been an important predictor of exercise for those who had received adjuvant therapy compared to those who had not because of treatment related complications. These results are meaningful since they provide information on how exercise determinants may

vary in this population based on some of the key medical and demographic variables. This is important information for designing optimal exercise interventions for different subgroups of bladder cancer survivors. Interventions aimed at older bladder cancer survivors would be the most effective if they focused on improving perceived behavioural control and provided education about the benefits of exercise. For younger survivors, however, interventions would be the most effective if they were made as enjoyable as possible. Survivors who had not received adjuvant therapy would benefit most from interventions that focused on improving perceived behavioural control.

The present study has a number of strengths and limitations. One strength is that this is the first to examine exercise determinants in bladder cancer survivors. Previous research of exercise in other groups of cancer survivors (2, 14, 16, 17, 37, 38) have indicated that while the TPB appears to be an effective framework for understanding exercise motivation in cancer survivors, the specific constructs that independently correlate with exercise intentions vary based on tumour type. Consequently, it is important to consider each tumour type separately and not make generalizations across cancer groups. Moreover, this study is the largest prospective study examining exercise determinants in cancer survivors, allowing sufficient power to detect small effects that may have been missed with smaller sample sizes. Additionally, this study is the first to look at a comprehensive model of exercise determinants in cancer survivors, examining the relative importance of the TPB, medical/demographic variables and planning in predicting exercise behaviour. Limitations of the study include the self-report measure of exercise, the transparency of the questionnaire, and the lack of information on clinical staging. Additionally, we claimed that the TPB mediated the association between several

demographic and medical variables, yet TPB variables and the demographic/medical information were both collected at baseline, making it theoretically difficult to claim a causal sequence. Nonetheless, adjuvant therapy and invasiveness occurred temporally before the survey data was collected, so likely did cause discrepancies in TPB variables. Additionally, it is not logical to assume that the TPB constructs caused age, so therefore we are confident that age caused changes in the TPB.

In conclusion, we examined exercise determinants in a prospective study of 397 bladder cancer survivors. We found support for the TPB as an effective theoretical framework for understanding exercise in this population and in mediating several important demographic and medical variables associated with exercise. We also found that several medical and demographic variables moderated some of the associations within the TPB. Our study provides the first data on the determinants of exercise in bladder cancer survivors and may be useful for designing effective exercise behaviour change interventions for this population.

Table 3-4-1.

Descriptive Statistics and Correlations for the Theory of Planned Behaviour (N = 397).

Variable	2.	3.	4.	5.	6.	7.	8.	<i>M</i>	<i>SD</i>
1. Exercise Behaviour	.41*	.33*	.37*	.34*	.34*	.24*	.10	0.6	0.8
2. Intention		.54*	.56*	.52*	.51*	.40*	.30*	4.2	2.3
3. Planning			.37*	.36*	.34*	.27*	.16*	0.4	0.5
4. Perceived Behavioural Control				.66*	.59*	.49*	.30*	4.9	1.5
5. Instrumental Attitude					.68*	.61*	.22*	5.8	1.3
6. Affective Attitude						.52*	.35*	5.0	1.4
7. Injunctive Norm							.40*	5.7	1.4
8. Descriptive Norm								5.0	1.2

* $p < .001$

Table 3-4-2.

Hierarchical Regression Analyses of Exercise Behaviour on the Theory of Planned Behaviour and Other Significant Predictors.

	F_{change}	df	R^2_{change}	β^1	β^2
(Block #1)	34.7	3,393	.21		
Intention				.25*	.25*
Perceived Beh. Control				.18†	.18†
Planning				.12‡	.12‡
(Block #2)	2.4	1,392	.01		
Adjuvant Therapy					-.07
Total Model		4,392	.21		
(Block #1)	34.7	3,393	.21		
Intention				.25*	.25*
Perceived Beh. Control				.18†	.18†
Planning				.13‡	.12‡
(Block #2)	1.1	1,392	.00		
Invasiveness					.05
Total Model		4,392	.21		
(Block #1)	34.7	3,393	.21		
Intention				.25*	.25*
Perceived Beh. Control				.18†	.18†
Planning				.12‡	.12‡
(Block #2)	1.5	1,392	.00		
Age					.00
Total Model		4,392	.21		

* $p < .001$

† $p < .01$

‡ $p < .05$

F = F ratio

df = degrees of freedom

R^2 = coefficient of determination

β^{1-2} = standardized regression coefficients for equations #1 and #2

β = partial regression coefficient

Table 3-4-3.

Regression Analysis of Exercise Intention on the Theory of Planned Behaviour.

<u>Exercise Intention</u>	<i>F</i>	<i>df</i>	<i>R</i> ²	<i>β</i>
Instrumental Attitude				.15*
Affective Attitude				.18 [†]
Injunctive Norm				.03
Descriptive Norm				.10*
Perceived Behavioural Control				.32 [‡]
Total Model	49.3	5,391	.39	

* $p < .05$

[†] $p < .01$

[‡] $p < .001$

F = F ratio

df = degrees of freedom

*R*² = coefficient of determination

*β*¹⁻² = standardized regression coefficients for equations #1 and #2

β = partial regression coefficient

Table 3-4-4.

Hierarchical Regression of Exercise Behaviour on Intention, Planning, Perceived Behavioural Control, Moderators, and Interaction Terms.

	<i>F</i> _{change}	<i>df</i>	<i>R</i> ² _{change}	β^1	β^2	β^3
(Block #1)	34.7	3,393	.21			
Intention				.25*	.25 [†]	.59*
Perceived Behavioural Control				.18 [†]	.18 [†]	-.17
Planning				.12 [‡]	.12 [‡]	.11 [‡]
(Block #2)	1.5	1,392	.00			
Age					-.06	-.37 [‡]
(Block #3)	8.7	2,390	.03			
Age*Intention						-.53*
Age*Perceived Behav Control						.76*
Total Model		6,390	.25			
(Block #1)	34.7	3,393	.21			
Intention				.25*	.25*	.13
Perceived Behavioural Control				.18 [†]	.18 [†]	.32 [†]
Planning				.12 [‡]	.12 [‡]	.12 [‡]
(Block #2)	2.4	1,392	.00			
Adjuvant Therapy					-.07	.10
(Block #3)	2.6	2,390	.01			
Adjuvant Therapy*Intention						.25
Adjuvant Therapy*						-.40 [‡]
Perceived Behavioural Control						
Total Model		6,390	.23			

* $p < .001$

[†] $p < .01$

[‡] $p < .05$

F = F ratio

df = degrees of freedom

*R*² = coefficient of determination

β^{1-3} = standardized regression coefficients for equations #1, #2 and #3

β = partial regression coefficient

Table 3-4-5.

Hierarchical Regression of Exercise Intention on the Theory of Planned Behavior, Moderators, and Interaction Terms.

	<i>F</i> _{change}	<i>df</i>	<i>R</i> ² _{change}	β^1	β^2	β^3
(Block #1)	49.3	5,391	.39			
Instrumental Attitude				.15*	.15*	.01
Affective Attitude				.18†	.18†	.33†
Injunctive Norm				.03	.03	.01
Descriptive Norm				.10*	.10*	.08
Perceived Behavioral Control				.32‡	.32‡	.40‡
(Block #2)	.01	6,390	.00			
Age					-.003	.01
(Block #3)	1.3	11,385	.01			
Age*Instrumental Attitude						.52
Age*Affective Attitude						-.47*
Age*Injunctive Norm						.08
Age*Descriptive Norm						.00
Age*Perceived Behavioral Control						-.18
Total Model		11,385	.40			

* $p < .05$

† $p < .01$

‡ $p < .001$

F = *F* ratio

df = degrees of freedom

*R*² = coefficient of determination

β^{1-3} = standardized regression coefficients for equations #1, #2 and #3

β = partial regression coefficient

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Paper 5:

**Exercise Programming and Counselling Preferences of a Population-Based
Sample of Bladder Cancer Survivors**

Introduction

Despite evidence of a number of physical, functional and emotional benefits of exercise in cancer survivors (1), exercise participation rates tend to decline after treatment and remain relatively low post-treatment (2, 3). Consequently, an understanding of factors that influence exercise participation in cancer survivors has become an important topic. Several studies to date have examined social cognitive determinants of exercise (4-7) in order to gain a better understanding of motives and barriers to exercise with the ultimate goal of designing optimal exercise interventions and trials for this population. Perhaps of equal importance, but much less studied, is knowledge of the specific exercise programming and counselling preferences of cancer survivors. Seemingly, this knowledge would be the cornerstone for effective and enjoyable exercise programming and counselling for cancer survivors. Despite this, few studies to date have examined exercise preferences in cancer survivors and no study has focused on bladder cancer survivors (8-13). In the present study, we report the exercise preferences of bladder cancer survivors as part of a larger population-based study we recently conducted in this group (14).

The primary purpose of the present study was to solicit the exercise programming and counselling preferences of bladder cancer survivors. The secondary purpose was to explore how select demographic and medical variables moderated these preferences. Based on previous research (9, 11-13), we hypothesized that bladder cancer survivors would indicate an interest in receiving exercise programming and would have a number of unique preferences for exercise. Specifically, we expected that this population, because of their older age and treatment related side-effects (e.g., urinary complications, ostomy

appliances) would be most interested in home-based, solitary activities. We also expected that this sample would particularly prefer low-impact activities such as walking.

Methods

Details about the methods of the study have been reported elsewhere (14). The Alberta Cancer Board Research Ethics Board and the University of Alberta Health Research Ethics Board gave approval to conduct the study. Information on all bladder cancer survivors diagnosed between January, 1989 and December, 2003 in Alberta, Canada was provided by the Alberta Cancer Registry. The study design was prospective for the purposes of collecting data for the determinants of exercise (data not presented here). Medical, demographic and exercise information were collected at baseline and data on exercise preferences were collected from the three-month questionnaire. Eligibility for the study included: (a) 18 years old or older, (b) able to provide written consent in English, (c) approval for contact from a family physician or primary oncologist (required by our ethics boards) and (d) confirmed diagnosis of bladder cancer in the past 15 years.

Participants

All eligible bladder cancer survivors received a baseline questionnaire package in the mail consisting of a cover letter, two copies of the consent form, the questionnaire and a postage paid business reply envelope. Survivors were asked to mail back the questionnaire and a copy of the consent form to the researchers. Those survivors who chose to participate were mailed the follow-up questionnaire three months later. For the mail protocol, we used a modified version of the Total Design Method (15) which included (a) mailing of the questionnaire package, (b) a postcard reminder two weeks later, and (c) a repeat mailing of the questionnaire package four weeks later to those who

had not yet responded. We used postage paid envelopes, coloured paper questionnaires, institution sponsorship, personalized cover letters, and confidentiality assurance to improve participation.

Measures

Demographic and Medical Information

Demographic and medical information were collected from the Alberta Cancer Registry and from the baseline questionnaire. Demographic information was gathered exclusively by self-report. For medical information, we used the registry data first and then supplemented missing information with self-report data.

Exercise Behaviour

A modified version of the Leisure Score Index (LSI) from the Godin Leisure Time Exercise Questionnaire (GLTEQ) (16) was used to assess exercise behaviour. The GLTEQ measures past month average weekly frequency and duration of mild (minimal effort and no perspiration), moderate (not exhausting and light perspiration), and strenuous (heart beats rapidly and sweating) exercise. Participants were classified as 'meeting' (accumulating an average of either 60 minutes of strenuous activity, or 150 minutes of moderate plus strenuous activity per week) or 'not meeting' public health guidelines for exercise as recommended by the Centers for Disease Control and Prevention and the American College of Sports Medicine (17). In comparison with nine other self-report measure of exercise, the LSI has been found to be valid and reliable (18). The LSI has been found to have a one-month test-retest reliability of .62 and concurrent validity coefficients of .32 with an accelerometer and .56 with maximal oxygen consumption.

Exercise preferences

Questions derived from previous studies on exercise preferences were used to measure exercise counselling and programming preferences (9, 11, 13). Ten closed-ended items asked about exercise programming preferences while three closed-ended items tapped exercise counselling preferences. Three open-ended items asked participants to list exercises they were most interested in doing and favourite summer and winter exercises. Two items asked about current fitness center memberships and details of any personal exercise equipment. Details of these items are listed in Tables 2 and 3.

Statistical Analysis

SPSS 14.0 (SPSS Inc., Chicago, IL) was used for all analyses. All demographic, medical and exercise variables were dichotomized. Details of these cut-points are displayed in Table 1. Frequencies and percentages of each response for the exercise preference items were calculated using descriptive statistics.

We tested the moderating effects of the demographic, medical and behavioral variables on exercise preferences by conducting a series of logistic regression analyses. Specifically, we tested the moderating effects of exercising regularly (meeting public health exercise guidelines vs. not meeting), sex, body mass index (non-obese vs. obese), age (under 65 years vs. over 65 years), adjuvant therapy (yes vs. no), invasiveness (superficial vs. invasive), months since diagnosis (under 60 months vs. 60 months and over), marital status (married vs. not married), income (less than \$40,000/year vs. \$40,000/year or more), employment (working vs. not working), education (completed high school or less vs. some post secondary or more) and smoking (smoker vs. non-smoker). For these analyses, we dichotomized exercise preference items by combining

multiple response options. We combined “yes” and “maybe” when the response options were “yes”, “no”, and “maybe”. For the item that asks when exercise programming was preferred, we made a dichotomy of the five response choices by creating “before/during treatment” and “post-treatment” options. We created the dichotomy “face-to-face” and “other” for the modality of counseling item. Preference of exercise partners was split into “alone” and “with others”. Response options for location preference were grouped into “at home” or “not at home”. Intensity preference was categorized as “light” and “moderate-to-vigorous”. Responses for “no preferences” were not coded for our logistic regression analyses.

Results

A detailed report of the flow of participants through the study is presented elsewhere (14). Briefly, we received a total of 525 completed questionnaires from the 1287 bladder cancer survivors who were mailed the baseline questionnaire. A total of 509 survivors were mailed the three month questionnaire because 16 indicated they did not want to further participate in the study. Of the 509 three month questionnaires that were mailed, we received 10 unopened (returned to sender), 13 indicated that they were too sick or disabled, one was deceased, 20 indicated that they no longer wished to participate, and we had no response from 68 for a response rate of 81.9% (397/485) based on those who were able and eligible to respond. Table 1 displays details of medical, demographic and behavioural variables of participants.

Exercise counselling preferences are displayed in Table 2. Results indicate that the most common preferences were for exercise counselling from an exercise specialist

affiliated with a cancer center (40.1%), to be counselled at a cancer center (40.7%) or in the survivor's home (37.0%), and in face-to-face format (77.7%).

Results of the descriptive analyses of the exercise programming preferences data indicate that 81.1% of participants indicated that they were or might be interested in an exercise program designed for bladder cancer survivors, and 84.3% felt they would be able to participate in such a program. Participants also indicated that their most common preference was to start an exercise program immediately after treatment (39.1%), to exercise alone (35.8%), at home (53.7%), in the morning (36.6%), at a moderate intensity (61.7%), and to do spontaneous/flexible sessions (56.9%) and unsupervised exercise (70.6%). Participants were equally split between whether they preferred the same activity each session (49.1%) or different activities (50.9%). The majority preferred walking in general (81.1%) and during both summer (68.1%) and winter (76.7%). The most commonly owned pieces of exercise equipment were a treadmill (36.8%), stationary bike (30.5%), and weights (27.2%). The majority of participants did not have a current fitness center membership (90.1%).

Results of the logistic regression analyses indicated that survivors who were meeting public health exercise guidelines were more likely to prefer to exercise away from home (41% vs. 23%; OR=5.90, 95% CI=1.18-4.56, $p=.015$) and to prefer moderate-to-vigorous intensity exercise (97% vs. 65%; OR=17.21, 95% CI=5.02-90.19, $p<.001$). Older survivors were more likely to prefer to exercise at home (77% vs. 68%; OR=4.21, 95% CI=.188-.962, $p=.040$; figure 1), do light intensity exercise (33% vs. 16%; OR=4.50, 95% CI=.208-.940, $p=.034$) and want unsupervised exercise sessions (75% vs. 62%; OR=4.60, 95% CI=1.07-4.08, $p=.032$). Participants who were obese were more likely to

prefer to exercise at home (88% vs. 70%; OR=6.13, 95% CI=.120-.781, p=.013). Participants who had received adjuvant therapy were more likely to want to begin an exercise program after treatment (73% vs. 59%; OR=4.07, 95% CI=.353-.985, p=.044; figure 2). Married survivors were more likely to indicate a preference for unsupervised exercise (74% vs. 57%; OR=5.72, 95% CI=1.14-3.71, p=.017). Participants with an income of less than \$40,000 per year were more likely to want to exercise alone (62% vs. 52%; OR=5.14, 95% CI=.263-.907, p=.023). Those who had received at least some post-secondary education were more likely to prefer face-to-face counselling (85% vs. 73%; OR=5.80, 95% CI=.275-.876, p=.016) and to exercise alone (52% vs. 39%; OR=6.33, 95% CI=1.18-3.88, p=.012). Sex, invasiveness, months since diagnosis, and smoking status did not influence exercise preferences.

Discussion

The primary purpose of this study was to document the exercise programming and counselling preferences of bladder cancer survivors and, secondarily, to explore how key demographic, medical, and behavioural variables influence these preferences. We found a number of unique programming and counselling preferences, as well as findings that are common with studies of other cancer survivors.

As hypothesized, the majority of bladder cancer survivors indicated an interest in exercise programming (81.1%) and most felt that they would or might be able to participate in such a program (84.3%). These findings are similar to studies of endometrial (13), non-Hodgkin's lymphoma (11), breast and prostate (9) and brain (12) cancer survivors that also indicated that cancer survivors are interested in an exercise program designed for them. These results are important because they indicate that cancer

survivors want exercise programs to be available to them, yet to date very little exercise programming is available specifically for this population, either within the cancer care setting or elsewhere (19).

The most common preferences for exercise counselling were to receive it from an exercise specialist associated with a cancer center (40.1%), at a cancer center (40.7%) and in face-to-face format (77.7%). These results are very similar to a recent survey of endometrial cancer survivors (13) and breast and prostate cancer survivors (9) that found similar preferences for exercise counselling. Interestingly, over 20% of participants indicated a preference for exercise counselling from an oncologist. This figure is similar to the endometrial cancer study (18.7%), but much higher than the study of breast and prostate cancer survivors (9.8%), suggesting a possible role for the oncologist in exercise counselling for bladder cancer survivors. Taken together, these findings suggest that for cancer survivors, receiving personable exercise counselling that is tied closely to a cancer center may be preferable to services intended for the general population. Seemingly, the experience of cancer creates unique needs that survivors feel must be addressed when considering exercise. This highlights the need for cancer centers to adopt exercise counselling services for cancer survivors, and not simply assume that they would be interested in attending services available to the general public.

We also found that participants were most interested in starting an exercise program after treatment (68.0%), particularly during the phase immediately after treatment (39.1%). This is similar to other studies of cancer survivors that have also indicated a preference for starting exercise programming post treatment (9, 11, 13) but differs because these other studies did not find such a large proportion of survivors

indicating a desire to start a program immediately after treatment. Only 26.8% of endometrial cancer survivors (13) and 23.5% of breast and prostate cancer survivors (9) wished to start a program during this time period. For endometrial cancer survivors (13), the greatest proportion preferred the period three to six months after treatment (39.3%), while for brain cancer survivors (9) before treatment was the most commonly preferred time period to start an exercise program (31.8%). This finding is perhaps a reflection of the differences in acute treatment-related side-effects, suggesting bladder cancer survivors may feel ready and able to exercise sooner after treatments compared to endometrial cancer survivors, but that treatment for cancer may be more of a barrier to exercise for bladder cancer survivors compared to breast and prostate cancer survivors. Additionally, survivors who received adjuvant therapy were more likely to prefer to start an exercise program after treatment, presumably because of perceptions of exercise barriers as a result of treatments. This suggests that for bladder cancer survivors that receive adjuvant therapy, exercise programming is best suited to commence during the post treatment phase, particularly immediately after treatments have ended.

Our hypothesis that bladder cancer survivors would prefer solitary, home-based exercise was supported. Specifically, the most common responses for choice of exercise partners were “no preference” (36.3%) and “alone” (35.8%) whereas “at home” was the preferred location for exercise (53.7%). These findings are similar to the previous cancer studies (9, 11, 12) (13). Preference for exercising at home was particularly strong in the present study compared to the other studies that found that only 39.8% of breast and prostate (9), 42.6% of NHL (11), 43.4% of brain (12) and 32.7% of endometrial (13) cancer survivors preferred to exercise at home. This discrepancy may be because of the

possible presence of treatment-related urinary issues in bladder cancer survivors that may make exercising in public places more difficult or embarrassing. Additionally, past research has indicated that older adults prefer to exercise at home, and the present study sample was older (mean=70.3 years) than the other studies (mean=60.8 to 64.5 years). Moreover, the results of our logistic regression analyses indicated that being over the age of 65 years was associated with a greater likelihood of preferring to exercise at home. Other relevant findings from our moderator analyses indicated that survivors who were not meeting public health exercise guidelines and those who were obese were more likely to prefer to exercise at home. This may be because survivors who are unfit or obese may feel self-conscious about exercising in front of others and therefore may prefer to exercise in the privacy of their own homes. Taken together, these results suggest that exercise programs for bladder cancer survivors would be best received if they were home-based and featured exercises that were designed to be done alone. This is especially true for older survivors, those who are not currently exercising regularly, and those who are obese.

The majority of participants indicated they preferred moderate intensity activity (61.7%). This finding is in line with those of other studies (56% to 62%) (9, 11, 12), and also with previous research that suggests that people generally prefer moderate intensity activity because they feel light activity is not difficult enough to be effective (20). Not surprisingly, survivors who were not meeting public health exercise guidelines were more likely to prefer light intensity activity, presumably because of lower levels of fitness and other physical limitations. Older survivors were more likely to prefer light intensity activities, again possibly due to physical limitations and perceived health barriers. This

suggests that moderate intensity activities would be best when designing exercise programs for bladder cancer survivors, but those who are non-exercisers or older may benefit from an option for light intensity activities to start.

We also found that bladder cancer survivors were fairly divided with preferences for other details of exercise programming and indicated that 36.6% preferred morning for exercising, 49.1% preferred the same activities each session, 70.6% would choose unsupervised sessions and 56.9% indicated they wanted spontaneous/flexible sessions. These results are somewhat similar to those of other studies (9, 11, 13), with the exception of the high percentage who preferred unsupervised sessions. In the previous studies, a much lower percentage (46.9% to 58.8%) indicated a preference for unsupervised exercise. This may be because, like the previous observation that the majority of participants preferred home-based exercise, bladder cancer survivors may be embarrassed by possible urinary complications during exercise. Additionally, older survivors were more likely to prefer unsupervised exercise sessions, which may be linked to their preferences for exercising at home. This suggests that the majority of bladder cancer survivors would prefer unsupervised sessions, and that this is especially true for older survivors. Also, it is important to note that because of the wide variety of preferences in terms of time of day for exercise, flexibility and variety of activities, it is important to provide several options for bladder cancer survivors.

As hypothesized, walking was the preferred modality (81.1%), and participants preferred this form of exercise in both summer (68.1%) and winter (76.7%). This is in line with past studies that have also found walking to be the preferred activity of cancer survivors (9, 11, 13). In the present study, however, the proportion of survivors who

prefer walking is substantially larger than for NHL (11) (55%) and endometrial (13) (68.6%) survivors. The study of breast and prostate cancer survivors (9) found a similar finding to the present study (80.6%), but is not directly comparable because the item in that study was not open-ended and featured a limited number of response options. We suspect that walking is particularly favourable for most bladder cancer survivors because of older age and urinary complications. Past studies in the general population have indicated that walking is a preferable activity for older adults compared to younger people (21, 22). Moreover, fears of urinary leakage have been found to be barriers to high-impact activities in older adults (23). Implications of this are that walking should be included as a main component of exercise programs designed for bladder cancer survivors.

Over a third of bladder cancer survivors reported having a treadmill at home and just under a third had a stationary bike. Additionally, very few (9.9%) reported having a current gym membership. This suggests that many bladder cancer survivors are equipped for exercising at home, but few have the motivation or ability to attend a fitness center. This result further supports the notion that the optimal exercise programming for bladder cancer survivors would be home-based.

Our study has several strengths and limitations that are important to note. First, this study is one of only a few that has examined exercise preferences in cancer survivors, and the first to examine bladder cancer survivors. Second, since this study was population-based, the results are generalizable to a wide number of survivors from a variety of different backgrounds and at various stages of survivorship. The main

limitation of the study is that there are possibly an inflated proportion of exercise enthusiasts within the sample due to self-selection of participants.

In summary, the results of this study suggest that most bladder cancer survivors are interested in receiving exercise counselling and programming. We also found a number of interesting preferences for exercise in terms of structure, modality, timing, location, and intensity, some of which are similar to other cancer survivor groups and some that are unique. In general, bladder cancer survivors seem to be most interested in home-based, solitary exercises that are unsupervised and include walking. These findings are important because they provide information on designing optimal exercise programming for this population that may improve QoL and long term survivorship.

Table 3-5-1.

Descriptive Statistics for Demographic, Medical, and Behavioural Variables.

Variable	Frequency	Percent
Sex (n=397)		
Male	295	74.3
Female	102	25.7
BMI (n=397)		
Non-obese	322	81.1
Obese	75	18.9
Age (n=397)		
Under 65 years	119	30.0
65 years and older	278	70.0
Adjuvant Treatment (n=397)		
Yes	258	65.0
No	139	35.0
Invasiveness (n=397)		
Superficial	260	65.5
Invasive	137	34.5
Months since Diagnosis (n=397)		
Under 60 months	185	46.6
60 months and over	212	53.4
Marital Status (n=397)		
Married/Common Law	314	79.1
Not Married	83	20.9
Income (n=397)		
Less than \$40,000/year	226	56.9
\$40,000/year or more	171	43.1
Employment (n=397)		
Working	95	23.9
Not Working	302	76.1
Education (n=397)		
Completed high school or less	247	62.2
Some post secondary or more	150	37.8
Meeting exercise guidelines (n=397)		
Yes	83	20.9
No	314	79.1
Smoking (n=397)		
Current Smoker	69	21.0
Non-smoker	328	82.6

Table 3-5-2.

Descriptive Statistics for Exercise Counselling Preferences.

Preference Variable	N	%
Who would you prefer to receive exercise counselling from?	347	
Oncologist		20.5
Nurse		12.7
Cancer patient/survivor		11.0
Exercise specialist from community		15.9
Exercise specialist from cancer center		40.1
Where would you have preferred counselling to take place?	354	
Cancer center		40.7
Community center		15.0
My home		37.0
Other		7.3
How would you have preferred to be counselled?	367	
Face to face		77.7
Telephone		3.5
Brochure		17.7
Other		1.1

Table 3-5-3.

Descriptive Statistics for Exercise Programming Preferences.

Preference Variable	N	%
Would you be interested in an exercise program?	382	
Yes		44.5
No		18.8
Maybe		36.6
Able to participate in an exercise program?	381	
Yes		47.0
No		15.7
Maybe		37.3
Types of exercise most interested in:	249	
Walking		81.1
Weight training		20.5
Cycling		16.1
Swimming		13.7
Stretching		7.6
When would you have preferred to start an exercise program?	322	
Before treatment		21.4
During treatment		10.6
Immediately after treatment		39.1
3-6 months after treatment		21.4
At least 1 year after treatment		7.5
Who would you prefer to exercise with?	369	
Alone		35.8
With other cancer survivors		6.0
With friends		9.5
With family		12.5
No preference		36.3
Where would you prefer to exercise?	361	
At home		53.7
At a community fitness center		11.4
At a cancer fitness center		7.8
No preference		27.2
What time of day would you prefer to exercise?	352	
Morning		36.6
Afternoon		15.6
Evening		11.4
No preference		36.4

What is your favourite exercise in the summer?	348	
Walking		68.1
Gardening		37.4
Golf		20.7
Swimming		7.5
Bicycling		7.2
What is your favourite exercise in the winter?	296	
Walking		76.7
Shovelling Snow		8.1
Curling		7.1
Skiing		6.8
Weight Training		6.8
What intensity would you prefer to exercise at?	371	
Light intensity		26.1
Moderate intensity		61.7
Vigorous intensity		6.7
No preference		5.4
Same or different activities for each exercise session?	348	
Same activity each exercise session		49.1
Different activity each exercise session		50.9
Supervised or unsupervised exercise sessions?	357	
Supervised		29.4
Unsupervised		70.6
Spontaneous/flexible or scheduled exercise sessions?	346	
Spontaneous/flexible		56.9
Scheduled		43.1
Do you have any of the following exercise equipment at home?	397	
Treadmill		36.8
Stationary bike		30.5
Weights		27.2
Stair stepper		10.1
Elliptical		4.3
Abdominal machine		4.0
Do you have a current membership at any fitness center?	382	
No		90.1
Yes		9.9

Figure 3-5-1.

Preference for home-based exercise based on age.

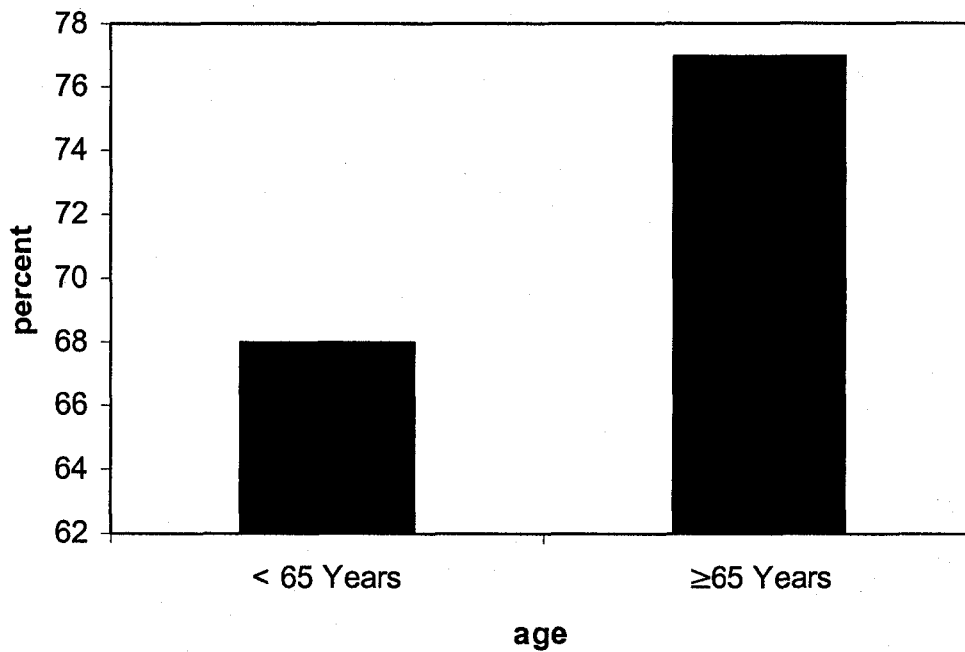
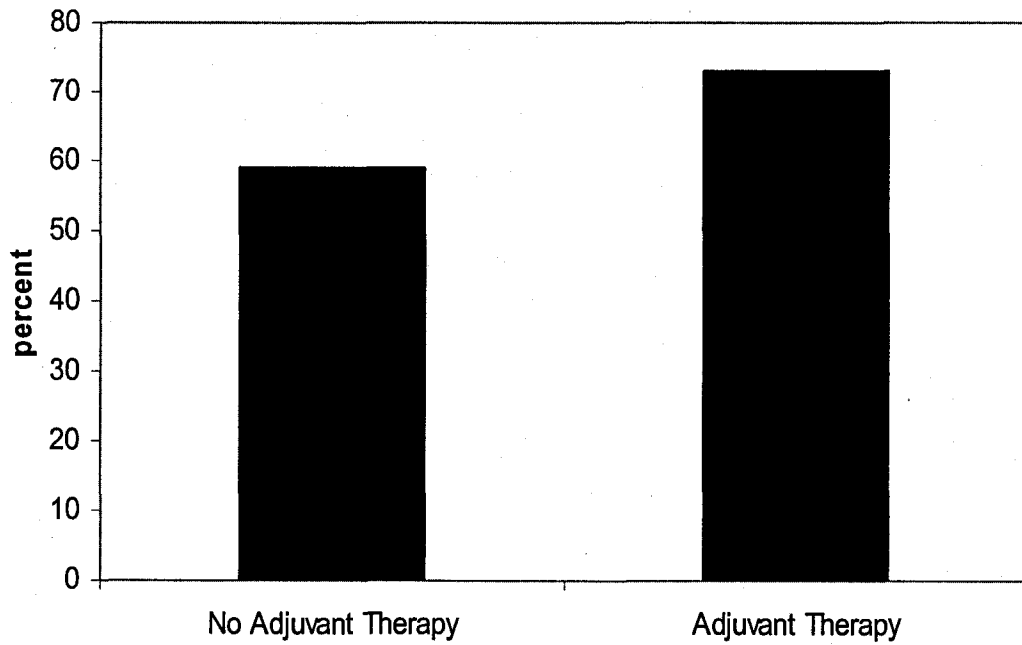


Figure 3-5-2.

Preference for starting an exercise program after treatments have ended based on receiving adjuvant therapy.



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CHAPTER 4 - CONCLUSIONS

The rising number of cancer survivors has led to a need for efficacious interventions to improve QoL and survival for this population. With this has come an increasing interest in the area of exercise as a possible means of alleviating some of the physical, functional, psychological and emotional impairments associated with surviving the cancer experience and its treatments as well increasing survival. While research to date in this field has progressed satisfactorily in the area of breast cancer, very little or no research has been conducted in survivors of other common tumour types. Recent reviews of the exercise literature in cancer survivors have brought attention to this gap (1-6) and recommendations have been made to extend the research to these other tumour types. Furthermore, another limitation of the research to date is the lack of information on older cancer survivors (7) despite the fact that the majority of cancer survivors are older adults (8). The purpose of this dissertation was to explore factors related to exercise in two previously unstudied, yet common, populations of cancer survivors, endometrial and bladder cancer, and to examine the moderating effects of age in both of these groups.

Exercise Prevalence Rates

Results from both the endometrial and bladder cancer studies (papers one and three) support the hypotheses that exercise prevalence rates would be relatively low in these populations. Specifically, only 30% of endometrial cancer survivors and 22% of bladder cancer survivors reported meeting public health exercise guidelines in the past month. These findings are in line with previous studies of breast (23%; 32%) (9, 10), multiple myeloma (20%) (11) and non-Hodgkin's lymphoma (24%) (12) survivors that have all found exercise prevalence rates to be lower than would be expected in the

general population (13, 14). Exercise prevalence rates in the bladder cancer study were particularly low and may be a reflection of tougher treatment protocols resulting in more enduring QoL issues (e.g., urinary leakage), the older age of this population, or potentially poorer lifestyle choices in general (e.g., greater incidence of smoking). In bladder cancer survivors, a smaller percentage of older survivors (20%) were meeting public health exercise guidelines compared to younger survivors (24%), but the difference was not found to be statistically significant. These findings are important because they indicate that a large proportion of endometrial and bladder cancer survivors are not exercising sufficiently to gain potential health and QoL benefits from physical activity.

Exercise Prevalence Rates Across the Cancer-Related Time Points

As hypothesized, exercise prevalence rates were the lowest during treatment in bladder cancer survivors (paper three). Specifically, exercise prevalence rates were reported to drop during treatment, were higher in the past month but not as high as pre-diagnosis levels. Similar to previous studies (15), these findings suggest that the experience of cancer has a detrimental effect on exercise levels, and that this effect continues for years after treatments have ended. This finding further indicates the need for exercise interventions for this population.

In the bladder cancer study, exercise patterns across the cancer-related time points were also investigated. According to these results, the majority of participants (68%) were found to be long-time non-exercisers. This suggests that future exercise interventions and studies may be challenging since many bladder cancer survivors have a long history of not exercising, and likely many have never exercised. Consequently,

future exercise interventions and studies with bladder cancer survivors would be wise to take into account that many bladder cancer survivors have very little experience with exercise and may need to deliver additional education, encouragement and support to be successful.

Exercise and Quality of Life

As hypothesized, this study found that exercise was positively associated with QoL and negatively associated with fatigue in bladder cancer survivors (paper three). Specifically, exercise correlated significantly with the FACT-BL, FACT-G, the TOI, the FWB subscale, the PWB subscale, the additional concerns subscale and several components of fatigue. These results are consistent with past research, both observational (12, 16) and controlled trials (2, 4, 6), that suggests that exercise may have the strongest relationship with QoL in the physical and functional domains. Interestingly, exercise was also found to be positively associated with two of the most common QoL concerns in bladder cancer survivors: sexual interest and erectile functioning. These findings are important because they indicate a strong association between exercise and a number of important QoL parameters. While it is impossible to conclude whether or not exercise caused improvements in QoL in bladder cancer survivors, or if participants with better QoL were more likely to exercise, these findings indicate that there is indeed a strong association that warrants further investigation. Further studies with this population will disentangle this causal relationship, and if exercise is found to improve some of these QoL issues, exercise may eventually be used as a QoL intervention for this population.

This study also found that age did not moderate the association between exercise and QoL. While it had been expected that an even stronger relationship would have been

found for older survivors, this study found that exercise was equally associated with QoL regardless of age group. Moreover, the only demographic or medical variable that moderated this association was BMI, with obese survivors indicating no significant association between exercise and QoL. These findings are important because they suggest that the significant association between exercise and QoL in bladder cancer survivors cuts across all age groups, both sexes, degree of invasiveness, current cancer status and whether or not adjuvant therapy was received, but not obesity levels. From these findings, future exercise trials and interventions can expect similar benefits from exercise for almost all bladder cancer survivors but may need to pay special attention to obese bladder cancer survivors.

Determinants of Exercise

The results of both the endometrial and bladder cancer studies support the hypothesis that the TPB would be an effective framework for understanding exercise and exercise motivation in these cancer populations (papers one and four). These findings are in line with past studies that have also found support for the TPB as a means of understanding exercise in cancer survivors (15). As expected, the specific constructs that correlated with exercise and exercise intention differed between the two studies. In the endometrial cancer study, intention and self-efficacy were independent correlates of exercise whereas in the bladder cancer study, intention, perceived behavioural control and planning independently predicted exercise. For intention, affective attitude and self-efficacy were the key correlates of intention in endometrial cancer survivors whereas in bladder cancer survivors, instrumental attitude, affective attitude, descriptive norm and

perceived behavioural control were the sole independent correlates.¹ These findings highlight the need to examine each tumour type separately in terms of exercise determinants in order to design optimal exercise studies and interventions tailored for these populations.

The bladder cancer study also examined how different levels of a number of medical, demographic and behavioural variables influenced exercise participation. Interestingly, all variables that significantly influenced exercise were mediated by the TPB. These findings not only provide interesting information on exercise prevalence rates based on different sub-groups of survivors (e.g., age, invasiveness, adjuvant therapy), but also provide details on the specific TPB constructs that mediate these relationships. These results provide opportunity for further tailoring in the design of future exercise studies and interventions to suit different subgroups of bladder cancer survivors.

Results from the endometrial and bladder cancer studies supported the hypotheses that age would moderate some of the relationships within the TPB. Several important differences were found between older and younger survivors. For both endometrial and bladder cancer survivors, perceived behavioural control were important correlates of exercise in older survivors, but not younger survivors. Additionally, in bladder cancer survivors, we found instrumental attitude to be a more important correlate of exercise intention in older adults whereas affective attitude appeared to be more important in younger adults. These differences in the relative importance of TPB constructs based on age are important findings. Firstly, they indicate that older cancer survivors may be a

¹ Although multiple regression was used for the analyses, the data for the bladder cancer study were also analyzed using structural equation modeling as a comparison (Appendix C). Results of the multiple regression analyses and structural equation modeling yielded similar findings.

unique group and that future research is needed to further understand motives and barriers to exercise for this group. Secondly, these findings suggest that age, more than other demographic, medical and behavioural variables, might be an important factor to consider when designing exercise studies and interventions for these populations.

Two other variables, BMI in the endometrial cancer study and adjuvant therapy in the bladder cancer study, also emerged as moderators in these studies. These findings offer further tools for tailoring optimal exercise studies and interventions for individual survivors.

Exercise Preferences

As expected, the majority of endometrial and bladder cancer survivors indicated an interest in an exercise program designed for them (papers two and five). Also, both groups reported a number of exercise preferences, some that were consistent with previous research on other groups of cancer survivors (17-20) and some that were unique. As hypothesized, because of the high incidence of urinary leakage and other urinary complications, bladder cancer survivors were more likely to indicate a preference for home-based, solitary activities that involved walking compared to breast and prostate (17), NHL (20) and endometrial cancer survivors (21). Additionally, while there were several demographic and medical variables that moderated exercise preferences, it is particularly noteworthy that age was an important moderator of many preferences in the bladder cancer study. Specifically, older survivors were more likely to want to exercise at home, prefer light intensity activity and prefer unsupervised exercise. These findings provide important information that can be incorporated into designing exercise studies and interventions that endometrial and bladder cancer survivors are most likely to adhere

to and enjoy. Additionally, since age may influence many exercise preferences, this should be taken into consideration when designing exercise programming and counselling for cancer survivors.

Strengths and Limitations

The endometrial and bladder cancer studies each have a number of strengths and limitations. One of the greatest strengths is that these studies are the first to examine exercise in these previously unstudied cancer survivor groups. Up to this point, nothing was known about exercise in either of these common cancer populations. The findings from these two studies are important because they not only warrant further studies with these populations, but give valuable information on the design of optimal programs that effectively target relevant determinants of motivation and programming preferences. Another strength of these studies is that they utilize large sample sizes that enable sufficient power for multiple comparisons. These studies also include a wide variety of participants from different demographic and medical backgrounds, increasing the generalizability of the study as well as allowing for comparisons based on these variables. Additionally, these studies include participants who are many years into survivorship (up to 10 years for the endometrial cancer study and 15 years for the bladder cancer study), rather than just those close to their diagnosis date. This gives a better representation of survivors, instead of just those shortly after treatments have ended.

These studies also have a number of limitations that are important to discuss. Firstly, because of the observational design, it is impossible to conclude causality when examining the associations between exercise, the TPB, and QoL. Nonetheless, the ultimate goal of the QoL component was not so much to make conclusions of the

effectiveness of exercise as a QoL intervention for bladder cancer survivors, but rather to establish whether or not there is an association between exercise and QoL as a means of justifying further studies.

Another limitation is the self-report measure of exercise. It has been often reported that people tend to over-report their activity levels (22, 23). Nonetheless, this likely means that the exercise prevalence rates we report are overestimates, but this should not affect associations with QoL, determinants of exercise or exercise preferences. Furthermore, it is also likely that survivors who are proponents of exercise are more likely to be interested in participating, and thus there may be a greater proportion of exercisers amongst the participants.

Another measurement issue that may cause limitations is the self-efficacy measure that was used. In both the endometrial and bladder cancer studies, self-efficacy was measured using Ajzen's guidelines (24) that state that self-efficacy and perceived control differ operationally but not conceptually. According to Ajzen, both lower order components of self-efficacy and perceived control refer broadly to perceptions of people's capabilities of performing a behaviour and that it is a mistake to assume that certain items exclusively reflect self-efficacy while others reflect perceived control. This definition differs from that of Bandura (25) who states more specifically that self-efficacy refers to an individual's perceptions of confidence in producing certain levels of performance. It is possible that the measure of self-efficacy that was used on the recommendations of Ajzen was not optimal, evidenced by the high correlation between perceived control and self-efficacy in the bladder cancer study. Future studies should look

at other definitions of self-efficacy such as Bandura's that may be more specific and consequently may tap into this construct better.

Additionally, these findings may also have limits with generalizability due to a high proportion of superficial and early stage cases in the samples. It is uncertain if more advanced endometrial and bladder cancer survivors would respond in a similar way to the participants of these studies.

Another important limitation is that it is difficult to distinguish which findings may be due to cancer and which to the normal aging process since a large proportion of participants were older adults. For the two papers that examined exercise motivation (papers one and four), the social cognitive determinants and correlates of exercise that were found to be most important may have been a reflection of perceptions due to aging rather than a product of surviving the cancer experience. For example, the finding that perceived behavioural control/self-efficacy were independent predictors of exercise may be related to aging related barriers to exercise rather than cancer related factors.

Similarly, in the QoL paper (paper three) it is difficult to determine which QoL outcomes were related to cancer and which to aging. For example, elevated fatigue levels may have been due to the normal aging process rather than from lingering effects from cancer treatments. Finally, in the preferences papers (papers two and five), many of the preferences stated by the participants may also have been influenced by age. For example, preferences for walking may have been more of a reflection of the age of the participants rather than because of cancer survivorship.

Future Directions

From the findings of this dissertation arise a number of important research questions that warrant further investigation. In terms of exercise prevalence, more studies are needed that examine details of exercise across the cancer experience, including changes in exercise intensity, activities and frequency. For example, in bladder cancer survivors, acute urinary side effects during treatment may not only cause exercise participation rates to fall, but also activities may become lower intensity and impact and be limited to areas with easy access to washrooms. As a result, the types of exercise interventions and programs offered during each phase of the cancer experience may be quite different. Details about exercise at each phase of the cancer experience would not only provide a better understanding of exercise across the cancer trajectory, but also help in the design of optimal exercise programs that would be appropriate for every phase.

Also of importance is more research on occupational and household activities in cancer survivors. For example, in the bladder cancer study, I anecdotally observed that some participants reported engaging regularly in physically demanding farm labour but not leisure time physical activity. These participants were therefore categorized as not meeting public health exercise guidelines yet they may have been quite physically active. Presumably physical activity from occupational and household labour may also have benefits for cancer survivors, yet these relationships have not been studied to date. Future studies using an objective measure of physical activity, such as pedometers and accelerometers, could help assess total physical activity levels (i.e., leisure time, household and occupational) in cancer survivors. Alternatively, questionnaires that tap into details of physical and occupational activities could be used along side the GLTEQ.

Findings from this dissertation indicate a need for an empirical examination of the nature of the strong association between exercise and QoL in endometrial and bladder cancer survivors. Specifically, further prospective, qualitative and intervention studies would help determine if exercise can in fact improve some QoL parameters in these two populations. Of particular interest in bladder cancer survivors is the role exercise may play in improving one of the most common threats to QoL in this population: lack of sexual interest/erectile dysfunction. If exercise can be found to improve these conditions, it may one day be used as a recommendation for bladder cancer survivors as a drug-free means of alleviating this common QoL issue.

More comprehensive research is also needed on the determinants of exercise in cancer survivors. Firstly, most research on exercise determinants of cancer survivors has focused almost exclusively on social cognitive determinants of exercise. Yet, findings from the bladder cancer study highlight the importance of also examining other exercise determinants (e.g., medical, demographic and behavioural variables). Future research in the determinants of exercise needs to examine a wider spectrum of exercise determinants that includes medical, demographic and behavioural variables as well as other factors such as the physical environment, culture, personality and policy. Only after these variables are explored will we have a more thorough understanding of the determinants of exercise in cancer survivors. Additionally, nearly all research to date has applied the TPB as a framework for understanding social cognitive components of exercise in cancer survivors. Although effective, there needs to be more vigorous testing of other theories in order to discover what are the most effective to use with cancer survivors. Additionally, it is important to note that social cognitive theories in general have limitations. For

example, social cognitive theories assume that people are rational and have the cognitive ability to make decisions and intentions. This point is particularly relevant to cancer survivors and older populations that often suffer from cognitive declines. Additionally, social cognitive theories do not optimally take into account emotional factors, such as fear, and environmental conditions, like lack of exercise facilities, that may also be important predictors of behaviour. Finally, social cognitive theories are also difficult to measure since they contain more abstract constructs, such as attitudes and self-efficacy, compared to more objective measures such as the environment in ecological models. For these reasons, exploration of theories and models of behaviour that go beyond social cognitive theories are also needed in the field of exercise and cancer.

More details about exercise preferences in cancer survivors are needed. For example, walking seems to be a preferred modality of exercise for cancer survivors, but we do not have specific details about preferences for frequency of walks, duration, intensity (e.g. strolling, dog walking, brisk walking) and location (e.g. treadmill, neighbourhood, mall). With more detailed information on exercise preferences we will have yet better tools for the design of more effective exercise programs for cancer survivors.

Another area of research that demands further attention is that of exercise in older cancer survivors. The present studies suggest that exercise determinants and preferences may be very different for younger compared to older endometrial and bladder cancer survivors. Since this is one of the first studies to examine exercise in older cancer survivors, there is still a lot of work that needs to be done in this important area. For example, future studies need to examine exercise in older cancer survivors in other

tumour types, including breast, prostate and colorectal cancer to see if similar differences exist. Additionally, further studies are needed to answer a number of questions, such as if exercise can improve QoL in older cancer survivors, if older cancer survivors can adhere to a program the same way as younger survivors, and specific motivational issues of older survivors.

Additionally, the uniqueness of each of these tumour types in terms of exercise determinants, preferences and associations with QoL highlights the need for studies that examine other unstudied cancer populations. For example, kidney, melanoma, thyroid, cervical and testicular cancers have not been studied in the exercise domain, yet are fairly common and have a relatively high survival rate. Future studies that examine these and other unstudied tumour types are imperative in order to gain a full understanding of exercise prevalence, associations with QoL, determinants and preferences in each of these populations.

Summary

The purpose of this dissertation was to investigate exercise in endometrial and bladder cancer survivors. Results indicated that exercise prevalence rates were relatively low in both of these groups. The TPB was found to be an effective framework for understanding exercise motivation and behaviour in both endometrial and bladder cancer survivors. Differences were found in the relative importance of the constructs that correlated with exercise motivation and behaviour for each tumour type. A number of exercise preferences were documented for both endometrial and bladder cancer survivors, some that were in line with previous research and others that were unique. Age moderated many of these findings. In bladder cancer survivors, exercise was also found

to be associated with many QoL parameters, particularly in the physical and functional domains. These findings are important because they provide valuable information and justification for the design of future exercise interventions and trials for endometrial and bladder cancer survivors. Moreover, these results also suggest the importance of considering age as an important moderating variable. The availability of future exercise programs that improve motivation and exercise behaviour in endometrial and bladder cancer survivors and feature activities that these groups will enjoy and adhere to may help improve the low exercise participation rates of these populations. Increased exercise in these populations in turn could improve general health and decrease mortality, as well as potentially improve QoL parameters associated with the cancer experience.

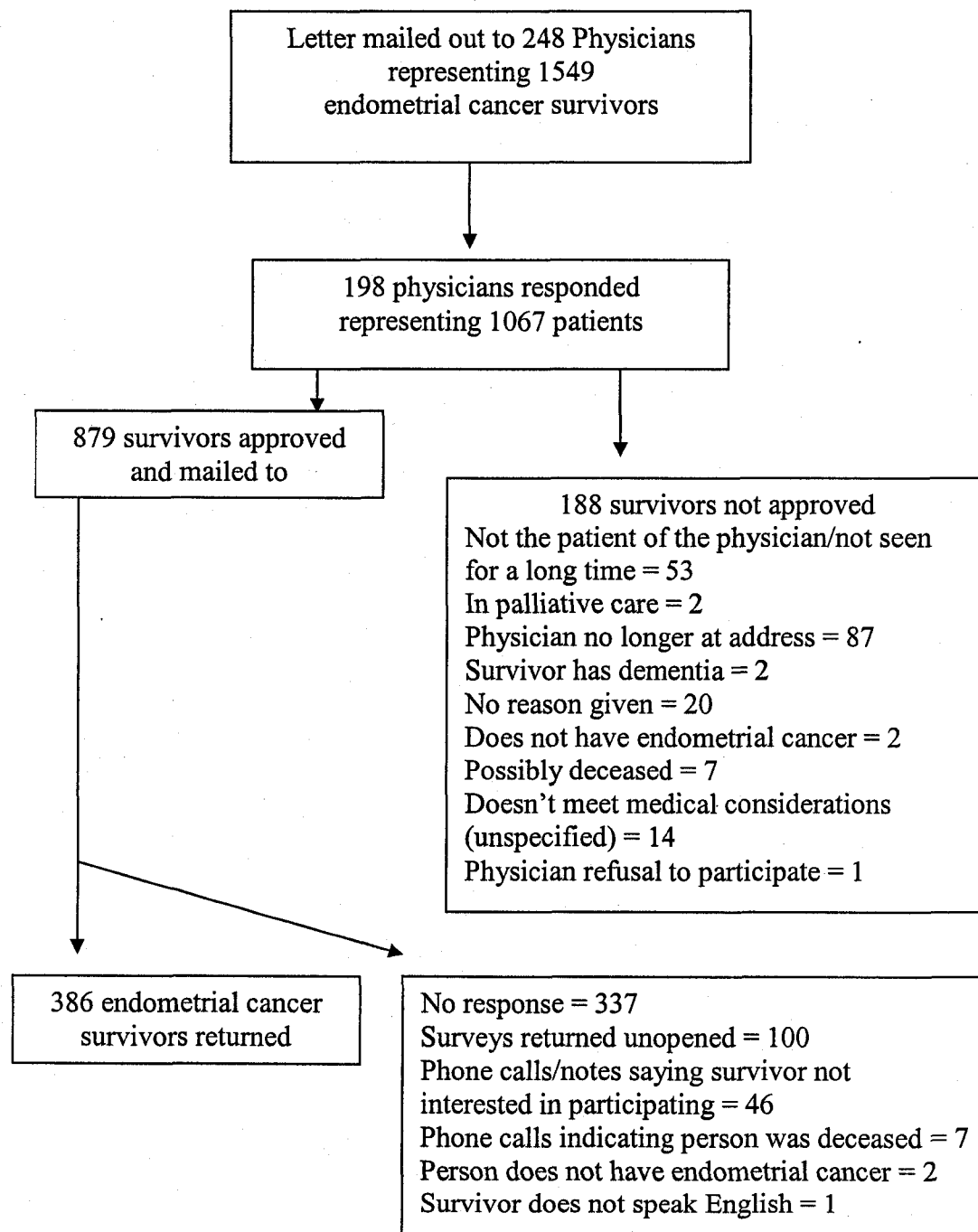
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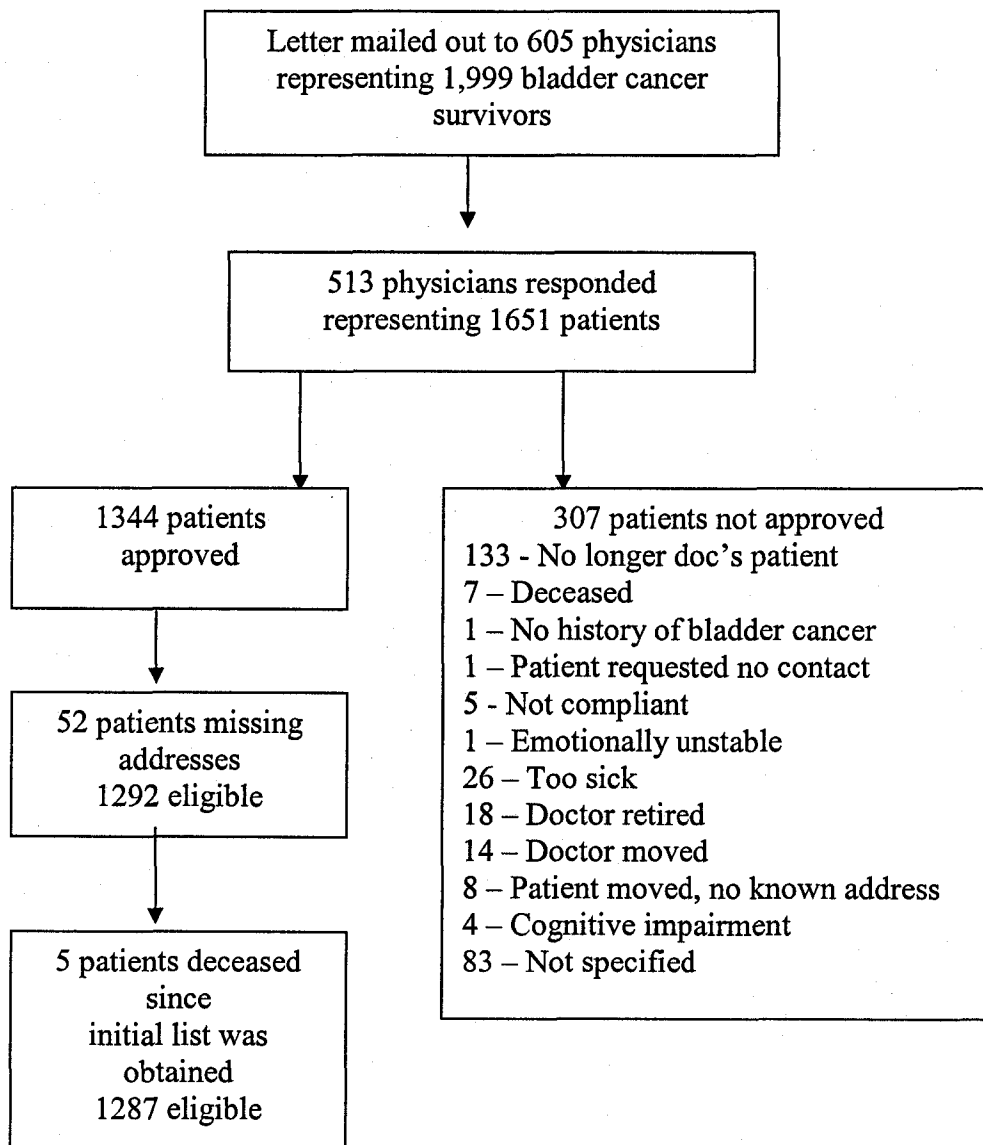
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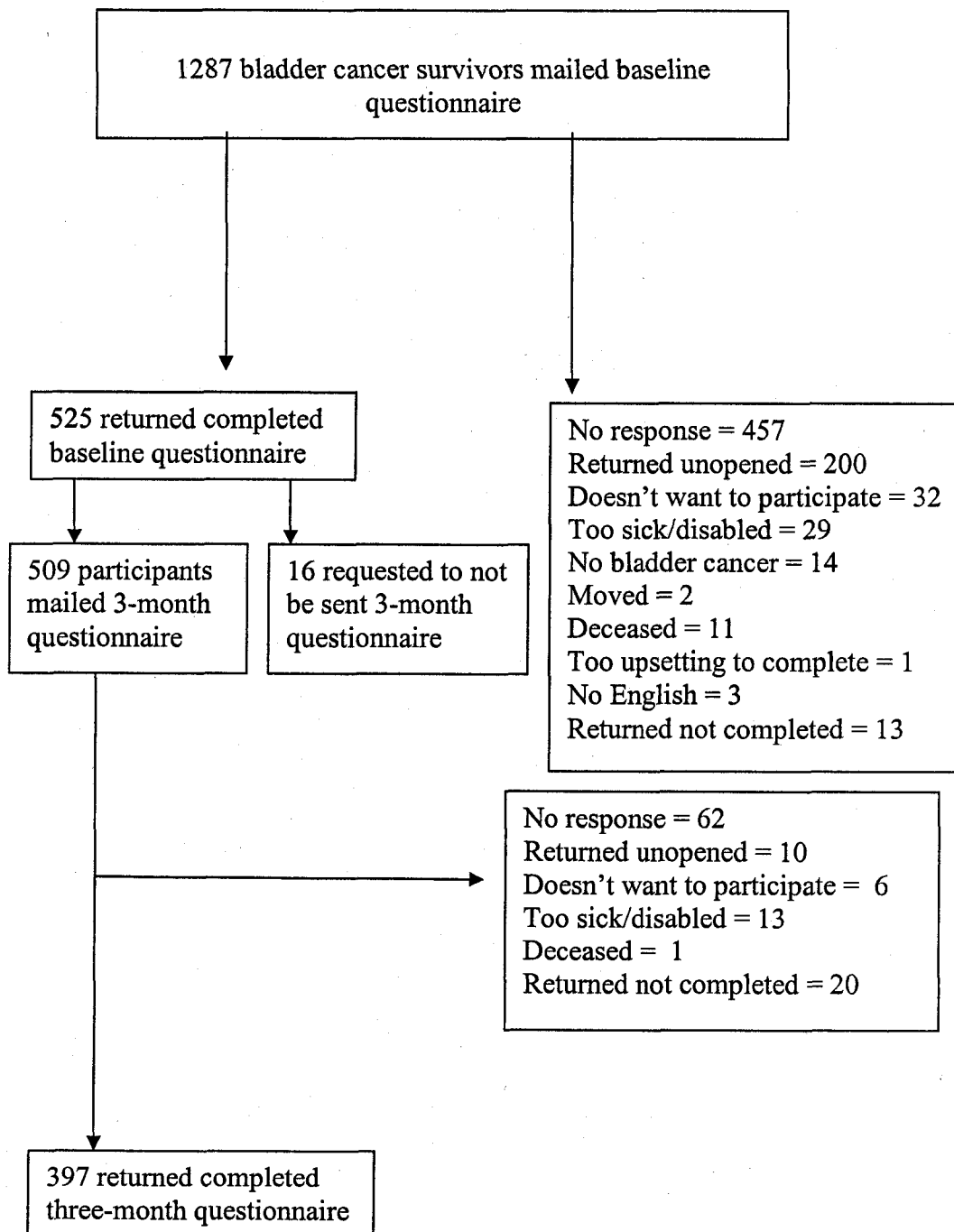
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Appendix A.
Flowchart of Participants through the Endometrial Cancer Study



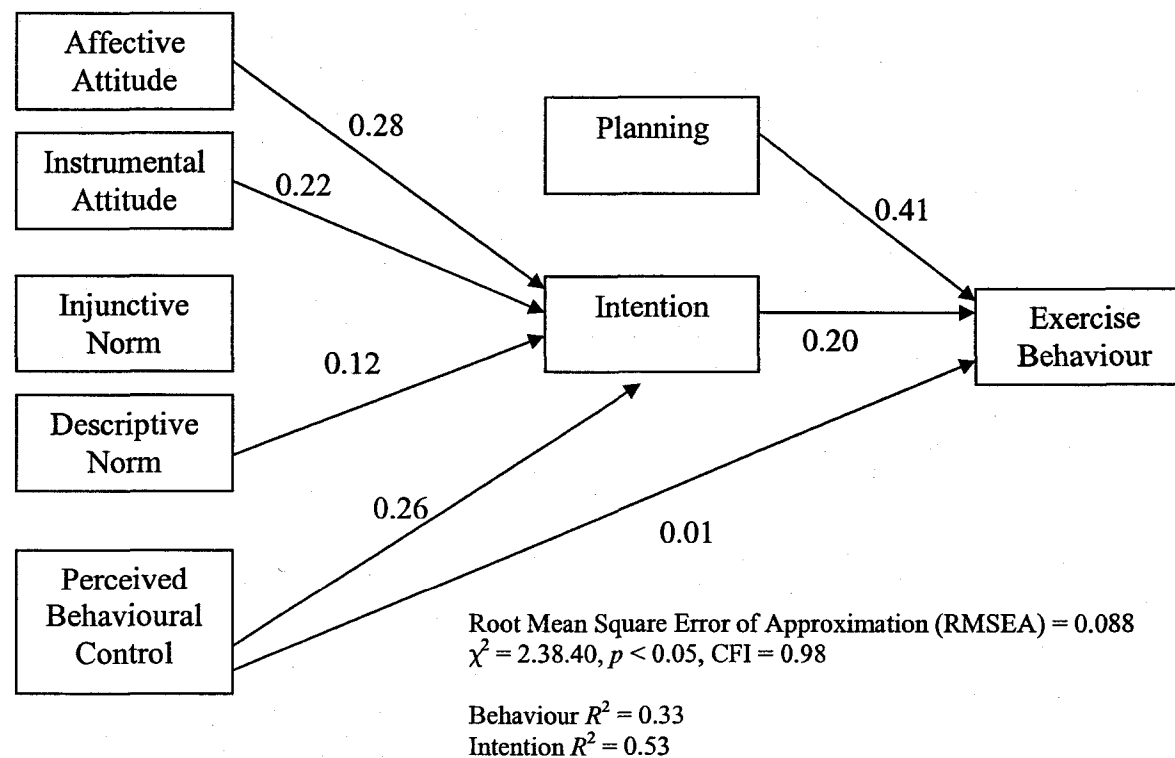
Appendix B.
Flowchart of Participants through the Bladder Cancer Study





Appendix C
Path Diagram of Theory of Planned Behaviour in Bladder Cancer Survivors

Path Diagram of Theory of Planned Behaviour in Bladder Cancer Survivors.



Appendix D
Endometrial Cancer Study Physician Cover Letter

<<Date>>
<<Name>>
<<Address>>
<<City/Province>>
<<Postal Code>>

Dear <<Salutation>>:

My name is Dr. Kerry Courneya and I am a Professor in the Faculty of Physical Education and an Adjunct Professor in the Department of Oncology at the University of Alberta. I am also a member of the Scientific Staff of the Cross Cancer Institute (Edmonton). As part of my responsibilities, I conduct research in the area of exercise and cancer. I am currently conducting a survey study which requires the voluntary participation of endometrial cancer survivors (please see the attached study protocol for more details). My co-investigator on the project is Dr. Katia Tonkin, a medical oncologist at the Cross Cancer Institute. This study has been reviewed by the Alberta Cancer Board's Research Ethics Board, and the University of Alberta Health Research Ethics Board, and has met the rigorous requirements for ethical approval. You have been contacted because you are the referring physician or surgeon of an individual, or individuals, whose name(s) have been identified through the Alberta Cancer Registry as meeting our inclusion criteria. As part of the current ethical approval process, we must obtain "active consent" from the physicians of these individuals before our study can commence.

We are only asking your permission to mail the identified patient(s) an information and questionnaire package. The patient will then have the option of whether to volunteer by completing the questionnaire or not. If you consent to the contact of this/these individuals(s), or there are any compelling reasons for not mailing this information to this/these individuals (e.g. patient is deceased, unable to give informed consent), please phone the Behavioral Medicine Laboratory: Kristina Karvinen (780) 492-2829, Fax (780) 492-8003, or email: karvinen@ualberta.ca.

I hope to hear from you, or from one of your representatives, in the near future. If I have not received correspondence from you within the next three weeks, I will then be in contact with you by telephone at that time. Thank you in advance for your cooperation.

Sincerely,

Kerry S. Courneya
Professor and CIHR Investigator
University of Alberta
E-424 Van Vliet Center
Edmonton, Alberta
T6G 2H9 CANADA
Tel: (780) 492-1031
Fax: (780) 492-8003

Individual(s) whose name(s) has been identified through the Alberta Cancer Registry as meeting our inclusion criteria:

Patient Name	Permission to Contact?	
1.	Yes	No
2.	Yes	No
3.	Yes	No
4.	Yes	No
5.	Yes	No
6.	Yes	No
7.	Yes	No
8.	Yes	No
9.	Yes	No
10.	Yes	No

Appendix E
Endometrial Cancer Study Patient Cover Letter

March 15, 2004

<<Name>>

<<Address>>

<<City/Province>>

<<Postal Code>>

Dear <<Salutation>>:

We are writing to request your participation in a research study exploring the potential role of physical exercise in endometrial cancer survivors. The study protocol has been approved by the Alberta Cancer Board's Research Ethics Board and the University of Alberta Health Research Ethics Board. Your Oncologist has given us permission to contact you.

Recent research has suggested that exercise is beneficial for cancer patients and survivors. However, no study to date has examined the potential role of exercise in endometrial cancer survivors. The information gained from this questionnaire will be used to evaluate the potential role of physical exercise as an intervention to improve quality of life and body image in endometrial cancer survivors. Any future secondary analyses of the information collected will require further approval from the above ethics boards.

To participate in the study all you need to do is complete the enclosed questionnaire and return it to us at your earliest convenience in the self-addressed stamped envelope. Even if you don't currently exercise, your participation in this study is still extremely valuable. Your participation involves only the completion of this questionnaire. For this study, you will not be asked to follow an exercise program; we are merely interested in your current and past exercise behaviours. It is only by understanding the issues of both exercisers and non-exercisers that we can hope to gain a complete understanding of the potential role of exercise in endometrial cancer survivors.

The questionnaire should take approximately 20-30 minutes to complete. There are no right or wrong answers and all we ask is that you provide responses that are as honest and accurate as possible. You may choose to leave any question in the questionnaire unanswered. Finally, please read and sign one copy of the Informed Consent and return it along with the questionnaire. A second copy of the Informed Consent is enclosed for your records.

If you have any questions about the study, or about completing the questionnaire, please feel free to contact Kristina Karvinen by telephone at (780) 492-2829 or e-mail at karvinen@ualberta.ca. Thank you for considering our study.

Sincerely,

Kerry S. Courneya, PhD
Professor
E-424 Van Vliet Center
University of Alberta
Edmonton, Alberta
T6G 2H9 CANADA
Tel: (780) 492-1031

Katia Tonkin, MD
Division of Medical Oncology
Cross Cancer Institute
Department of Oncology
University of Alberta
11560 University Ave.
Edmonton, Alberta
T6G 1Z2 CANADA
Tel: (780) 432-8514

Appendix F
Endometrial Cancer Study Consent Form

A Pilot Study Examining the Relationship Between Physical Exercise and Quality of Life in Endometrial Cancer Survivors

(Physical Exercise and Quality of Life in Endometrial Cancer Survivors)

CONSENT FORM

This consent form is part of the process of informed consent. It is designed to give you an idea of what this research study is about and what will happen to you if you choose to be in the study. Read this form carefully to make sure you understand all the information it provides. You will get a copy of this form to keep.

Your participation in this study is entirely voluntary. You do not have to take part in this study and your care does not depend on whether you choose to participate or not. This study may or may not help you directly, but we hope that it will teach us something that will help other endometrial cancer survivors in the future.

BACKGROUND INFORMATION

Recent research has indicated that physical exercise may be beneficial for cancer survivors. To date, no study has examined the role of exercise in improving quality of life and body image in endometrial cancer survivors. The information gained from this study will be used to evaluate the effectiveness of physical exercise in improving quality of life and body image in endometrial cancer survivors.

STUDY PURPOSE

The purpose of this study will be to assess the role of physical exercise in quality of life and body image in endometrial cancer survivors, as well as their attitudes and beliefs towards exercise.

STUDY DESIGN

If you agree to participate in this research study, you will be asked to complete the attached questionnaire and sign one copy of this consent form. We request that you return both the questionnaire and the signed consent by mailing them in the

Patient Initials: _____ Date: _____

self-addressed stamped envelope provided. The questionnaire will take approximately 20 to 30 minutes to complete. If any of the questions ask for information that you are not comfortable in providing, please feel free to leave those questions blank and move on to the next question.

POTENTIAL RISKS AND BENEFITS

Some possible risk is involved if you choose to participate in this study. We will be asking you to recall your cancer experience, which for some may be traumatic. If this is problematic for you, you need not participate. If you would like someone to speak to about your cancer experience, you may contact the Department of Psychology at the Cross Cancer Institute (780) 432-8703 / (780) 432-8771 (switchboard) or the Department of Psychosocial Resources at the Tom Baker Cancer Centre (403) 670-1767. We do not expect that participation in this study will personally benefit you, however, your participation may help improve patient care in the long term.

CONFIDENTIALITY

The information that we collect as part of this study will be shared with other researchers and doctors. You, however, will not be identified in any of these reports. All information collected for this study will be stored in a safe storage area.

Potentially identifying information will be collected during this study from the questionnaire package. This information may be used by the researchers who are carrying out the study, and may be disclosed to others as described below. Any research program that uses information that identifies you for a purpose other than this study must be approved in advance by the ACB Research Ethics Board.

Your identifiable information may need to be inspected or copied from time to time for quality assurance (to make sure the information being used in the study is accurate) and for data analysis (to do statistical analysis that will not identify you). The following organization will do this inspection:

- Alberta Cancer Board Research Ethics Board, the institutional review board at this centre

Direct access to your identifiable information collected for this study will be restricted to the researchers who are directly involved in this study except in

Patient Initials: _____ Date: _____

the following circumstances. Records may be reviewed by the Alberta Cancer Board Research Ethics Board and/or the University of Alberta Health Research Ethics Board Panel B.

UNDERSTANDING OF PARTICIPANTS

- I have read and understood all of the information in this consent form. I have asked questions, and received answers concerning areas I did not understand. I have had the opportunity to take this consent form home for review and discussion. My consent has not been forced or influenced in any way. I consent to participate in this research study. Upon signing this form I will receive a signed copy of the consent.
- I can refuse to take part or withdraw from this study at any time without jeopardizing my health care. If I continue to take part in the study, I am to be kept as informed as my initial consent. I am free to ask for further explanations about this study. I understand that I may contact Kristina Karvinen at (780) 492-2829, Dr. Kerry Courneya at (780) 492-1031, or Dr. Katia Tonkin at (780) 432-8514, or page her through the Cross Cancer Institute Switchboard at (780) 432-8771 to answer any questions I have about this study.
- If I feel at any time that I have not been informed to my satisfaction about the risks, benefits, or alternatives of this study, or that I have been encouraged to continue in this study after I wanted to withdraw, I can call the Patient Representative at (780) 432-8585.
- I will get to keep a copy of this consent for information and for future reference.

Patient Initials: _____ Date: _____

(PRINT NAMES)

Name of Patient

Signature of Patient

Date

Name of Witness

Signature of Witness

Date

Name of Investigator

Signature of Investigator

Date

Appendix G
Endometrial Cancer Study Questionnaire



Exercise and Endometrial Cancer Questionnaire

Kerry S. Courneya, PhD & Katia Tonkin, MD

**CROSS CANCER INSTITUTE AND UNIVERSITY OF
ALBERTA**

Instructions*

Thank-you for agreeing to participate in this study. In this questionnaire, we are going to ask you a series of questions about yourself. There are no right or wrong answers and all we ask is that you provide responses that are as honest and accurate as possible. The questionnaire should take about 20-30 minutes to complete. All responses are completely confidential and will never be used in any way that could link them to you.

Below is a list of statements that other people with cancer have said are important to their quality of life. Please indicate the extent to which you have experienced each of the statements during the past 7 days by circling the appropriate number using the following scale. It is important that you answer these questions even if it has been many years since your endometrial cancer diagnosis.

0	1	2	3	4
not at all	a little bit	somewhat	quite a bit	very much

During the past week:

PHYSICAL WELL-BEING

- | | | | | | |
|--|---|---|---|---|---|
| 1. I have a lack of energy | 0 | 1 | 2 | 3 | 4 |
| 2. I have nausea | 0 | 1 | 2 | 3 | 4 |
| 3. Because of my physical condition, I have trouble meeting the needs of my family | 0 | 1 | 2 | 3 | 4 |
| 4. I have pain | 0 | 1 | 2 | 3 | 4 |
| 5. I am bothered by side effects of treatment | 0 | 1 | 2 | 3 | 4 |
| 6. I feel sick | 0 | 1 | 2 | 3 | 4 |
| 7. I am forced to spend time in bed | 0 | 1 | 2 | 3 | 4 |

SOCIAL/FAMILY WELL-BEING

- | | | | | | |
|---|---|---|---|---|---|
| 8. I feel close to my friends | 0 | 1 | 2 | 3 | 4 |
| 9. I get emotional support from my family | 0 | 1 | 2 | 3 | 4 |
| 10. I get support from my friends | 0 | 1 | 2 | 3 | 4 |
| 11. My family has accepted my illness | 0 | 1 | 2 | 3 | 4 |
| 12. I am satisfied with family communication about my illness | 0 | 1 | 2 | 3 | 4 |
| 13. I feel close to my partner (or the person who is my main support) | 0 | 1 | 2 | 3 | 4 |

0	1	2	3	4
not at all	a little bit	somewhat	quite a bit	very much

During the past week:

EMOTIONAL WELL-BEING

15. I feel sad	0	1	2	3	4
16. I am proud of how I am coping with my illness	0	1	2	3	4
17. I am losing hope in the fight against my illness	0	1	2	3	4
18. I feel nervous	0	1	2	3	4
19. I worry about dying	0	1	2	3	4
20. I worry that my condition will get worse	0	1	2	3	4

FUNCTIONAL WELL-BEING

21. I am able to work (include work at home)	0	1	2	3	4
22. My work is fulfilling (include work at home)	0	1	2	3	4
23. I am able to enjoy life	0	1	2	3	4
24. I have accepted my illness	0	1	2	3	4
25. I am sleeping well	0	1	2	3	4
26. I am enjoying the things I usually do for fun	0	1	2	3	4
27. I am content with the quality of my life right now	0	1	2	3	4

FATIGUE AND ANEMIA SUBSCALE

40. I feel fatigued	0	1	2	3	4
41. I feel weak all over	0	1	2	3	4
42. I feel listless ("washed out")	0	1	2	3	4
43. I feel tired	0	1	2	3	4
44. I have trouble starting things because I am tired	0	1	2	3	4
45. I have trouble finishing things because I am tired	0	1	2	3	4
46. I have energy	0	1	2	3	4
47. I have trouble walking	0	1	2	3	4
48. I am able to do my usual activities	0	1	2	3	4
49. I need to sleep during the day	0	1	2	3	4
50. I feel lightheaded (dizzy)	0	1	2	3	4
51. I get headaches	0	1	2	3	4
52. I have been short of breath	0	1	2	3	4
53. I have pain in my chest	0	1	2	3	4
54. I am too tired to eat	0	1	2	3	4
55. I am interested in sex	0	1	2	3	4
56. I am motivated to do my usual activities	0	1	2	3	4
57. I need help doing my usual activities	0	1	2	3	4
58. I am frustrated by being too tired to do the things I want to do	0	1	2	3	4
59. I have to limit my social activity because I am tired	0	1	2	3	4

The following question asks you to rate, on average, how happy or unhappy you felt over the past week. Please read all the statements first and then check the one statement (between 0 and 10) that best describes your average level of happiness over the past week. Check only ONE item.

On average, over the past week I have felt:

- _____ 10. Extremely happy (feeling ecstatic, joyous, fantastic!)
- _____ 9. Very happy (feeling really good, elated!)
- _____ 8. Pretty happy (spirits high, feeling good)
- _____ 7. Mildly happy (feeling fairly good, somewhat cheerful)
- _____ 6. Slightly happy (just a bit above neutral)
- _____ 5. Neutral (not particularly happy or unhappy)
- _____ 4. Slightly unhappy (just a bit below neutral)
- _____ 3. Mildly unhappy (just a little low)
- _____ 2. Pretty unhappy (somewhat 'blue,' spirits down)
- _____ 1. Very unhappy (depressed, spirits very low)
- _____ 0. Extremely unhappy (utterly depressed, completely down)

This next question asks you to estimate the percentage of time, on average, that you felt happy, unhappy, and neutral (neither happy nor unhappy) over the past week. Write down your best estimates in the spaces below. Make sure the three figures add up to 100 percent.

Over the past week:

The percentage of time I felt happy was: _____%

The percentage of time I felt unhappy was: _____%

The percentage of time I felt neutral was: _____%

Total 100%

The following questions concern the general perceptions that you currently have about yourself. Please circle the number that best reflects your current view of yourself using the following scale as a guide for your responses.

	1	2	3	4
	strongly disagree	disagree	agree	strongly agree
1. On the whole I am satisfied with myself.	1	2	3	4
2. At times I think that I am no good at all.	1	2	3	4
3. I feel that I have a number of good qualities.	1	2	3	4
4. I am able to do things as well as most other people.	1	2	3	4
5. I feel I do not have much to be proud of.	1	2	3	4
6. I certainly feel useless at times.	1	2	3	4
7. I feel that I am a person of worth, at least on an equal plane with others.	1	2	3	4
8. I wish I could have more respect for myself.	1	2	3	4
9. All in all, I am inclined to feel that I am a failure.	1	2	3	4
10. I take a positive attitude toward myself.	1	2	3	4

The following questions ask how you feel about your appearance, and about any changes that may have resulted from your disease or treatment. Please read each item carefully, and place a firm tick on the line alongside the reply which comes closest to the way you have been feeling about yourself, during the past week.

	Not at all	A little	Quite a bit	Very much	
1. Have you been feeling self-conscious about your appearance?	_____	_____	_____	_____	
2. Have you felt <u>less</u> physically attractive as a result of your disease or treatment?	_____	_____	_____	_____	
3. Have you been <u>dissatisfied</u> with your appearance when dressed?	_____	_____	_____	_____	
4. Have you been feeling <u>less</u> feminine as a result of your disease or treatment?	_____	_____	_____	_____	
5. Did you find it difficult to look at yourself naked?	_____	_____	_____	_____	
6. Have you been feeling less sexually attractive as a result of your disease or treatment?	_____	_____	_____	_____	
7. Did you avoid people because of the way you felt about your appearance?	_____	_____	_____	_____	
8. Have you been feeling the treatment left your body less whole?	_____	_____	_____	_____	
9. Have you felt <u>dissatisfied</u> with your body?	_____	_____	_____	_____	
10. Have you felt <u>dissatisfied</u> with the appearance of your scar?	_____	_____	_____	_____	not applicable

For the next three questions, we would like you to recall your average weekly exercise in the **months before your endometrial cancer diagnosis, during any treatment(s) you received for endometrial cancer, and in the last month.**

When answering these questions please:

- Only count exercise sessions that lasted 10 minutes or longer in duration
- Only count exercise that was done during free time (i.e., not occupation or housework)
- Note that the main difference between the three categories is the intensity of the exercise
- Please write the average frequency on the first line and the average duration on the second. If you did not perform any exercise at a given intensity, please write '0' in that space.

1. Recall your average weekly exercise in the **months before you were diagnosed** with endometrial cancer. Considering a typical week (7 days), how many times, on average, did you perform the following kinds of exercise:

	Times Per Week	Average Duration
a. STRENUOUS EXERCISE (HEART BEATS RAPIDLY, SWEATING) (e.g., running, aerobics classes, cross country skiing, vigorous swimming, vigorous bicycling)	_____	_____
b. MODERATE EXERCISE (NOT EXHAUSTING, LIGHT PERSPIRATION) (e.g., fast walking, tennis, easy bicycling, easy swimming, popular and folk dancing)	_____	_____
c. MILD EXERCISE (MINIMAL EFFORT, NO PERSPIRATION) (e.g., easy walking, yoga, bowling, lawn bowling, shuffleboard, golf)	_____	_____

2. Recall your average weekly exercise **during the time you were receiving treatment** for endometrial cancer (e.g. radiotherapy, chemotherapy). Considering a typical week (7 days), how many times, on average, did you perform the following kinds of exercise:

	Times Per Week	Average Duration
d. STRENUOUS EXERCISE (HEART BEATS RAPIDLY, SWEATING) (e.g., running, aerobics classes, cross country skiing, vigorous swimming, vigorous bicycling)	_____	_____
e. MODERATE EXERCISE (NOT EXHAUSTING, LIGHT PERSPIRATION) (e.g., fast walking, tennis, easy bicycling, easy swimming, popular and folk dancing)	_____	_____
f. MILD EXERCISE (MINIMAL EFFORT, NO PERSPIRATION) (e.g., easy walking, yoga, bowling, lawn bowling, shuffleboard, golf)	_____	_____

3. Recall your average weekly exercise **in the past month**. Considering a typical week (7 days), how many times, on average, have you performed the following kinds of exercise:

	Times Per Week	Average Duration
g. STRENUOUS EXERCISE (HEART BEATS RAPIDLY, SWEATING) (e.g., running, aerobics classes, cross country skiing, vigorous swimming, vigorous bicycling)	_____	_____
h. MODERATE EXERCISE (NOT EXHAUSTING, LIGHT PERSPIRATION) (e.g., fast walking, tennis, easy bicycling, easy swimming, popular and folk dancing)	_____	_____
i. MILD EXERCISE (MINIMAL EFFORT, NO PERSPIRATION) (e.g., easy walking, yoga, bowling, lawn bowling, shuffleboard, golf)	_____	_____

For this next set of questions, we ask you to focus specifically on regular exercise. We define regular exercise as any physical activity performed either at moderate intensity (e.g. brisk walking, dancing, tennis) for at least 30 minutes, 5 times per week, or at vigorous intensity (e.g. running, vigorous bicycling, aerobics) for at least 20 minutes, 3 times per week.

What do you think, for you, would be the main advantages and disadvantages of participating in regular exercise?

Main Advantages

Main Disadvantages

What factors do you think would it make it easier or more difficult for you to exercise regularly?

Factors that would make it more difficult

Factors that would make it easier

What people or groups would approve or disapprove of you performing regular exercise? (e.g. husband, doctor, daughter, etc., do not provide actual names of individuals)

People that would approve

People that would disapprove

Please respond to the following questions by circling the number that corresponds to the answer in *each* row that best describes how you feel about exercise.

1) For me, exercising regularly over the next month would be:

a)

1	2	3	4	5	6	7
extremely useless	quite useless	slightly useless		slightly useful	quite useful	extremely useful

b)

1	2	3	4	5	6	7
extremely unenjoyable	quite unenjoyable	slightly unenjoyable		slightly enjoyable	quite enjoyable	extremely enjoyable

c)

1	2	3	4	5	6	7
extremely harmful	quite harmful	slightly harmful		slightly beneficial	quite beneficial	extremely beneficial

d)

1	2	3	4	5	6	7
extremely boring	quite boring	slightly boring		slightly fun	quite fun	extremely fun

e)

1	2	3	4	5	6	7
extremely foolish	quite foolish	slightly foolish		slightly wise	quite wise	extremely wise

f)

1	2	3	4	5	6	7
extremely unpleasant	quite unpleasant	slightly unpleasant		slightly pleasant	quite pleasant	extremely pleasant

g)

1	2	3	4	5	6	7
extremely bad	quite bad	slightly bad		slightly good	quite good	extremely good

Please use the scale below each question to guide your responses to the next set of questions.

1. Most people who are important to me think I should exercise regularly over the next month

1	2	3	4	5	6	7
strongly disagree	moderately disagree	slightly disagree	neither	moderately agree	moderately agree	strongly agree

2. Most people who are important to me would encourage me to exercise regularly over the next month

1	2	3	4	5	6	7
strongly disagree	moderately disagree	slightly disagree	neither	moderately agree	moderately agree	strongly agree

3. Most people who are important to me would approve of me exercising regularly over the next month

1	2	3	4	5	6	7
strongly disagree	moderately disagree	slightly disagree	neither	moderately agree	moderately agree	strongly agree

Please use the scale below each question to guide your responses to the next set of questions

If I were really motivated, exercising regularly over the next month would be

1	2	3	4	5	6	7
extremely difficult	quite difficult	slightly difficult	Neither	slightly easy	quite easy	extremely easy

2. If you were really motivated, how confident are you that you would be capable of exercising regularly over the next month?

1	2	3	4	5	6	7
not at all confident			moderately confident			extremely confident

3. If you were really motivated, how much control do you feel you would have over exercising regularly over the next month?

1	2	3	4	5	6	7
Very little control			moderate control			complete control

4. If I wanted to, I could easily exercise regularly over the next month

1	2	3	4	5	6	7
strongly disagree	moderately disagree	slightly disagree	neither	slightly agree	moderately agree	strongly agree

The next set of questions ask you about your plans for regular exercise over the next month.

1. I intend to exercise at least ____ times per week (please insert a number that indicates how many times you intend to exercise), at a duration of ____ minutes per session, at a _____ (please choose light, moderate, or vigorous) intensity over the next month.

2. I intend to exercise for at least 30 minutes, 5 days per week at a moderate intensity.

1	2	3	4	5	6	7
strongly disagree	moderately disagree	slightly disagree	neither	slightly agree	moderately agree	strongly agree

3. I intend to exercise for at least 20 minutes, 3 days per week at a vigorous intensity.

1	2	3	4	5	6	7
strongly disagree	moderately disagree	slightly disagree	neither	slightly agree	moderately agree	strongly agree

The next set of questions asks about your exercise counseling preferences. Check only one response for each question unless otherwise indicated.

1. I would have preferred to have been counseled about exercise at some point after my diagnosis of endometrial cancer

yes _____ no _____ maybe _____

*Even if you responded NO to the above question, please answer the following set of questions:

2. If you were to receive exercise counseling, who would you prefer this counseling from?

a. oncologist _____ b. nurse _____ c. a cancer patient or survivor _____

d. exercise specialist affiliated with _____ e. exercise specialist affiliated with _____
a community fitness centre a cancer center

3. If you were to receive exercise counseling, when would you prefer this counseling?

1	2	3	4	5
before treatment	during treatment	immediately after treatment	3-6 months after treatment	at least 1 year after treatment

4. If you were to receive exercise counseling, where would you prefer this counseling to take place?

a. cancer center _____ b. community center _____ c. my home _____
d. other _____ (specify)

5. If you were to receive exercise counseling, how would you prefer to be counseled?

a. face to face ___ b. telephone ___ c. brochure ___ d. other (specify): _____

The next set of questions asks about your exercise programming preferences. Check only one response for each question unless otherwise indicated

1. Would you be interested in an exercise program designed for endometrial cancer survivors?
yes _____ no _____ maybe _____

2. Do you think you would be able to participate in an exercise program designed for endometrial cancer survivors?

yes _____ no _____ maybe _____

3. If you were to exercise, what types of exercises would you be most interested in doing?

1. _____ 2. _____ 3. _____

4. If you were to begin an exercise program, when would you prefer this program to start?

1	2	3	4	5
before treatment	during treatment	immediately after treatment	3-6 months after treatment	at least 1 year after treatment

5. If I were to exercise regularly, I would prefer to exercise (check only one for each question):

1. ___ alone ___ with other cancer survivors ___ with friends ___ with family ___ no preference

___ at home ___ at a community fitness center ___ at a cancer fitness center ___ no preference

3. ___ morning ___ afternoon ___ evening ___ no preference

6. My favorite exercise during the summer is:
Please list:

7. My favorite exercise during the winter is:
Please list:

8. If I were to exercise regularly, I would prefer the exercise to be (check only one for each question):

1. light intensity moderate intensity vigorous intensity no preference

2. the same activity each exercise session different activities each exercise session

3. supervised/instructed unsupervised/self-paced

4. spontaneous/flexible scheduled (i.e., specific days/times)

9. Do you have any of the following exercise equipment in your home? (please check all that apply):

treadmill cycle ergometer stair rowing skiing
(stationary bike) stepper machine machine

abdominal machine other (please list) _____

10. Do you have a current membership at any fitness center?

no yes (please list) _____

This part of the questionnaire is needed to help understand the characteristics of the people participating in the study. For this reason it is very important information. All information is held in strict confidence.

1. Age: _____

2. Marital status:

never _____ married _____ common law _____ separated _____
married

widowed _____ divorced _____

3. Number of children:

a. number of children _____ b. number of children living at home: _____

4. Education (please check highest level attained):

some high school _____ completed high school _____

some university/college _____ completed university/college _____

some graduate school _____ completed graduate school _____

5. Annual family income:

< 20,000 _____ 20-39,999 _____ 40-59,999 _____

60-79,999 _____ 80-99,999 _____ >100,000 _____

6. Employment status

disability _____ retired _____ part-time _____

full-time _____ temporarily unemployed _____

7. Height: _____

8. Weight: _____

This part of the questionnaire is needed to help understand the medical characteristics of the people participating in the study. For this reason it is very important information. All information is held in strict confidence. If you do not know the answers to some of the medical questions, just circle 'don't know' (DK). Please answer the questions to the best of your knowledge.

1. When were you diagnosed with endometrial cancer _____ DK
(month/year)?

2. What was the stage of your cancer at diagnosis (i.e, I, II, III)? _____ DK

3. Did your treatment include surgery (please circle)? yes no DK

a. If yes, what kind of surgery did you have? _____ DK

b. If yes, what was the date of your surgery _____ DK
(month/year)?

4. Did your treatment include chemotherapy (please circle)? yes no DK

a. If yes, how many cycles or courses did you receive? _____ DK

b. If yes, when did it end (month/year)? _____ DK

5. Did your treatment include external radiation therapy (please circle)? yes no DK

a. If yes, for how many weeks? _____ DK

b. If yes, when did it end (month/year)? _____ DK

6. Did your treatment include internal radiation therapy (please circle)? yes no DK

a. If yes, for how many weeks? _____ DK

b. If yes, when did it end (month/year)? _____ DK

7. Did your treatment include hormone therapy (please circle)? yes no DK

a. If yes, for how many weeks? _____ DK

b. If yes, when did it end (month/year)? _____ DK

Appendix H
Bladder Cancer Study Physician Cover Letter

<<Date>>
<<Name>>
<<Address>>
<<City/Province>>
<<Postal Code>>

Dear <<Salutation>>:

My name is Dr. Kerry Courneya and I am a Professor in the Faculty of Physical Education and an Adjunct Professor in the Department of Oncology at the University of Alberta. I am also a member of the Scientific Staff of the Cross Cancer Institute (Edmonton). As part of my responsibilities, I conduct research in the area of exercise and cancer. I am currently conducting a survey study which requires the voluntary participation of bladder cancer survivors (please see the attached study protocol for more details). My co-investigators on the project are Dr. Peter Venner and Dr. Scott North, medical oncologists at the Cross Cancer Institute. This study has been reviewed by the Alberta Cancer Board's Research Ethics Board, and the University of Alberta Health Research Ethics Board, and has met the rigorous requirements for ethical approval. You have been contacted because you are the referring physician or surgeon of an individual, or individuals, whose name(s) have been identified through the Alberta Cancer Registry as meeting our inclusion criteria. As part of the current ethical approval process, we must obtain "active consent" from the physicians of these individuals before our study can commence.

We are only asking your permission to mail the identified patient(s) an information and questionnaire package. The patient will then have the option of whether to volunteer by completing the questionnaire or not. If you consent to the contact of this/these individuals(s), or there are any compelling reasons for not mailing this information to this/these individuals (e.g. patient is deceased, unable to give informed consent), please phone the Behavioral Medicine Laboratory: Kristina Karvinen (780) 492-2829, Fax (780) 492-8003, or email: karvinen@ualberta.ca.

I hope to hear from you, or from one of your representatives, in the near future. If I have not received correspondence from you within the next three weeks, I will then be in contact with you by telephone at that time. Thank you in advance for your cooperation.

Sincerely,

Kerry S. Courneya, PhD
Professor
E-424 Van Vliet Center
University of Alberta
Edmonton, Alberta
T6G 2H9 CANADA
Fax (780) 492-8003

Individual(s) whose name(s) has been identified through the Alberta Cancer Registry as meeting our inclusion criteria:

Patient Name	Permission to Contact?	
1.	Yes	No
2.	Yes	No
3.	Yes	No
4.	Yes	No
5.	Yes	No
6.	Yes	No
7.	Yes	No
8.	Yes	No
9.	Yes	No
10.	Yes	No

Appendix I
Bladder Cancer Study Patient Cover Letter

<<Date>>

<<Name>>

<<Address>>

<<City/Province>>

<<Postal Code>>

Dear <<Salutation>>:

We are writing to request your participation in a research study exploring the potential role of physical exercise in bladder cancer survivors. The study protocol has been approved by the Alberta Cancer Board's Research Ethics Board and the University of Alberta Health Research Ethics Board. Your oncologist or physician has given us permission to contact you.

Recent research has suggested that exercise is beneficial for cancer patients and survivors. However, no study to date has examined the potential role of exercise in bladder cancer survivors. The information gained from this questionnaire will be used to evaluate the potential role of physical exercise as an intervention to improve quality of life in bladder cancer survivors. Any future secondary analyses of the information collected will require further approval from the above ethics boards.

To participate in the study all you need to do is complete the enclosed questionnaire and return it to us at your earliest convenience in the self-addressed stamped envelope. In approximately three months, we will mail you another, similar questionnaire that we will ask you to return. Even if you don't currently exercise, your participation in this study is still extremely valuable. Your participation involves only the completion of these questionnaires. For this study, you will not be asked to follow an exercise program; we are merely interested in your current and past exercise behaviours. It is only by understanding the issues of both exercisers and non-exercisers that we can hope to gain a complete understanding of the potential role of exercise in bladder cancer survivors.

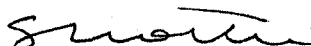
Each questionnaire should take approximately 45 to 60 minutes each to complete. There are no right or wrong answers and all we ask is that you provide responses that are as honest and accurate as possible. You may choose to leave any question in the questionnaire unanswered. Finally, please read and sign one copy of the consent form and return it along with the questionnaire. A second copy of the consent form is enclosed for your records.

If you have any questions about the study, or about completing the questionnaire, please feel free to contact Tina Karvinen by telephone at (780) 492-2829 or e-mail at karvinen@ualberta.ca. Thank you for considering our study.


Sincerely,



Kerry S. Courneya, PhD
Professor
E-424 Van Vliet Center
University of Alberta
Edmonton, Alberta
T6G 2H9 CANADA
Tel: (780) 492-1031



Scott North, MD
Medical Oncologist
Department of Medicine
Cross Cancer Institute
11560 University Ave.
Edmonton, Alberta
T6G 1Z2 CANADA
Tel: (780) 432-8762



Peter Venner, MD
Medical Oncologist
Department of Medicine
Cross Cancer Institute
11560 University Ave.
Edmonton, Alberta
T6G 1Z2 CANADA
Tel: (780) 432-8757

Appendix J
Bladder Cancer Study Consent Form

A Pilot Study Examining the Relationship Between Physical Exercise and Quality of Life in Bladder Cancer Survivors

(Physical Exercise and Quality of Life in Bladder Cancer Survivors)

CONSENT FORM

This consent form is part of the process of informed consent. It is designed to give you an idea of what this research study is about and what will happen to you if you choose to be in the study. Read this form carefully to make sure you understand all the information it provides. You will get a copy of this form to keep.

Your participation in this study is entirely voluntary. You do not have to take part in this study and your care does not depend on whether you choose to participate or not. This study may or may not help you directly, but we hope that it will teach us something that will help other bladder cancer survivors in the future.

BACKGROUND INFORMATION

Recent research has indicated that physical exercise may be beneficial for cancer survivors. To date, no study has examined the role of exercise in improving quality of life in bladder cancer survivors. The information gained from this study will be used to evaluate the effectiveness of physical exercise in improving quality of life in bladder cancer survivors.

STUDY PURPOSE

The purpose of this study will be to assess the role of physical exercise in quality of life in bladder cancer survivors, as well as their attitudes and beliefs towards exercise.

STUDY DESIGN

If you agree to participate in this research study, you will be asked to complete the attached questionnaire and sign one copy of this consent form. We request that you return both the questionnaire and the signed consent by mailing them in the

Patient Initials: _____ Date: _____

postage-paid envelope provided. The questionnaire will take approximately 45 to 60 minutes to complete. In three months time we will mail you another similar questionnaire that we will ask you to complete and return to us. If any of the questions ask for information that you are not comfortable in providing, please feel free to leave those questions blank and move on to the next question.

POTENTIAL RISKS AND BENEFITS

Some possible risk is involved if you choose to participate in this study. We will be asking you to recall your cancer experience, which for some may be traumatic. If this is problematic for you, you need not participate. If you would like someone to speak to about your cancer experience, you may contact the Department of Psychology at the Cross Cancer Institute (780) 432-8703 / (780) 432-8771 (switchboard) or the Department of Psychosocial Resources at the Tom Baker Cancer Centre (403) 670-1767. We do not expect that participation in this study will personally benefit you, however, your participation may help improve patient care in the long term.

CONFIDENTIALITY

The information that we collect as part of this study will be shared with other researchers and doctors. You, however, will not be identified in any of these reports. All questionnaires that are mailed to you will be marked with a study number so we are aware who has responded. Additionally, this number will be used to link information from the first questionnaire to the second questionnaire and to data available from the Alberta Cancer Registry. All information collected for this study will be stored in a safe storage area in the Behavioural Medicine Laboratory at the University of Alberta.

Potentially identifying information will be collected during this study from the questionnaire package. This information may be used by the researchers who are carrying out the study, and may be disclosed to others as described below. Any research program that uses information that identifies you for a purpose other than this study must be approved in advance by the ACB Research Ethics Board.

Your identifiable information may need to be inspected or copied from time to time for quality assurance (to make sure the information being used in the study is accurate) and for data analysis (to do statistical analysis that will not identify you). The following organization will do this inspection:

- Alberta Cancer Board Research Ethics Board, the institutional review board at this centre
- University of Alberta Behavioural Medicine Laboratory
- Office of the Information and Privacy Commissioner

Patient Initials: _____ Date: _____

Direct access to your identifiable information collected for this study will be restricted to the researchers who are directly involved in this study except in the following circumstances. Records may be reviewed by the Alberta Cancer Board Research Ethics Board and/or the University of Alberta Health Research Ethics Board Panel B.

UNDERSTANDING OF PARTICIPANTS

- I have read and understood all of the information in this consent form. I have asked questions, and received answers concerning areas I did not understand. My consent has not been forced or influenced in any way. I consent to participate in this research study. Upon signing this form I will receive a signed copy of the consent.
- I can refuse to take part or withdraw from this study at any time without jeopardizing my health care. If I continue to take part in the study, I am to be kept as informed as my initial consent. I am free to ask for further explanations about this study. I understand that I may contact Kristina Karvinen at (780) 492-2829, Dr. Kerry Courneya at (780) 492-1031, Dr. Peter Venner at (780) 432-8757, or Dr. Scott North at (780) 432-8762 to answer any questions I have about this study.
- If I feel at any time that I have not been informed to my satisfaction about the risks, benefits, or alternatives of this study, or that I have been encouraged to continue in this study after I wanted to withdraw, I can call the Patient Representative at (780) 432-8585.
- I will get to keep a copy of this consent for information and for future reference.

Patient Initials: _____ Date: _____

(PRINT NAMES)

Name of Patient

Signature of Patient

Date

Name of Witness

Signature of Witness

Date

Name of Investigator

Signature of Investigator

Date

Appendix K
Bladder Cancer Study Baseline Questionnaire



Exercise and Bladder Cancer Questionnaire

**Kerry S. Courneya, PhD, Peter Venner, MD,
& Scott North, MD**

CROSS CANCER INSTITUTE AND UNIVERSITY OF ALBERTA

Instructions*

Thank you for your participation in this study. In this questionnaire, we are going to ask you a series of questions about yourself. There are no right or wrong answers and all we ask is that you provide responses that are as honest and accurate as possible. The questionnaire should take about 45-60 minutes to complete. All responses are completely confidential and will never be used in any way that could link them to you.

Below is a list of statements that other people with cancer have said are important to their quality of life. Please indicate the extent to which you have experienced each of the statements during the past 7 days by circling the appropriate number using the following scale. It is important that you answer these questions even if it has been many years since your bladder cancer diagnosis.

0	1	2	3	4
Not at all	a little bit	somewhat	quite a bit	very much

During the past week:

PHYSICAL WELL-BEING

1. I have a lack of energy	0	1	2	3	4
2. I have nausea	0	1	2	3	4
3. Because of my physical condition, I have trouble meeting the needs of my family	0	1	2	3	4
4. I have pain	0	1	2	3	4
5. I am bothered by side effects of treatment	0	1	2	3	4
6. I feel sick	0	1	2	3	4
7. I am forced to spend time in bed	0	1	2	3	4

SOCIAL/FAMILY WELL-BEING

8. I feel close to my friends	0	1	2	3	4
9. I get emotional support from my family	0	1	2	3	4
10. I get support from my friends	0	1	2	3	4
11. My family has accepted my illness	0	1	2	3	4
12. I am satisfied with family communication about my illness	0	1	2	3	4
13. I feel close to my partner (or the person who is my main support)	0	1	2	3	4

EMOTIONAL WELL-BEING

14. I feel sad	0	1	2	3	4
15. I am proud of how I am coping with my illness	0	1	2	3	4
16. I am losing hope in the fight against my illness	0	1	2	3	4

0	1	2	3	4
not at all	a little bit	somewhat	quite a bit	very much

During the past week:

17. I feel nervous	0	1	2	3	4
18. I worry about dying	0	1	2	3	4
19. I worry that my condition will get worse	0	1	2	3	4

FUNCTIONAL WELL-BEING

20. I am able to work (include work at home)	0	1	2	3	4
21. My work is fulfilling (include work at home)	0	1	2	3	4
22. I am able to enjoy life	0	1	2	3	4
23. I have accepted my illness	0	1	2	3	4
24. I am sleeping well	0	1	2	3	4
25. I am enjoying the things I usually do for fun	0	1	2	3	4
26. I am content with the quality of my life right now	0	1	2	3	4

ADDITIONAL CONCERNS

27. I have trouble controlling my urine	0	1	2	3	4
28. I am losing weight	0	1	2	3	4
29. I have control of my bowels	0	1	2	3	4
30. I urinate more frequently than usual	0	1	2	3	4
31. I have diarrhea	0	1	2	3	4
32. I have a good appetite	0	1	2	3	4
33. I like the appearance of my body	0	1	2	3	4
34. It burns when I urinate	0	1	2	3	4

	0	1	2	3	4
	Not at all	a little bit	somewhat	quite a bit	very much
35. I am interested in sex				0	1 2 3 4
36. (For men only) I am able to have and maintain an erection				0	1 2 3 4
37. Do you have an ostomy appliance? No ___ Yes ___ If yes, answer the following two items					
38. I am embarrassed by my ostomy appliance				0	1 2 3 4
39. Caring for my ostomy appliance is difficult				0	1 2 3 4

The following section asks about any fatigue that you have been feeling. For each of the questions, circle the one number that best indicates how that question applies to you.

1. Rate your level of fatigue on the day you **felt most** fatigued during the past week.

0 1 2 3 4 5 6 7 8 9 10
Not at all fatigued As fatigued as I could be

2. Rate your level of fatigue on the day you **felt least** fatigued during the past week.

0 1 2 3 4 5 6 7 8 9 10
Not at all fatigued As fatigued as I could be

3. Rate your level of fatigue on the **average** in the last week.

0 1 2 3 4 5 6 7 8 9 10
Not at all fatigued As fatigued as I could be

4. Rate your level of fatigue **right now**.

0 1 2 3 4 5 6 7 8 9 10
Not at all fatigued As fatigued as I could be

5. Rate how much, in the past week, fatigue interfered with your **general level of activity**.

0 1 2 3 4 5 6 7 8 9 10
No interference Extreme interference

6. Rate how much, in the past week, fatigue interfered with your **ability to bathe and dress yourself.**

0 1 2 3 4 5 6 7 8 9 10
No interference Extreme interference

7. Rate how much, in the past week, fatigue interfered with your **normal work activity** (includes both work outside the home and housework).

0 1 2 3 4 5 6 7 8 9 10
No interference Extreme interference

8. Rate how much, in the past week, fatigue interfered with your **ability to concentrate.**

0 1 2 3 4 5 6 7 8 9 10
No interference Extreme interference

9. Rate how much, in the past week, fatigue interfered with your **relations with other people.**

0 1 2 3 4 5 6 7 8 9 10
No interference Extreme interference

10. Rate how much, in the past week, fatigue interfered with your **enjoyment of life.**

0 1 2 3 4 5 6 7 8 9 10
No interference Extreme interference

11. Rate how much, in the past week, fatigue interfered with your **mood.**

0 1 2 3 4 5 6 7 8 9 10
No interference Extreme interference

12. Indicate **how many days**, in the past week, you felt fatigued for any part of the day.

0 1 2 3 4 5 6 7
Days Days

13. Rate **how much of the day**, on average, you felt fatigued in the past week.

0 1 2 3 4 5 6 7 8 9 10
None of the day The entire day

For the next three questions, we would like you to recall your average weekly exercise in the **months before your bladder cancer diagnosis, during any treatment(s) you received for bladder cancer, and in the last three months.**

When answering these questions please:

- Only count exercise sessions that lasted 10 minutes or longer in duration
- Only count exercise that was done during free time (i.e., not occupation or housework)
- Note that the main difference between the three categories is the intensity of the exercise
- Please write the average frequency on the first line and the average duration on the second. If you did not perform any exercise at a given intensity, please write '0' in that space.

1. For this first question, we would like you to recall your average weekly exercise in the **months before you were diagnosed** with bladder cancer. Considering a typical week (7 days), how many times, on average, did you perform the following kinds of exercise:

	Times Per Week	Average Duration
j. MILD EXERCISE (MINIMAL EFFORT, NO PERSPIRATION) (e.g., easy walking, yoga, bowling, lawn bowling, shuffleboard, golf)	_____	_____
k. MODERATE EXERCISE (NOT EXHAUSTING, LIGHT PERSPIRATION) (e.g., fast walking, tennis, easy bicycling, easy swimming, popular and folk dancing)	_____	_____
l. STRENUOUS EXERCISE (HEART BEATS RAPIDLY, SWEATING) (e.g., running, aerobics classes, cross country skiing, vigorous swimming, vigorous bicycling)	_____	_____

2. For this second question, we would like you to recall your average weekly exercise **during the time you were receiving treatment** for bladder cancer (e.g. radiotherapy, chemotherapy). Considering a typical week (7 days), how many times, on average, did you perform the following kinds of exercise:

	Times Per Week	Average Duration
m. MILD EXERCISE (MINIMAL EFFORT, NO PERSPIRATION) (e.g., easy walking, yoga, bowling, lawn bowling, shuffleboard, golf)	_____	_____
n. MODERATE EXERCISE (NOT EXHAUSTING, LIGHT PERSPIRATION) (e.g., fast walking, tennis, easy bicycling, easy swimming, popular and folk dancing)	_____	_____
o. STRENUOUS EXERCISE (HEART BEATS RAPIDLY, SWEATING) (e.g., running, aerobics classes, cross country skiing, vigorous swimming, vigorous bicycling)	_____	_____

3. For this final question, we would like you to recall your average weekly exercise **in the last three months**. Considering a typical week (7 days), how many times, on average, have you performed the following kinds of exercise:

	Times Per Week	Average Duration
p. MILD EXERCISE (MINIMAL EFFORT, NO PERSPIRATION) (e.g., easy walking, yoga, bowling, lawn bowling, shuffleboard, golf)	_____	_____
q. MODERATE EXERCISE (NOT EXHAUSTING, LIGHT PERSPIRATION) (e.g., fast walking, tennis, easy bicycling, easy swimming, popular and folk dancing)	_____	_____
r. STRENUOUS EXERCISE (HEART BEATS RAPIDLY, SWEATING) (e.g., running, aerobics classes, cross country skiing, vigorous swimming, vigorous bicycling)	_____	_____

The following section asks you to recall how often, in a **typical week** over the past three months, you spent time doing the following **sport and recreational activities**:

- sitting activities
- walking
- light intensity activities
- moderate intensity activities
- vigorous intensity activities

Please complete this section by either circling the correct response or filling in the blank.

1. Over the past 3 months, how often, in a **typical week**, did you participate in **sitting** activities such as reading, watching TV, or doing handicrafts?

[0] NEVER

[1] SELDOM
(1-2 DAYS)

[2] SOMETIMES
(3-4 DAYS)

[3] OFTEN
(5-7 DAYS)

↓
GO TO
QUESTION
2

1a. What were these activities?

1b. On average, how many hours per day did you engage in these sitting activities?

[1] LESS THAN 1 HOUR [2] LESS THAN 2 HOURS

[3] 2-4 HOURS [4] MORE THAN 4 HOURS

2. Over the past 3 months, how often, in a **typical week**, did you **take a walk** outside your home or yard for any reason? For example, for fun or exercise, walking to work, walking the dog, etc.?

[0] NEVER

[1] SELDOM
(1-2 DAYS)

[2] SOMETIMES
(3-4 DAYS)

[3] OFTEN
(5-7 DAYS)

↓
GO TO
QUESTION
3

2a. On average, how many hours per day did you spend walking?

[1] LESS THAN 1 HOUR [2] LESS THAN 2 HOURS

[3] 2-4 HOURS [4] MORE THAN 4 HOURS

3. Over the past 3 months, how often, **in a typical week**, did you engage in **light sport or recreational activities** such as bowling, golf with a cart, shuffleboard, fishing from a boat or pier, or other similar activities?

[0] NEVER

[1] SELDOM
(1-2 DAYS)

[2] SOMETIMES
(3-4 DAYS)

[3] OFTEN
(5-7 DAYS)

↓
GO TO
QUESTION
4

3a. What were these activities?

3b. On average, how many hours per day did you engage in these light sport or recreational activities?

[1] LESS THAN 1 HOUR [2] LESS THAN 2 HOURS

[3] 2-4 HOURS [4] MORE THAN 4 HOURS

4. Over the past 3 months, how often, **in a typical week**, did you engage in **moderate sport and recreational activities** such as doubles tennis, ballroom dancing, hunting, ice skating, golf without a cart, softball, or other similar activities?

[0] NEVER

[1] SELDOM
(1-2 DAYS)

[2] SOMETIMES
(3-4 DAYS)

[3] OFTEN
(5-7 DAYS)

↓
GO TO
QUESTION
5

4a. What were these activities?

4b. On average, how many hours per day did you engage in these moderate sport and recreational activities?

[1] LESS THAN 1 HOUR [2] LESS THAN 2 HOURS

[3] 2-4 HOURS [4] MORE THAN 4 HOURS

5. Over the past 3 months, how often, **in a typical week**, did you engage in **strenuous sport and recreational activities** such as jogging, swimming, cycling, singles tennis, aerobic dance, skiing (downhill or cross-country) or other similar activities?

[0] NEVER

[1] SELDOM
(1-2 DAYS)

[2] SOMETIMES
(3-4 DAYS)

[3] OFTEN
(5-7 DAYS)

↓
GO TO
QUESTION
6

5a. What were these activities?

5b. On average, how many hours per day did you engage in these strenuous sport and recreational activities?

[1] LESS THAN 1 HOUR [2] LESS THAN 2 HOURS

[3] 2-4 HOURS [4] MORE THAN 4 HOURS

6. Over the past 3 months, how often, **in a typical week**, did you do any exercises specifically to increase **muscle strength and endurance**, such as lifting weights or pushups, etc?

[0] NEVER

[1] SELDOM
(1-2 DAYS)

[2] SOMETIMES
(3-4 DAYS)

[3] OFTEN
(5-7 DAYS)

↓
GO TO
QUESTION
7

6a. What were these activities?

6b. On average, how many hours per day did you engage in exercises to increase muscle strength and endurance?

[1] LESS THAN 1 HOUR [2] LESS THAN 2 HOURS

[3] 2-4 HOURS [4] MORE THAN 4 HOURS

The following section asks you about any housework, chores, or work for pay or as a volunteer that you have did in a **typical week** over the past three months. Please circle the correct response:

7. During the past 3 months, **in a typical week**, did you do any **light housework**, such as dusting or washing dishes?

[1] NO [2] YES

8. During the past 3 months, **in a typical week**, did you do any **heavy housework or chores**, such as vacuuming, scrubbing floors, washing windows, or carrying wood?

[1] NO [2] YES

9. During the past 3 months, **in a typical week**, did you engage in any of the following activities?

(a) Home repairs like painting, wallpapering, electrical work, etc.

[1] NO [2] YES

(b) Lawn work or yard care, including snow or leaf removal, wood chopping, etc

[1] NO [2] YES

(c) Outdoor gardening

[1] NO [2] YES

(d) Caring for an other person, such as children, dependent spouse, or another adult

[1] NO [2] YES

10. During the past 3 months, **in a typical week**, did you work for pay or as a volunteer?

[1] NO [2] YES

If yes, please complete the next two questions (10a, 10b):

10a. How many hours per week did you work for pay and/or as a volunteer?

_____ hours

10b. Which of the following categories best describes the amount of physical activity required in your job and/or volunteer work? (circle one)

- [1] Mainly sitting with slight arm movements (examples: office worker, watchmaker, seated assembly line worker, bus driver, etc)
- [2] Sitting or standing with some walking (examples: cashier, general office worker, light tool and machinery worker)
- [3] Walking, with some handling of materials generally weighing less than 50 pounds (examples: mailman, waiter/waitress, construction worker, heavy tool and machinery worker)
- [4] Walking and heavy manual work often requiring handling of materials weighing over 50 pounds (examples: lumberjack, stone mason, farm or general labourer)

For this next set of questions, we ask you to focus specifically on regular exercise. **We define regular exercise as any physical activity performed either at moderate intensity (e.g. brisk walking, dancing, tennis) for at least 30 minutes, 5 times per week, or at vigorous intensity (e.g. running, vigorous bicycling, aerobics) for at least 20 minutes, 3 times per week.**

What do you think, for you, would be the main advantages and disadvantages of participating in regular exercise?

Main Advantages

Main Disadvantages

_____	_____
_____	_____
_____	_____

What factors do you think would it make it easier or more difficult for you to exercise regularly?

Preventive Factors

Helpful Factors

_____	_____
_____	_____
_____	_____

What people or groups would approve or disapprove of you performing regular exercise? (e.g. husband, doctor, daughter, etc., do not provide actual names of individuals)

People that would approve

People that would disapprove

_____	_____
_____	_____
_____	_____

Please respond to the following questions by circling the number that corresponds to the answer in *each* row that best describes how you feel about exercise.

1) For me, exercising regularly over the next three months would be:

- a)
- | | | | | | | |
|----------------------|------------------|---------------------|---|--------------------|-----------------|---------------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| extremely
useless | quite
useless | slightly
useless | | slightly
useful | quite
useful | extremely
useful |
- b)
- | | | | | | | |
|--------------------------|----------------------|-------------------------|---|-----------------------|--------------------|------------------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| extremely
unenjoyable | quite
unenjoyable | slightly
unenjoyable | | slightly
enjoyable | quite
enjoyable | extremely
enjoyable |
- c)
- | | | | | | | |
|----------------------|------------------|---------------------|---|------------------------|---------------------|-------------------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| extremely
harmful | quite
harmful | slightly
harmful | | slightly
beneficial | quite
beneficial | extremely
beneficial |
- d)
- | | | | | | | |
|---------------------|-----------------|--------------------|---|-----------------|--------------|------------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| extremely
boring | quite
boring | slightly
boring | | slightly
fun | quite
fun | extremely
fun |
- e)
- | | | | | | | |
|----------------------|------------------|---------------------|---|------------------|---------------|-------------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| extremely
foolish | quite
foolish | slightly
foolish | | slightly
wise | quite
wise | extremely
wise |
- f)
- | | | | | | | |
|-------------------------|---------------------|------------------------|---|----------------------|-------------------|-----------------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| extremely
unpleasant | quite
unpleasant | slightly
unpleasant | | slightly
pleasant | quite
pleasant | extremely
pleasant |

1. Most people who are important to me think I should exercise regularly over the next three months:

- | | | | | | | |
|----------------------|------------------------|----------------------|---------|-------------------|---------------------|-------------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| strongly
disagree | moderately
disagree | slightly
disagree | neither | slightly
agree | moderately
agree | strongly
agree |

2. Most people who are important to me would encourage me to exercise regularly over the next three months:

- | | | | | | | |
|----------------------|------------------------|----------------------|---------|-------------------|---------------------|-------------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| strongly
disagree | moderately
disagree | slightly
disagree | neither | slightly
agree | moderately
agree | strongly
agree |

3. Most people who are important to me would support me exercising regularly over the next three months:

- | | | | | | | |
|----------------------|------------------------|----------------------|---------|-------------------|---------------------|-------------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| strongly
disagree | moderately
disagree | slightly
disagree | neither | slightly
agree | moderately
agree | strongly
agree |

4. Most people who are important to me will be doing an exercise program themselves over the next three months:

1	2	3	4	5	6	7
strongly disagree	moderately disagree	slightly disagree	neither	slightly agree	moderately agree	strongly agree

5. In the next three months, most people who are important to me will be:

1	2	3	4	5	6	7
extremely inactive	quite inactive	slightly inactive	neutral	slightly active	quite active	extremely active

6. In the next three months, exercise levels of most people who are important to me will be:

1	2	3	4	5	6	7
extremely low	quite low	slightly low	neutral	slightly high	quite high	extremely high

Please use the scale below each question to guide your responses to the next set of questions

If you were really motivated, exercising regularly over the next three months would be:

1	2	3	4	5	6	7
extremely difficult	quite difficult	slightly difficult	neither	slightly easy	quite easy	extremely easy

If you were really motivated, how confident are you that you would be capable of exercising regularly over the next three months?

1	2	3	4	5	6	7
not at all confident			moderately confident			extremely confident

If you were really motivated, how much control do you feel you would have over exercising regularly over the next three months?

1	2	3	4	5	6	7
very little control			moderate control			complete control

If you were really motivated, how certain or uncertain would you be that you could exercise regularly over the next month?

1	2	3	4	5	6	7
extremely uncertain	quite uncertain	slightly uncertain	neutral	slightly certain	quite certain	extremely certain

The next set of questions ask you about your plans for regular exercise over the next three months.

4. I intend to exercise at least ____ times per week (please insert a number that indicates how many times you intend to exercise), at a duration of ____ minutes per session, at a **moderate** intensity over the next three months.
5. I intend to exercise at least ____ times per week (please insert a number that indicates how many times you intend to exercise), at a duration of ____ minutes per session, at a **vigorous** intensity over the next three months.
6. I intend to exercise for at least 30 minutes, 5 days per week at a moderate intensity over the next three months.

1	2	3	4	5	6	7
strongly disagree	moderately disagree	slightly disagree	neither	slightly agree	moderately agree	strongly agree

7. I intend to exercise for at least 20 minutes, 3 days per week at a vigorous intensity over the next three months.

1	2	3	4	5	6	7
strongly disagree	moderately disagree	slightly disagree	neither	slightly agree	moderately agree	strongly agree

8. I have decided exactly how I am going to exercise vigorously at least 3 times per week for the next 2 weeks.

<i>Definitely Yes</i>	1	2	3	4	5	6	7
<i>Definitely No</i>							

9. I have made plans about how I am going to exercise vigorously at least 3 times per week for the next 2 weeks.

<i>Strongly Disagree</i>	1	2	3	4	5	6	7
<i>Strongly Agree</i>							

10. I have made a detailed plan regarding...

- a. when to exercise over the next week true not at all true 1 2 3 4 5 6 7 exactly true
- b. where to exercise over the next week true not at all true 1 2 3 4 5 6 7 exactly true
- c. how to exercise over the next week true not at all true 1 2 3 4 5 6 7 exactly true
- d. how often to exercise over the next week true not at all true 1 2 3 4 5 6 7 exactly true

The following question asks you to recall your current exercise pattern. Read all statements first, then place an "X" beside the statement that best describes your current exercise pattern.

Currently:

_____ I am not exercising regularly and I am not thinking about starting in the near future.

_____ I am not exercising regularly, but I am thinking about starting in the near future.

_____ I am not exercising regularly, but have decided to start in the next month.

_____ I am exercising regularly but have only begun to do so in the last six months.

_____ I am exercising regularly and have been doing so for longer than six months

This part of the questionnaire is needed to help understand the characteristics of the people participating in the study. For this reason it is very important information. All information is held in strict confidence.

Age: _____

Marital status:

never _____ married _____ common law _____ separated _____
married

widowed _____ divorced _____

Number of children:

a. number of children _____ number of children living at home: _____

Education (please check highest level attained):

some elementary _____ completed elementary school _____
school

some high school _____ completed high school _____

Some university/college _____ completed university/college _____

some graduate school _____ completed graduate school (e.g. Masters degree, PhD) _____
(e.g. Masters degree, PhD)

Annual family income:

< 20,000 _____ 20-39,999 _____ 40-59,999 _____

60-79,999 _____ 80-99,999 _____ >100,000 _____

Employment status

disability _____ retired _____ part-time _____

full-time _____ temporarily unemployed _____

7. Height: _____

8. Weight: _____

9. What is your ethnic origin or ancestry? _____

This part of the questionnaire is needed to help understand the medical characteristics of the people participating in the study. For this reason it is very important information. All information is held in strict confidence. If you do not know the answers to some of the medical questions, just circle 'don't know' (DK). Please answer the questions to the best of your knowledge.

1. When were you first diagnosed with bladder cancer _____ DK
(month/year)?

2. Did your treatment include transurethral resection yes no DK
(TUR)(scraping of the bladder) (please circle)?

3. Did your treatment include intravesical therapy yes no DK
(treatment injected in the bladder) (please circle)?

4. Did your treatment include systemic chemotherapy (in the yes no DK
vein) (please circle)?

Did your treatment include radiation therapy (please yes no DK
circle)?

6. Did your treatment include cystectomy (surgical yes no DK
removal of the bladder) (please circle)?

7. Since your first treatment of bladder cancer, have you experienced a recurrence? yes no DK

a. If yes, when was your most recent recurrence diagnosed? _____ DK

8. What is the current status of your bladder cancer?

_____ the doctors have told me that bladder cancer is gone from my body.

_____ the doctors have told me that I still have bladder cancer in my body

9. Which of the following best describes your current smoking status?

_____ Never Smoked _____ Ex-Smoker _____ Occasional Smoker

_____ Regular Smoker (smoke every day)

10. Has a doctor or nurse ever told you that you had any of the following conditions? (please check)

High blood pressure _____ No _____ Yes High cholesterol _____ No
 _____ Yes

Heart attack _____ No _____ Yes Stroke _____ No
 _____ Yes

Emphysema _____ No _____ Yes Chronic bronchitis _____ No
 _____ Yes

Diabetes _____ No _____ Yes Other cancer _____ No
 _____ Yes

Angina (chest pains) _____ No _____ Yes Arthritis _____ No _____ Yes

Any other long term health condition?

How long did it take you to complete this questionnaire? _____

Appendix L
Bladder Cancer Study Patient Three-Month Cover Letter

<<Date>>
<<Name>>
<<Address>>
<<City/Province>>
<<Postal Code>>

Dear <<Salutation>>:

Thank you for your continued participation in our exercise study! We very much appreciated your completion of the questionnaire we mailed you 3 months ago. We actually had over 500 bladder cancer survivors complete the questionnaire and provide us with very important information! We now need everyone to complete the second and final part of the study to make the study a success. The final part of this study only involves the completion of the enclosed questionnaire, nothing else. You will not be asked to complete any more questionnaires. This is the last component of the study.

To continue participating in the study all you need to do is complete the enclosed questionnaire and return it to us at your earliest convenience in the self-addressed stamped envelope. Your continued participation in the study is absolutely vital to the study's success. If you decide you do not wish to participate in the study any further, simply send us back the unanswered questionnaire and that way we know not to contact you again. If we have not heard from you in a couple of weeks, we will send you a post card reminder in the mail followed by another copy of the questionnaire a couple of weeks after that.

Thank you again for your important contribution to this study. It is only through the good will of people like yourself that we are able to obtain important information that we can use to help improve the care of bladder cancer survivors. If you have any questions about the study, or about completing the questionnaire, please feel free to contact Tina Karvinen by phone at (780) 492-2829 (call collect if necessary) or e-mail at karvinen@ualberta.ca. We hope to hear from you soon.

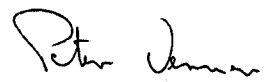
Sincerely,



Kerry S. Courneya, PhD
Professor
University of Alberta



Scott North, MD
Medical Oncologist
Cross Cancer Institute



Peter Verner, MD
Medical Oncologist
Cross Cancer Institute

Appendix M
Bladder Cancer Study Three-Month Questionnaire



Exercise and Bladder Cancer Three Month Questionnaire

Kerry S. Courneya, PhD, Peter Venner, MD,
& Scott North, MD

**CROSS CANCER INSTITUTE AND UNIVERSITY OF
ALBERTA**

Instructions*

Thank-you for your continued participation in this study. In this questionnaire, we are going to ask you a series of questions about yourself; some that are new and some that are the same as the previous questionnaire. It is important to answer these questions based on what you are thinking and feeling right now, and not how you answered the questions the last time. There are no right or wrong answers and all we ask is that you provide responses that are as honest and accurate as possible. The questionnaire should take about 30-45 minutes to complete. All responses are completely confidential and will never be used in any way that could link them to you.

For this first question, we would like you to recall your average weekly exercise **in the last three months**.

When answering these questions please:

- Only count exercise sessions that lasted 10 minutes or longer in duration
- Only count exercise that was done during free time (i.e., not occupation or housework)
- Note that the main difference between the three categories is the intensity of the exercise
- Please write the average frequency on the first line and the average duration on the second. If you did not perform any exercise at a given intensity, please write '0' in that space.

1. Recall your average weekly exercise **in the past three months**. Considering a typical week (7 days), how many times, on average, have you performed the following kinds of exercise:

	Times Per Week	Average Duration
s. MILD EXERCISE (MINIMAL EFFORT, NO PERSPIRATION) (e.g., easy walking, yoga, bowling, lawn bowling, shuffleboard, golf)	_____	_____
t. MODERATE EXERCISE (NOT EXHAUSTING, LIGHT PERSPIRATION) (e.g., fast walking, tennis, easy bicycling, easy swimming, popular and folk dancing)	_____	_____
u. STRENUOUS EXERCISE (HEART BEATS RAPIDLY, SWEATING) (e.g., running, aerobics classes, cross country skiing, vigorous swimming, vigorous bicycling)	_____	_____

The following section asks you to recall how often, in a **typical week** over the past three months, you spent time doing the following **sport and recreational activities**:

- sitting activities
- walking
- light intensity activities
- moderate intensity activities
- vigorous intensity activities

Please complete this section by either circling the correct response or filling in the blank.

1. Over the past 3 months, **in a typical week**, how often did you participate in **sitting** activities such as reading, watching TV, or doing handicrafts?

[0] NEVER

[1] SELDOM
(1-2 DAYS)

[2] SOMETIMES
(3-4 DAYS)

[3] OFTEN
(5-7 DAYS)

↓
GO TO
QUESTION
2

1a. What were these activities?

1b. On average, how many hours per day did you engage in these sitting activities?

[1] LESS THAN 1 HOUR [2] LESS THAN 2 HOURS

[3] 2-4 HOURS [4] MORE THAN 4 HOURS

2. Over the past 3 months, how often, **in a typical week**, did you **take a walk** outside your home or yard for any reason? For example, for fun or exercise, walking to work, walking the dog, etc.?

[0] NEVER

[1] SELDOM
(1-2 DAYS)

[2] SOMETIMES
(3-4 DAYS)

[3] OFTEN
(5-7 DAYS)

↓
GO TO
QUESTION
3

2a. On average, how many hours per day did you spend walking?

[1] LESS THAN 1 HOUR [2] LESS THAN 2 HOURS

[3] 2-4 HOURS [4] MORE THAN 4 HOURS

3. Over the past 3 months, how often, **in a typical week**, did you engage in **light sport or recreational activities** such as bowling, golf with a cart, shuffleboard, fishing from a boat or pier, or other similar activities?

[0] NEVER

[1] SELDOM
(1-2 DAYS)

[2] SOMETIMES
(3-4 DAYS)

[3] OFTEN
(5-7 DAYS)

↓
GO TO
QUESTION
4

3a. What were these activities?

3b. On average, how many hours per day did you engage in these light sport or recreational activities?

[1] LESS THAN 1 HOUR [2] LESS THAN 2 HOURS

[3] 2-4 HOURS [4] MORE THAN 4 HOURS

4. Over the past 3 months, how often, **in a typical week**, did you engage in **moderate sport and recreational activities** such as doubles tennis, ballroom dancing, hunting, ice skating, golf without a cart, softball, or other similar activities?

[0] NEVER

[1] SELDOM
(1-2 DAYS)

[2] SOMETIMES
(3-4 DAYS)

[3] OFTEN
(5-7 DAYS)

↓
GO TO
QUESTION
5

4a. What were these activities?

4b. On average, how many hours per day did you engage in these moderate sport and recreational activities?

[1] LESS THAN 1 HOUR [2] LESS THAN 2 HOURS

[3] 2-4 HOURS [4] MORE THAN 4 HOURS

5. Over the past 3 months, how often, **in a typical week**, did you engage in **strenuous sport and recreational activities** such as jogging, swimming, cycling, singles tennis, aerobic dance, skiing (downhill or cross-country) or other similar activities?

[0] NEVER

[1] SELDOM
(1-2 DAYS)

[2] SOMETIMES
(3-4 DAYS)

[3] OFTEN
(5-7 DAYS)

↓
GO TO
QUESTION
6

5a. What were these activities?

5b. On average, how many hours per day did you engage in these strenuous sport and recreational activities?

[1] LESS THAN 1 HOUR [2] LESS THAN 2 HOURS

[3] 2-4 HOURS [4] MORE THAN 4 HOURS

6. Over the past 3 months, how often, **in a typical week**, did you do any exercises specifically to increase **muscle strength and endurance**, such as lifting weights or pushups, etc?

[0] NEVER

[1] SELDOM
(1-2 DAYS)

[2] SOMETIMES
(3-4 DAYS)

[3] OFTEN
(5-7 DAYS)

↓
GO TO
QUESTION
7

6a. What were these activities?

6b. On average, how many hours per day did you engage in exercises to increase muscle strength and endurance?

[1] LESS THAN 1 HOUR [2] LESS THAN 2 HOURS

[3] 2-4 HOURS [4] MORE THAN 4 HOURS

The following section asks you about any **housework, chores, or work for pay or as a volunteer** that you have did in a **typical week** over the past three months. Please circle the correct response:

7. During the past 3 months, **in a typical week**, did you do any **light housework**, such as dusting or washing dishes?

[1] NO [2] YES

8. During the past 3 months, **in a typical week**, did you do any **heavy housework or chores**, such as vacuuming, scrubbing floors, washing windows, or carrying wood?

[1] NO [2] YES

9. During the past 3 months, **in a typical week**, did you engage in any of the following activities?

(e) Home repairs like painting, wallpapering, electrical work, etc.

[1] NO [2] YES

(f) Lawn work or yard care, including snow or leaf removal, wood chopping, etc

[1] NO [2] YES

(g) Outdoor gardening

[1] NO [2] YES

(h) Caring for an other person, such as children, dependent spouse, or another adult

[1] NO [2] YES

10. During the past 3 months, **in a typical week**, did you work for pay or as a volunteer?

[1] NO

[2] YES

If yes, please complete the next two questions (10a, 10b):

10a. How many hours per week did you work for pay and/or as a volunteer?

_____ hours

10b. Which of the following categories best describes the amount of physical activity required in your job and/or volunteer work? (circle one)

- [1] Mainly sitting with slight arm movements (examples: office worker, watchmaker, seated assembly line worker, bus driver, etc)
- [2] Sitting or standing with some walking (examples: cashier, general office worker, light tool and machinery worker)
- [3] Walking, with some handling of materials generally weighing less than 50 pounds (examples: mailman, waiter/waitress, construction worker, heavy tool and machinery worker)
- [4] Walking and heavy manual work often requiring handling of materials weighing over 50 pounds (examples: lumberjack, stone mason, farm or general labourer)

Please respond to the following questions by circling the number that corresponds to the answer in *each* row that best describes how you feel about exercise. Exercise is defined here as any activity performed on a repeated basis over an extended period of time with the intention of improving physical fitness and health. We define regular exercise as any physical activity performed either at moderate intensity (e.g. brisk walking, dancing, tennis) for at least 30 minutes, 5 times per week, or at vigorous intensity (e.g. running, vigorous bicycling, aerobics) for at least 20 minutes, 3 times per week.

1) For me, exercising regularly over the next three months would be:

- a)
- | | | | | | | |
|----------------------|------------------|---------------------|---|--------------------|-----------------|---------------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| extremely
useless | quite
useless | slightly
useless | | slightly
useful | quite
useful | extremely
useful |
- b)
- | | | | | | | |
|--------------------------|----------------------|-------------------------|---|-----------------------|--------------------|------------------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| extremely
unenjoyable | quite
unenjoyable | slightly
unenjoyable | | slightly
enjoyable | quite
enjoyable | extremely
enjoyable |
- c)
- | | | | | | | |
|----------------------|------------------|---------------------|---|------------------------|---------------------|-------------------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| extremely
harmful | quite
harmful | slightly
harmful | | slightly
beneficial | quite
beneficial | extremely
beneficial |
- d)
- | | | | | | | |
|---------------------|-----------------|--------------------|---|-----------------|--------------|------------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| extremely
boring | quite
boring | slightly
boring | | slightly
fun | quite
fun | extremely
fun |
- e)
- | | | | | | | |
|----------------------|------------------|---------------------|---|------------------|---------------|-------------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| extremely
foolish | quite
foolish | slightly
foolish | | slightly
wise | quite
wise | extremely
wise |
- f)
- | | | | | | | |
|-------------------------|---------------------|------------------------|---|----------------------|-------------------|-----------------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| extremely
unpleasant | quite
unpleasant | slightly
unpleasant | | slightly
pleasant | quite
pleasant | extremely
pleasant |

1) Most people who are important to me think I should exercise regularly over the next three months:

- | | | | | | | |
|----------------------|-------------------------|----------------------|---------|-------------------|---------------------|-------------------|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 |
| strongly
disagree | moderatel
y disagree | slightly
disagree | neither | slightly
agree | moderately
agree | strongly
agree |

2. Most people who are important to me would encourage me to exercise regularly over the next three months:

1	2	3	4	5	6	7
strongly disagree	moderately disagree	slightly disagree	neither	slightly agree	moderately agree	strongly agree

3. Most people who are important to me would support me exercising regularly over the next three months:

1	2	3	4	5	6	7
strongly disagree	moderately disagree	slightly disagree	neither	slightly agree	moderately agree	strongly agree

4. Most people who are important to me will be doing an exercise program themselves over the next three months:

1	2	3	4	5	6	7
strongly disagree	moderately disagree	slightly disagree	neither	slightly agree	moderately agree	strongly agree

5. In the next three months, most people who are important to me will be:

1	2	3	4	5	6	7
extremely inactive	quite inactive	slightly inactive	neutral	slightly active	quite active	extremely active

6. In the next three months, exercise levels of most people who are important to me will be:

1	2	3	4	5	6	7
extremely low	quite low	slightly low	neutral	slightly high	quite high	extremely high

Please use the scale below each question to guide your responses to the next set of questions

If you were really motivated, exercising regularly over the next three months would be:

1	2	3	4	5	6	7
extremely difficult	quite difficult	slightly difficult	neither	slightly easy	quite easy	extremely easy

If you were really motivated, how confident are you that you would be capable of exercising regularly over the next three months?

1	2	3	4	5	6	7
not at all confident			moderately confident			extremely confident

If you were really motivated, how much control do you feel you would have over exercising regularly over the next three months?

1	2	3	4	5	6	7
very little control			moderate control			complete control

If you were really motivated, how certain or uncertain would you be that you could exercise regularly over the next month?

1	2	3	4	5	6	7
extremely uncertain	quite uncertain	slightly uncertain	neutral	slightly certain	quite certain	extremely certain

The next set of questions ask you about your plans for regular exercise over the next three months.

2. I intend to exercise at least ____ times per week (please insert a number that indicates how many times you intend to exercise), at a duration of ____ minutes per session, at a **moderate** intensity over the next three months.
3. I intend to exercise at least ____ times per week (please insert a number that indicates how many times you intend to exercise), at a duration of ____ minutes per session, at a **vigorous** intensity over the next three months.
4. I intend to exercise for at least 30 minutes, 5 days per week at a moderate intensity over the next three months.

1	2	3	4	5	6	7
strongly disagree	moderately disagree	slightly disagree	neither	slightly agree	moderately agree	strongly agree

5. I intend to exercise for at least 20 minutes, 3 days per week at a vigorous intensity over the next three months.

1	2	3	4	5	6	7
strongly disagree	moderately disagree	slightly disagree	neither	slightly agree	moderately agree	strongly agree

This next set of questions ask you to rate how likely it is that certain outcomes would result in the next three months if you exercised regularly. Please use the following scale to guide your responses and circle the number that best reflects your beliefs.

1	2	3	4	5	6	7
extremely unlikely	quite unlikely	slightly unlikely		slightly likely	quite likely	extremely likely

If I were to exercise regularly, it would help me to...

a) have better health	1	2	3	4	5	6	7
b) stay in shape and be fit	1	2	3	4	5	6	7
c) lose weight	1	2	3	4	5	6	7
d) feel better	1	2	3	4	5	6	7
e) get stronger muscles	1	2	3	4	5	6	7
f) maintain my weight	1	2	3	4	5	6	7
g) have more energy	1	2	3	4	5	6	7
h) keep my joints flexible	1	2	3	4	5	6	7

The next set of questions ask you to rate how confident you are that you could exercise regularly in the next three months given the following circumstances. Please use the following scale to guide your responses and circle the number that best reflects your beliefs.

1	2	3	4	5	6	7
not at all confident			moderately confident			extremely confident

If you were really motivated, how confident are you that you could exercise regularly even if...

a) you had limited time	1	2	3	4	5	6	7
b) you had health problems	1	2	3	4	5	6	7
c) you had pain	1	2	3	4	5	6	7
d) the weather was bad	1	2	3	4	5	6	7
e) you felt tired or fatigued	1	2	3	4	5	6	7
f) you felt you were too old	1	2	3	4	5	6	7
g) you find exercise unenjoyable	1	2	3	4	5	6	7
h) you had no one to exercise with	1	2	3	4	5	6	7

The next set of questions ask you to rate whether important people in your life would support you if you tried to exercise regularly in the next three months. Please use the following scale to guide your responses and circle the number that most accurately reflects your belief.

1	2	3	4	5	6	7
extremely unsupportive	quite unsupportive	slightly unsupportive		slightly supportive	quite supportive	extremely supportive

How much support would each of the following persons give you if you tried to exercise regularly?

a) doctor	1	2	3	4	5	6	7
b) spouse/partner	1	2	3	4	5	6	7
c) children	1	2	3	4	5	6	7
d) other family members	1	2	3	4	5	6	7
e) friends	1	2	3	4	5	6	7

The following question asks you to recall your current exercise pattern. Read all statements first, then place an "X" beside the statement that best describes your current exercise pattern. Currently:

_____ I am not exercising regularly and I am not thinking about starting in the near future.

_____ I am not exercising regularly, but I am thinking about starting in the near future.

_____ I am not exercising regularly, but I have decided to start in the next month.

_____ I am exercising regularly but have only begun to do so in the last six months.

_____ I am exercising regularly and have been doing so for longer than six months

The next set of questions asks about your exercise preferences. Check only one response for each question unless otherwise indicated.

1. I would have preferred to have been counseled about exercise at some point after my diagnosis of bladder cancer

yes _____ no _____ maybe _____

*Even if you responded NO to the above question, please answer the following set of questions:

2. If you were to receive exercise counseling, who would you prefer this counseling from?

a. oncologist _____ b. nurse _____ c. a cancer patient or survivor _____

d. exercise specialist affiliated with _____ e. exercise specialist affiliated with _____
a community fitness centre a cancer center

3. If you were to receive exercise counseling, when would you prefer this counseling?

1	2	3	4	5
before	during	immediately	3-6 months after	at least 1 year
treatment	treatment	after treatment	treatment	after treatment

4. If you were to receive exercise counseling, where would you prefer this counseling to take place?

a. cancer center _____ b. community center _____ c. my home _____
d. other _____ (specify)

5. If you were to receive exercise counseling, how would you prefer to be counseled?

a. face to face ___ b. telephone ___ c. brochure ___ d. other (specify): _____

The next set of questions asks about your exercise programming preferences. Check only one response for each question unless otherwise indicated

1. Would you be interested in an exercise program designed for bladder cancer survivors?

yes _____ no _____ maybe _____

2. Do you think you would be able to participate in an exercise program designed for bladder cancer survivors?

yes _____ no _____ maybe _____

3. If you were to exercise, what types of exercises would you be most interested in doing?

1. _____ 2. _____ 3. _____

4. If you were to begin an exercise program, when would you prefer this program to start?

1	2	3	4	5
before treatment	during treatment	immediately after treatment	3-6 months after treatment	at least 1 year after treatment

5. If I were to exercise regularly, I would prefer to exercise (check only one for each question):

1. alone with other cancer survivors with friends with family no preference

2. at home at a community fitness center at a cancer fitness center no preference

3. morning afternoon evening no preference

6. My favorite exercise during the summer is:

Please list:

7. My favorite exercise during the winter is:

Please list:

The next few questions are about the neighborhood you live in. For each statement, please tell us if you strongly disagree, disagree, are unsure, agree, or strongly agree with what we have said:

		Strongly disagree	Dis-agree	Un-sure	Agree	Strongly agree
1.	It is safe to walk in your neighborhood.	1	2	3	4	5
2.	Dogs frighten people who walk in your neighborhood.	1	2	3	4	5
3.	The neighborhood is friendly.	1	2	3	4	5
4.	Crime is high in the neighborhood.	1	2	3	4	5
5.	There are pleasant walks to do in your neighborhood.	1	2	3	4	5
6.	Shops and services are in walking distance.	1	2	3	4	5
7.	You often see people out on walks in your neighborhood.	1	2	3	4	5
8.	Your neighborhood is kept clean and tidy.	1	2	3	4	5
9.	There are busy streets to cross when out on walks.	1	2	3	4	5
10.	The footpaths are in good condition.	1	2	3	4	5
11.	There is heavy traffic.	1	2	3	4	5
12.	It is safe to cycle in your neighborhood.	1	2	3	4	5
13.	The streets are well lit.	1	2	3	4	5
14.	There are steep hills.	1	2	3	4	5
15.	There are open spaces for people to walk in or around my neighborhood	1	2	3	4	5

How long did it take you to complete this questionnaire? _____

Thank you very much for your participation in this research project. Please place the completed questionnaire in the business reply envelope provided.