

**PSYCHOLOGICAL DISTRESS AND PHYSICAL SYMPTOM EXPERIENCE IN
POST-SURGICAL COLORECTAL CANCER PATIENTS**

BY

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

MASTER OF NURSING

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University of Manitoba
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Of

MASTER OF NURSING

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ABSTRACT

Colorectal cancer (CRC) is the third most common type of cancer and second the most frequent cause of cancer-related deaths among Canadians (NCIC, 2003). The primary treatment for CRC is surgical resection resulting in reanastomosis of the bowel or formation of colostomy (Berg, 2003). Patients often experience many unpleasant symptoms as a result of their cancer or related treatment. Patients can also experience psychological distress which can lead to an exacerbation of physical symptoms (Zaza & Baine, 2002). The purpose of this pilot study was to determine the prevalence rates of psychological distress, physical symptom experience, and the relationship between these two variables in post-surgical CRC patients.

The Theory of Unpleasant Symptoms (Lenz et al., 1997) was the theoretical framework used to guide this descriptive, correlational study. Psychological distress was measured by the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983), and the total physical symptom experience was measured by the Memorial Symptom Assessment Scale (Portenoy et al., 1994) in a convenience sample ($n = 35$) of the target population. Open-ended questions were also used to supplement the empirical data.

The prevalence of overall psychological distress among CRC patients was 43%. Rates of anxiety (57%) were higher than rates of depressive symptomology (37%). The most prevalent physical symptoms reported were lack of energy (89%), pain (83%), dry mouth (83%), and difficulty concentrating (66%). There was a significant relationship between psychological distress and the physical symptom experience

($r = 0.573$, $p < 0.001$). The open-ended questions revealed that the majority of patients were aware of their cancer diagnosis and relied on family or God for support. In addition, almost half of the patients had no concerns about hospital discharge.

These findings suggest that many patients are experiencing significant psychological and physical symptoms post-operatively and prior to hospital discharge. Furthermore, patients are not aware of the potential problems they may experience once at home as evidenced in the literature. Standardized screening for psychological distress and physical symptoms may help so that high risk patients are identified and treated. Patient education regarding psychosocial care, symptom management, and about what to expect after surgery is also required to ensure a successful transition from hospital to home.

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Chapter I

Statement of the Problem

Introduction

Colorectal cancer (CRC) is the third most common type of cancer and the second most frequent cause of cancer-related death among Canadian men and women (National Cancer Institute of Canada, 2003). Surgery continues to be the primary curative treatment for colorectal cancer and approximately three-quarters of people with colorectal cancer will require some form of surgery (Sargent & Murphy, 2003). The type of surgery is determined by the location of the tumor, size of tumor, and whether metastatic disease is present (Baker, 2001; Berg, 2003; Dest, 2000). The goal of colorectal surgery is to remove the entire tumor, affected lymph nodes, and blood supply to the tumor (Lewis, Collier & Heitkemper, 1996). Most often, the affected portion of the colon is resected and the healthy bowel is reanastomosed, although a colostomy may be indicated for some patients with complicated or low-lying rectal tumors (Sargent & Murphy).

The symptom experience is important. Not only do symptoms act as subjective indicators of illness or change in health status, they frequently provide the impetus for health-related intervention (McDaniel & Rhodes, 1995; O'Neill & Morrow, 2001). Symptom experience is a multidimensional concept which includes symptom occurrence (i.e., frequency and severity) and symptom distress. This experience is subjective and dynamic as it interacts with the perception of the symptoms, evaluation of the meaning of symptoms, and response to the total experience (Fu, LeMone & McDaniel, 2004). Cancer and cancer-related treatments can produce multiple unpleasant symptoms for patients. Symptoms common to colorectal cancer in the post-operative period include:

pain, fatigue, nausea, gas and/or bowel incontinence (Whynes & Neilson, 1997), sexual dysfunction (DeCosse & Cennerazzo, 1997), and poor appetite (Given, Given & Stommel, 1994).

A negative symptom experience has the capacity to influence health status. Uncontrolled or severe symptoms may interrupt cancer treatment and have a negative influence on the treatment's effectiveness (Cleeland, Mendoza, Wang, Chou, Harle, Morrissey et al., 2000). The presence of multiple symptoms in patients with cancer is linked to decreased wound healing, immune suppression, and progression of metastases (Armstrong, 2003; DeKeyser, Wainstock, Rose, Converse, & Dooley, 1998; Kiecolt-Glaser, Page, Marucha, MacCallum, & Glaser, 1998). Furthermore, symptom distress has also been associated with decreased functional status, cognitive ability, disease progression, and even survival (Armstrong).

A comprehensive assessment of cancer-related symptoms is important not only to capture the patient's symptom experience, but to ensure that appropriate and effective symptom management strategies are used to alleviate the distress caused by symptoms. Not only do uncontrolled or poorly managed symptoms diminish quality of life, they can also put a tremendous strain on the health care budget. Complicated recovery times due to poor symptom control can result in prolonged length of hospital stay, higher rates of institutionalization, increased need for home care; and therefore, increased overall health care expenditures (Carlson & Bultz, 2003; Hodgson & Given, 2004).

Many patients with cancer also experience significant psychological distress related to the diagnosis and treatment of their illness. Zabora, Brintzenhofesoc, Curbow, Hooker, and Piantadosi (2001) measured the prevalence of psychological

distress in a large sample of patients with cancer (n=4496) and found that the overall prevalence of psychological distress in cancer patients was 35.1%, and slightly lower at 31.6% among CRC patients. It is estimated that the prevalence rates may be higher in instances that are associated with greater patient burden such as adjustment to new colostomy. This is of great concern as it has been reported that fewer than 10% of cancer patients are actually referred for psycho-social assistance (National Comprehensive Cancer Network [NCCN], 2004). Reported prevalence rates, however, vary widely in research and several explanations have been used to explain this discrepancy. First, psychological distress has lacked conceptual clarity in health-related research as it has traditionally been defined by its empirical referents. Psychological distress in cancer patients has been frequently investigated; hence, this variable has been measured using many different empirical tools across various stages of many types of cancer. Subsequently, prevalence rates of psychological distress may be comparable only within the same tumor site group and at specific points of measurement (e.g., pre-operative measurement). Caution must be exercised as results should not be generalized beyond these recommendations (Nordin, Berglund, Glimelius & Sjoden, 2001).

Psychological distress among cancer patients can negatively impact overall health status. Psychological distress is associated with poor coping styles (Compas, Stoll, Thomsen, Oppedisano, Epping-Jordon & Krag, 1999; Koopman, Angell, Turner-Cobb, Kreshka, Donnelly, McCoy, et al., 2001), decreased quality of life (Kurtz, Kurtz, Stommel, Given, & Given, 2002), and can exacerbate physical symptoms such as pain (Zara & Baine, 2002; Zimmerman, Turner Gaston-Johansson & Rowles, 1996), fatigue

(Tchekmedyan, Kallich, McDermott, Fayers & Erder, 2003), and nausea (Van Servellen, Sarna, Padilla & Brecht, 1996).

According to the National Cancer Institute of Canada (NCIC; 2002), common periods of crisis that occur in the cancer population which can lead to significant distress include: diagnosis, treatment, post-treatment and remission, recurrence, and palliative care. There have been no studies that measure prevalence rates of psychological distress prior to hospital discharge after having surgery for colon or rectal tumors. Furthermore, no research to date has yet to examine the relationship between psychological distress and the physical symptom experience in the CRC population. In the current Canadian health care environment, emphasis is placed upon cost-control, efficiency, and minimal length of post-operative hospital stay; therefore, the importance of assessing a patient's physical and psychological status prior to discharge is essential to ensure a successful transition from hospital to home (Baker, 2001). Due to the fact that CRC patients are recovering from major abdominal surgery, coping with a cancer diagnosis, preparing for hospital discharge, caring for surgical wounds, and possibly a new stoma, it is reasonable and in fact imperative to ascertain the prevalence rates of psychological distress and physical symptom experiences in the acute phase of their recovery.

Research Questions

The purpose of this study is to determine the prevalence rates of psychological distress and physical symptom experience and to examine the relationship between these two variables in post-operative CRC patients prior to hospital discharge. The following questions were addressed in this pilot study:

- 1) What is the prevalence of psychological distress in post-surgical colorectal cancer patients?
 - (a) What is the prevalence of anxiety?
 - (b) What is the prevalence of depression?
 - (c) What is the prevalence of overall psychological distress?
- 2) What is the prevalence of symptom experience in post-surgical colorectal cancer patients?
 - (a) What symptoms are most prevalent?
 - (b) How frequent are symptoms?
 - (c) How severe are symptoms?
 - (d) How much distress is experienced?
- 3) What is the relationship between psychological distress and symptom experience in post-surgical colorectal cancer patients?

Operational Definitions of the Research Variables

The following definitions were established to provide clarity to the concepts examined in this pilot project. These definitions were explored in more detail in the literature review found in the next chapter.

- *Psychological Distress*: “An unpleasant experience of emotional, psychological, social or spiritual nature that interferes with the ability to cope with cancer treatment. It extends along a continuum, common normal feelings of vulnerability, sadness, and fears, to problems that are disabling such as true anxiety, depression, panic and feelings of isolation or in spiritual

crisis” (NCCN, 1999, pp, 10). The Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) will be used to quantify psychological distress.

- *Anxiety*: Vague, subjective feelings of apprehension, worry, uneasiness, dread or impending doom often accompanied with physiological changes such as motor tension (e.g., restless fidgeting), and autonomic over-activity (e.g., lightheadedness, tachycardia, dry mouth). It occurs as a threat to one’s physiologic, biologic or social integrity from external influences (Bowman, 2001; Fortinash & Holoday-Worret, 2000).
- *Depression*: A mood disorder affecting one’s emotions (e.g., dejected mood, sadness), cognitive ability (e.g., inability to concentrate or make decisions), behavioral (e.g., insomnia, fatigue), and social functioning (e.g., withdrawal from family). (Bowman, 2001; Fortinash & Holoday-Worret, 2000).
- *Symptom(s)*: “subjective phenomenon regarded by an individual as an indication or characteristic of a condition departing from a normal function, sensation, or appearance” (Rhodes & Watson, 1987, pp, 242).
- *Symptom Experience*: A subjective perception of the frequency, severity and distress as symptoms are produced and expressed (Armstrong, 2003; McDaniel & Rhodes, 1995). It is a multidimensional and dynamic experience which interacts with the perception of the symptom(s), evaluation of the meaning of a symptom(s), and response to the experience (Fu et al., 2004). The Memorial Symptom Assessment Scale (MSAS; Portenoy, Thaler,

Kornblith, McCarthy Lepore, Friedlander-Klar, Kiyasu et al., 1994) was used to quantify symptom experience.

- *Symptom frequency*: "...number of times a symptom is experienced by an individual within a given time frame" (Fu et al., 2004).
- *Symptom severity*: The level of strength or intensity as perceived by the individual (Armstrong, 2003).
- *Symptom distress*: The amount of anguish, suffering, discomfort or bother experienced from a symptom as perceived by an individual (Fu et al., 2004; Rhodes & Watson, 1987).
- *Colorectal Cancer (CRC)*: A medically diagnosed malignant neoplasm involving the colon or rectum (Lewis et al., 1996).
- *Colorectal Cancer Surgery*: A surgical resection of colon or rectal tumor, surrounding tissue and lymph vessels, blood supply and mesentery (Warmkessel, 1997), followed by restoration of intestinal continuity through reanastomosis or colostomy (Lunn, Hurrell, & Campbell, 1999).

Significance

The results of this study contribute to the current state of oncology nursing literature by providing an increased understanding of the psychological and physical experiences of post-surgical patients with colorectal cancer. The results will identify areas where nursing interventions can be developed or existing nursing interventions can be utilized to ease or alleviate psychological or physical symptom distress. The instruments used in this study may be useful to health care professionals to facilitate the

identification and assessment of patients who are distressed so that appropriate measures are taken before hospital discharge. Finally, the results of this research will be used to identify certain areas that require further investigation for future research endeavors.

Chapter II

Literature Review

Introduction

An analysis of the current state of knowledge pertinent to this research was conducted. The physical symptom experience and psychological distress in the cancer population, particularly colorectal cancer (CRC), were the two concepts central to the study. The purpose of this literature review is to identify past research and explore the current state of knowledge regarding the linkage between symptom experience and psychological distress in CRC patients. The literature review includes four sections: 1) Colorectal cancer and surgical intervention, 2) symptom experience, 3) psychological distress, and 4) psychological distress and symptom experience.

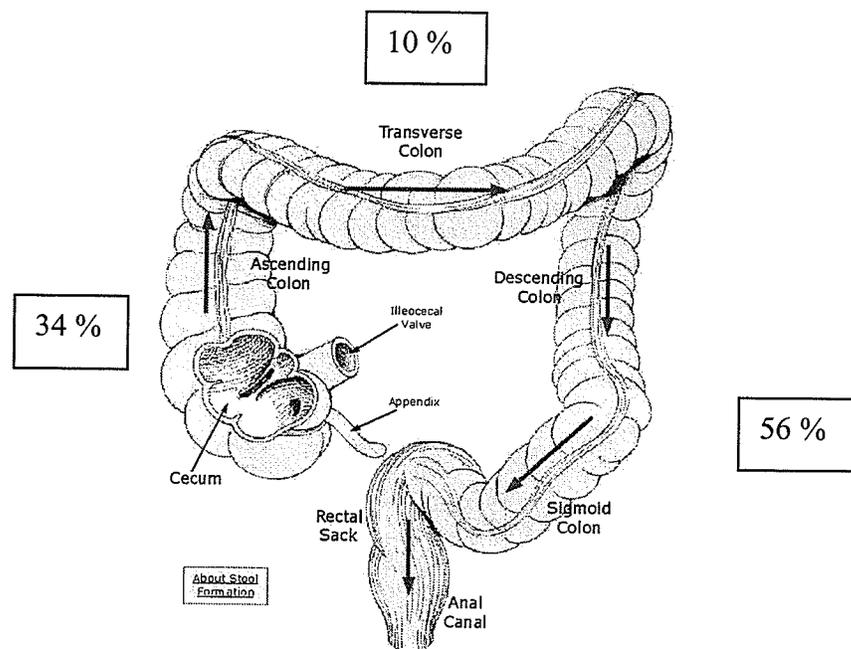
Colorectal Cancer and Surgical Intervention

Epidemiology and Trends in Colorectal Cancer

Colorectal cancer (CRC) is one of the most frequent types of cancer among both men and women (Renner, Rosen, Novi, Holbling & Schiessel, 1999). CRC is the third most common type of cancer and the second most frequent cause of cancer-related deaths among Canadian men and women (NCIC, 2003). Approximately 18,000 people will be diagnosed with CRC and over 8,000 deaths will occur annually in Canada as a result of this disease. In 2003, roughly 340 Manitoban men and women died as a result of CRC. It has been estimated that there will be 390 newly diagnosed men and 340 newly diagnosed women with CRC this year (NCIC). Due to growth and aging of the Canadian population, the numbers of new cases will continue to rise steadily among men and women (NCIC).

CRC rarely occurs before age of 30 and the highest incidence is found in patients over 70 years of age (Keyes, Bisno, Richardson & Marston, 1987). The overall lifetime risk for developing CRC is six percent (NCIC, 2003). The incidence of CRC varies according to the location of the tumor (See Figure 2.1). Approximately one third of tumors arise in the cecum or ascending colon and only about ten percent of tumors develop in the transverse portion of the colon. In the descending colon, sigmoid colon, and rectum the tumor incidence rises to about 56% (Berg, 2003; Gordon & Nivatvongs, 2000).

Figure 2.1 Tumor Incidence and Anatomical Location



Although CRC is the third leading cause of death (after lung and prostate in men, and lung and breast in women), mortality rates for CRC have been decreasing.

According to the Canadian Cancer Society (2003), mortality rates have decreased by 23%

in women and 15% in men since 1988. Improved survival rates are likely related to improvements in surgical technique, adjuvant chemotherapy, radiation therapy, and early detection (Sandler, 1996). Survival rates in colorectal cancer vary widely by cancer stage. If treatment occurs in its early stages, a five-year survival rate can be greater than 90%, but if distant metastases are present when cancer is diagnosed, the five-year survival rate drops to less than 9% (Berg, 2003; McCormick, Kibbe, & Morgan, 2002).

Risk Factors

Although the specific cause of CRC is unknown, there are many risk factors that have been identified which are associated with an increased incidence in tumor development. Several modifiable and non-modifiable risk factors have been linked to CRC; however, about 75% of all new CRC cases present with no known pre-disposing factors (Sargent & Murphy, 2003).

Non-modifiable risk factors. Many non-modifiable risk factors have been linked to the development of CRC. Age is considered to be the number one risk factor for CRC. The development of CRC is associated with increasing age. CRC is rare before 30 years of age, and the median age of diagnosis is 67 years (Berg, 2003). The presence of adenomatous polyps or adenomas poses a risk for CRC. Polyps are known as the precursor lesions to cancer development; in fact between 70 and 90 % of all colorectal tumors arise from adenomatous polyps (Gordon & Nivatvongs, 2000; Rudy & Zdon, 2000). Family history is another risk factor, particularly if a parent or sibling acquires CRC before the age of 60 or more than one relative is affected at any age (Sargent & Murphy, 2003). Hereditary syndromes such as familial adenomatous polyposis (FAP), and hereditary non-polyposis colon cancer (HNPCC) account for approximately six

percent of all colon or rectal tumors. Also, individuals with inflammatory bowel disease such as ulcerative colitis or Crohn's disease have a 30 fold increased risk for developing CRC (Berg, 2003).

Modifiable risk factors. There are also many risk factors for CRC that are modifiable such as a diet high in animal fat, cholesterol, and protein. Similarly, a diet low in fiber, calcium, fruits, and vegetables is also linked to CRC development. In addition, smoking, obesity, and sedentary lifestyle are all examples of modifiable risk factors that contribute to the development of CRC (Berg, 2003; Sandler, 1996).

Signs and Symptoms

Presentation of colorectal cancer can occur in one of three ways. First, there may be an insidious onset of chronic symptoms. CRC is often known as a silent killer because patients are frequently asymptomatic until the cancer is advanced (Gordon & Nivatvongs, 2000; McCormick et al., 2002). Second, CRC may present as a partial or complete bowel obstruction. This occurs in approximately six to 16% of new cases. And finally, about two to seven percent of the time, CRC may be diagnosed as a result of an initial presentation of bowel perforation (Gordon & Nivatvongs).

Ascending colon. Symptoms are specific to the site of the tumor. The most common signs and symptoms of CRC can be vague and often mimic other medical conditions, particularly in the ascending colon (Dest, 2000). Tumors in the ascending colon often first present with fatigue and weakness related to iron deficiency anemia. Occult blood is present in stool, anorexia, and weight loss may also occur (Shelton, 2002). Tumors in the ascending colon may become quite large and palpable before symptoms first occur because in this area the stool is liquid and the bowel is quite

distensible (Berg, 2003; Warmkessel, 1997). These large bulky tumors are associated with vague and dull pain (Shelton). Right-sided tumors are well-differentiated, more genetically stable, have a 'cauliflower' like appearance, and are generally associated with a better prognosis if caught early enough (Melville, Sheldon, Gray & Sowden, 1998).

Transverse colon. Malignancies in the transverse portion of the colon also have unique symptoms. Pain, a change in bowel habits (constipation or diarrhea), and bloody stools are common symptoms to this portion of the colon (Shelton, 2002). Obstruction is most likely in this portion of the bowel because stool is thicker and the bowel is narrowed at the hepatic and splenic flexures which can prevent stool passage (Warmkessel, 1997).

Descending and sigmoid tumors. Tumors in the left portion of the bowel may cause a sense of fullness or cramps. Patients may experience colicky pain, nausea, vomiting, and alternate between constipation and diarrhea. If the tumor in the descending or sigmoid colon bleeds, stools may contain streaks of bright red blood (Berg, 2003; Shelton, 2002; Warmkessel, 1997). Tumors in the left-side of the colon are ulcerative, genetically unstable, and are associated with a poorer prognosis. However, tumors in the left side of the colon are often diagnosed earlier because symptoms are more obvious and appear sooner than in the ascending portion of the colon (Dest, 2000).

Rectal tumors. Tumors in the rectum are characterized by morning bowel movements, urgency, tenesmus (feelings of incomplete evacuation), and pencil-like stools which can be bright red and bloody (Gordon & Nivatvongs; McCormick et al.; Sargent & Murphy, 2003; Shelton, 2002). Rectal carcinoma is also associated with colicky pain, lower back pain, feelings of rectal fullness, and pressure (Dest, 2000).

Staging

After a colon or rectal cancer is diagnosed, accurate staging is imperative for determining prognosis and to facilitate the selection of the most appropriate therapeutic treatment option(s). Pathological stage is the most important determinant of prognosis (Shelton, 2002). Staging of CRC is based on depth of tumor penetration through the bowel wall, the presence of regional lymph node involvement, and whether or not distant metastasis has occurred. Tumor size is not included in CRC staging (Berg, 2003). The classic staging system for CRC has been the Dukes classification. However, the American Joint Committee on Cancer (AJCC) Tumor-Node-Metastasis System (TNM) staging system is the preferred method for staging colorectal tumors as it provides more detail than other systems (See Table 2.1; Gordon & Nivatvongs, 2000; Rudy & Zdon, 2000).

Table 2.1 Dukes and TNM Staging Systems for CRC

DUKES STAGING SYSTEM	T	N	M
-	TIS	N0	M0
A	T1	N0	M0
	T2	N0	M0
B	T3	N0	M0
	T4	N0	M0
C	Any T	N1	M0
	Any T	N2, N3	M0
D	Any T	Any N	M ≥ 1

T = tumor (size, extent or depth of penetration of primary tumor); N = node (absence or presence and extent of regional lymph node involvement); M = metastasis (absence or presence of distant metastasis); TIS = carcinoma in situ, T1 = tumor invades submucosa, T2 = tumor invades muscularis propria, T3 = tumor invades through muscularis propria, T4 = tumor invades serosa, nodes, and adjacent organs; N0 = negative lymph nodes at surgery, N1 = one to three positive lymph nodes, N2 = more than three positive lymph nodes, N3 = positive lymph nodes on vascular trunk; M0 = no metastasis, M1 = distant metastasis (Rudy & Zdon, 2000).

Surgical Intervention

Treatment of colorectal cancer is based on tumor size, location, extent of the tumor, and the patient's overall general health status (McCormick et al, 2002). Smaller lesions may be removed through colonoscopy, but surgery is the most common treatment to remove larger lesions (Gordon & Nivatvongs, 2000). The primary treatment for colon and rectal cancer is surgical resection of the tumor, surrounding tissues, and lymphatic

vessels (Lunn, et al., 1999; Sargent & Murphy, 2003). It is the only treatment option for CRC that is potentially curable and approximately 80% of CRC tumors are treated with some type of surgical intervention (Leslie & Steele, 2002). The goals of CRC surgery include: removal of the tumor with adequate proximal margins (approximately 2.5 centimeters); en bloc resection of involved organs, draining lymphatic vessels, and involved blood supply; avoiding tumor implantation, restoring intestinal continuity, and restore optimal physical, social, and sexual function (Baker, 2001; DeCosse & Cennerazzo, 1997; Dest, 2000).

There are many different types of surgical procedures used in the treatment of colon cancer. A right hemi-colectomy or extended right hemi-colectomy is a surgical procedure in which the tumor is resected and the ileum and left transverse colon are anastomosed. This type of surgery is used most often for uncomplicated tumors of the cecum, ascending colon, hepatic flexure, and transverse colon (Berg, 2003; Gordon & Nivatvongs, 2000). A transverse colectomy removes tumors in the transverse portion of the large bowel and the ascending and descending colon is subsequently anastomosed. A left hemi-colectomy is indicated in uncomplicated tumors of the right, transverse, or descending colon. A sigmoid colectomy or low anterior resection is performed on tumors in the sigmoid colon, recto-sigmoid, and upper rectum. The upper two-thirds of the rectum is anastomosed with the distal descending colon (Berg; Sargent & Murphy, 2003). A sub-total colectomy may be indicated when multiple tumors are involved. In this surgery, the distal ileum and rectum are joined together after resection of the colon (Gordon & Nivatvongs).

There has been a growing trend toward laparoscopic surgery for the treatment of colon cancer. This type of surgery uses a minimally invasive technique to remove the tumor using pneumoperitoneum and video-assisted manipulation to visualize and resect the bowel (Baker, 2001). The benefits of this technique include smaller incision, reduced pain and analgesic use, and faster overall post-operative recovery (Canter & Williams, 2002; Lacy, 2002). Some of the risks that have been associated with this surgical approach include its technical difficulty, surgeon's limited ability to retrieve adequate node sampling and obtain wide surgical margins, inability to palpate bowel, and potential for port site implantation (Canter & Williams). Current studies comparing laparoscopic versus open colectomy have been methodologically flawed, providing no conclusive evidence regarding overall survival benefit and therefore its use should be limited to prospective clinical trials (Canter & Williams).

There are also many different surgical treatment options used in the treatment of rectal cancers. The goal for rectal cancer surgery is to maintain adequate anal sphincter control, urinary and sexual function without compromising cure and local control. Depending on the location, rectal tumors can be removed by local excision, low anterior resection, abdominal-perineal resection (APR), and total mesorectal excision (TME; Baker, 2001). Local excision is limited to small, well-differentiated T1 or T2 tumors (Baker; Gordon & Nivatvongs, 2000). Low anterior resection is performed on tumors in the upper rectum and the APR is reserved for tumors located in the distal rectum and anus. The APR is a surgical procedure which involves the removal of the rectum and anus, closing of the perineum, and formation of a permanent colostomy. APR is associated with a risk of damaging nerves that are responsible for urinary and sexual

functioning (Berg, 2003). The TME is becoming the standard of care for uncomplicated mid to low rectal tumors. A TME is an en bloc resection of rectum and mesentery with negative distal and radial margins. Damage to pelvic nerves which are responsible for urinary and sexual function is minimized with this type of surgery (Melville et al., 1999; Berg, 2003).

Most often, the affected bowel is resected and subsequently reanastomosed; however, the formation of a temporary or permanent colostomy is sometimes indicated (McCormick et al., 2002). A stoma is created when the bowel is brought through the abdominal wall and sutured to the skin. Fecal matter is diverted through the stoma to the outside on the abdominal wall; an ostomy pouch is worn to collect the fecal matter (Lewis, et al., 1996). Complicated tumors resulting in perforation, obstruction, or ischemia of the bowel may result in permanent or temporary colostomy. A stoma may be necessary when there are multiple primary tumors, tumors that have adhered to adjacent tissues, to avoid fecal contamination, or to promote healing at the anastomotic site (Sargent & Murphy, 2003; Warmkessel, 1997). A permanent colostomy may be also indicated for low lying rectal tumors close to the anal verge or when the bowel is damaged from radiation enteritis (Baker, 2001; Berg, 2003; Hampton & Bryant, 1992).

Post-Operative Recovery

The immediate post-operative recovery from colorectal cancer surgery focuses on symptom control and prevention of complications. Nursing care is focused on alleviating pain and preventing nausea and vomiting (Berg, 2003). Care is also focused on preventing infection at the incision site (Lewis et al., 1996). Early ambulation, deep-

breathing, and coughing is promoted to prevent common post-operative complications such as deep vein thrombosis (DVT), paralytic ileus, and pneumonia (Warmkessel, 1997).

Symptoms common to colorectal cancer in the post-operative period include pain, fatigue, nausea, gas and /or bowel incontinence (Whynes & Neilson, 1997), dry mouth (Forsberg, Bjorvell & Cedermark, 1996), sexual dysfunction (DeCosse & Cennerazzo, 1997), and poor appetite (Given, Given & Stommel, 1994). A problem with mobility is another common problem in the post-operative period, particularly for elderly patients (Forsberg et al.). Much of the post-operative care tends to focus on the physical aspects of recovery; however, post-operative colorectal cancer patients are also at risk for developing psychological problems. Concerns or fears may include the cancer diagnosis, cancer recurrence, surgery, change in elimination patterns, demands of recovery process, and threat of mortality. Surgery for CRC can also seriously affect body image and self-esteem particularly if the patient has a new colostomy (Dest, 2000; Hampton & Bryant, 1992). These concerns or fears may manifest themselves as anxiety, depression, anger, grief, despair, helplessness, and hopelessness (Hampton & Bryant). Consequently, careful psychological assessment and support should be provided for patients and families (Lewis et al., 1996).

The formation of a colostomy for patients with colorectal cancer can often be overwhelming. An ostomy may be accompanied by several physical and psychological problems in the post-operative recovery period. Some of the problems may include unpleasant odor and noises from the ostomy, peristomal dermatitis, intolerance to certain foods, dehydration, altered body image, feelings of being mutilated, and alteration in

sexual functioning (Aron, Carrareto, Janning Prazeres, Barbosa de Cerqueira, & Santos, 1999; Berg, 2003; Hampton & Bryant, 1992). Enterostomal nurse therapists (ETNs) are pivotal in the care of patients with new colostomies. ETNs are care providers, educators, consultants, and patient and family advocates. ETNs initiate and implement pre and post-operative management. Patient assessment is focused on physical, psychosocial, and sexual adjustment of patients and families. Education is tailored to suit individual needs of patients and families (Comb, 2003). Post-operatively, ETNs visit the patient frequently, assessing ostomy and surgical wounds, teaching self-care, addressing psychological concerns, and planning for discharge (Baker, 2001; Dest, 2000).

The length of hospital stay for patients who have had a surgical resection for the bowel is dependent upon which surgical procedure was performed. A patient may be in the hospital for four to six days for post-operative recovery from a right, transverse, or left hemi-colectomy. A person who has undergone an APR will stay longer; approximately seven to ten days post-operatively due to the nature and extent of the surgical procedure (Lewis et al., 1996). Due to the rising costs of health care, the length of hospital stay post-operatively is shorter and patients are being discharged from hospital sicker. This often places the burden of care on family members or the patients' themselves. Discharge planning and education is therefore focused on self-care, wound care, symptom control, and prevention of post-operative complications such as wound infection (Berg, 2003). Although physical care is often the priority for discharge planning, resources for psychological support should also be included in discharge preparation (Lewis et al.).

Summary of Colorectal Cancer

Colorectal cancer is a significant disease as it is the third most common type of cancer and second most frequent cause of cancer-related death among Canadian men and women (NCIC, 2003). Risk factors include age, family history, history of IBD, adenomatous polyps, genetic syndromes (FAP or HNPCC), and lifestyle factors such as a high fat, low fiber diet (Berg, 2003). Symptoms of colorectal cancer include pain, fatigue, weight loss, change in bowel habits, and rectal bleeding. Symptoms are often vague and can mimic other illnesses such as IBD (Berg; Dest, 2000; McCormick et al., 2002; Sargent & Murphy, 2003). Survival rates vary according to stage of disease. If caught early, five year survival rates are as high as 90%; however, if caught later (T4 tumor), survival rates drop to less than 10%. Surgery is the first-line treatment option for colorectal cancer and is the only treatment that is potentially curative (Leslie & Steele, 2002). Post-operative recovery should focus on both the physical and psychosocial aspects of care (Lewis et al., 1996).

The Symptom Experience

The symptom experience is important. Not only do symptoms act as subjective indicators of illness or change in health status, they also frequently provide the impetus for health-related intervention (McDaniel & Rhodes, 1995; O'Neill & Morrow, 2001). Symptoms and their perceived experiences are a focus of nursing care and are often used to evaluate whether or not the care has been effective (McDaniel & Rhodes, 1995). Symptom management is a fundamental aspect of cancer care across the illness trajectory (Fu et al., 2004). Many different terms are used to conceptualize symptoms and their experience. Lack of conceptual clarity within health-related literature can lead to

confusion related to what assessment tools are appropriate for use in the clinical setting and in research. This can ultimately lead to inappropriate symptom management for patients with cancer. It is therefore imperative to define and differentiate between the various descriptors that are frequently associated with symptoms. This provides a basis for further evaluation and exploration of the meaning of symptoms to patients (Armstrong, 2003)

Symptoms

Symptoms are highly subjective and as a result can be defined and interpreted in various ways. Rhodes and Watson (1987) defined symptoms as "...subjective phenomenon regarded by an individual as an indication or characteristic of a condition departing from a normal function, sensation, or appearance" (pp, 242). Symptoms are often indicators of a disease or change in health status as perceived by the patient. That is, symptoms are what the patient experiences and reports as manifestations of their problem (O'Neill & Morrow, 2001). The mere report of a symptom however, does not necessarily imply that it is burdensome or in need of treatment (Ingham & Portenoy, 1996).

Symptoms are a reflection of biopsychosocial function, sensation, or cognitive changes (McDaniel & Rhodes, 1995). Interpretation of symptoms is an individual experience and is an expression of the patient's sense of reality. This reality is linked to previous experience which is comprised of both personal and cultural meaning (Tishelman, Taube & Sachs, 1991). Symptoms trigger a cognitive process that results in the formation of an illness representation. This representation operates as standards against which new information is matched and appraised. An individual compares

current sensations to cognitive representations. This permits an interpretation of new symptoms and allows for an evaluation of their severity (O'Neill & Morrow, 2001).

Although often associated with illness, symptoms may also arise from certain developmental transitions such as pregnancy or menopause. Symptoms can also result from treatment of a disease or health condition (Henly, Kallas, Klatt, & Swenson, 2003). There are many symptoms that are frequently associated with cancer and cancer-related treatments. Patients with cancer frequently experience many unpleasant symptoms from treatments such as chemotherapy, radiation, surgery, or from the tumor itself (Fu et al., 2004). Symptoms resulting from cancer treatments may trigger an acute onset, while symptoms as a result of the tumor itself may persist over time (Kurtz, Kurtz, Stommel, Given & Given, 1999). The broad range of cancer-related symptoms can include pain, nausea, vomiting, fatigue, drowsiness, weakness, anorexia, weight loss, alopecia, dyspnea, dysphagia, dry mouth, mucositis, constipation, diarrhea, feeling bloated, lack of concentration, and insomnia (McMillan & Small, 2002; Fu et al.; Whyne & Neilson, 1997).

Symptom Occurrence

Symptom occurrence encompasses both the frequency and severity by which the symptom is perceived. Symptom duration and persistence can also be included in this definition (McDaniel & Rhodes, 1995; McMillan & Small, 2002). All of the components of symptom occurrence may be broken down and further defined. *Symptom frequency* has been defined as the "...number of times a symptom is experienced by an individual within a given time frame" (Fu et al., 2004, pp, 66). *Symptom severity* or *intensity* is conceptualized as the amount or level of discomfort experienced as a result of the

symptom (Armstrong, 2003; McMillan & Small). *Symptom duration* refers to the length of time in which the symptom persists (Fu et al.; McDaniel & Rhodes).

Symptom Distress

Symptom Distress is one aspect of the total symptom experience which includes the human response to symptom occurrence (Rhodes, McDaniel, Homan, Johnson & Madsen, 2000). McCorkle and Young (1978) have conceptually defined symptom distress as the degree of discomfort reported by an individual in relation to their perception of the symptoms being experienced. Another similar and frequently cited definition of symptom distress was created by Rhodes and Watson (1987). They defined symptom distress as one's physical and mental anguish that results from the experience of symptom occurrence. It is an important aspect of the symptom experience as it includes the awareness of the distress and recognition of the degree of upset (McDaniel & Rhodes, 1995). Symptom distress is an individual's response to the symptom(s) occurrence, thus the individual's interpretation of the importance of the symptoms ultimately determines the level of distress (MacDaniel & Rhodes, 1995; Ridner, 2004; Tishelman et al., 1991).

Symptom distress is a multifaceted concept. Tishelman et al. (1991) explored four variables in relation to symptom distress. The variables include demographic (e.g., age, gender), medical (e.g., disease, co-morbidity, treatment), psychosocial (e.g., social support, resources), and perceptions of care (e.g., satisfaction with doctors, care, information provided). Tishelman et al.'s work with adult cancer patients (n=46) revealed that symptom distress reflects medical, personal, and cultural experiences; that is, the disease itself was not necessarily indicative of the degree of symptom distress.

Age, gender, marital status, and type of treatment were significantly related to an individual's degree of symptom distress (Tishelman et al.). Race, culture, education, socioeconomic status, values, and past experiences can also influence symptom distress in adult cancer patients (McClement, Woodgate & Degner, 1997).

McClement et al. (1997) recognized that much of the existing research related to symptom distress has been focused on lung and breast cancer populations. Hence, it was recommended that more attention be placed on different types of cancers to fill this research gap and provide a greater understanding of the concept. Timing was also acknowledged as an imperative measurement because of the dynamic nature of the concept and its ability to change over time (McClement et al., 1997). Symptom distress needs to be investigated at different points in the illness trajectory to gain further insight into the trends of distress across time. In order to alleviate symptom distress, nurses and other health care professionals need to have an adequate understanding of the concept and what it represents to each individual patient.

Definitions of Symptom Experience

Several conceptual definitions of *symptom experience* are utilized in the literature. According to McDaniel and Rhodes (1995), the total symptom experience includes four aspects: frequency, severity, duration or symptom occurrence, and distress. It is a dynamic process that involves perception, evaluation, meaning of, and response to a symptom (McDaniel & Rhodes). Lenz, Pugh, Mulligan, and Suppe's (1995) depiction of the symptom experience is similar; however, the four aspects they identified include: timing, intensity, quality, and distress.

In a recent concept analysis, Armstrong (2003) defined symptom experience as "...the perception of the frequency, intensity, distress and meaning occurring as symptoms are produced and expressed" (pp. 602). McDaniel and Rhodes (1995) conceptualized symptom experience as "a dynamic process that involves the perception, evaluation, and meaning of and the response to a symptom" (pp, 223). Similarly, the University of California, San Francisco School of Nursing Symptoms Management Faculty Group (1994) described symptom experience as a dynamic and subjective perception that includes the evaluation of the meaning of a symptom and response to a symptom. Symptom experience has also been defined as an individual's perception and response to both symptom occurrence and distress (Armstrong). Symptom experience is therefore an "... expression of patient's feeling about the total experience, whereas symptom occurrence and distress are separate entities involving different levels of response from the patient" (Rhodes et al., 2000, pp, 50).

The subjective nature of the symptom experience may be problematic as a patient's perceived symptom experience may be much different than a nurse's health assessment. Symptoms are still often equated with symptom frequency or symptom intensity even though literature has shown that the most frequently occurring symptoms are not necessarily the most distressing (McClement, et al., 1997; Tishelman et al., 2000).

Colorectal Cancer Symptom Experience

There are several symptoms that are common in CRC that have the potential to cause symptom distress in patients including pain, fatigue, bowel dysfunction (i.e., constipation, diarrhea, incontinence, and gas), dry mouth, sweats, urinary symptoms, sexual dysfunction, lack of appetite, and weight loss (Camilleri-Brennan & Steele, 1998;

MacDonald & Anderson, 1985; Olsson, Bergbom, Bosaeus, 2002; Whynes & Neilson, 1997; Yan & Sellick, 2004). It has been reported that physical symptom distress was a major problem for more than 75% of CRC patients in the first three months after surgery even if symptoms were not the most severe or the most frequent (Oberst & Scott, 1988). Whynes and Neilson examined physical symptoms common to CRC before surgery and three months post-surgery (n=53). Loss of appetite, rectal bleeding, and urgency of bowel movement were among the most common symptoms pre-operatively. These symptoms were noted to decline three months post-operatively. Other common physical symptoms such as sleep disturbance, fatigue, pain, and physical mobility did not significantly decrease three months post-operatively, suggesting that these symptoms are still bothersome to patients (Whynes & Neilson). Similarly, Forsberg, Bjorvell, and Cedermark (1996) found that patients who had surgery for colon cancer reported some improvements in pain and bowel function six weeks after surgery. Other symptoms that persisted post-operatively included fatigue, impaired mobility, sleep disturbance, nutrition, and wound complications (Forsberg et al.; Olsson et al.).

Time and Symptom Experience

Time is an important aspect of symptom experience. Sudden onset of symptoms may indicate an acute health condition that requires immediate intervention. Conversely, persistent symptom clusters over time may indicate a chronic condition (Henly et al., 2003). The symptom experience is a sequence of events that begins with the awareness of symptoms by an individual and is completed when symptoms are no longer perceptible (Henly et al). Anticipation of symptoms or their actual occurrence initiates a cognitive awareness which then elicits an emotional response. Correct and timely identification of

the etiology of symptoms can be critical to appropriate treatment and survival.

Furthermore, a timely intervention may reduce the impact of symptom severity, thereby easing the emotional response which in turn, may reduce a negative perception the symptom experience (Henly et al.).

Influencing Factors on Symptom Experience

Rhodes and Watson (1987) described three factors which influence and can be influenced by one's symptom experience: physiologic, psychologic, and situational (social) factors. These factors were later incorporated into Lenz et al.'s (1995) *Theory of Unpleasant Symptoms*. All three of these factors have reciprocal relationships with one another. In addition, they influence how an individual perceives the occurrence, severity, timing, and quality of the symptom experience (Lenz, Pugh, Milligan, Gift & Suppe, 1997). A *physiologic factor* can refer to one's physical capacity, co-morbidities, and disease type and stage. Examples of *psychologic factors* include personality, cognitive ability, coping style, motivation, and psychiatric morbidity. *Situational factors* consist of various aspects of a person's physical surroundings and social environment.

Employment status, marital status, social support, and access to health care are all examples of situational factors (Lenz et al.). All three of these factors will be discussed in further detail in the conceptual framework section found in Chapter III.

The meaning a person ascribes to their symptom experience is another important aspect to consider. The meaning assigned to one's symptom experience influences whether or not it is perceived as positive or negative (Armstrong, 2003). Many unpleasant symptoms that patients with cancer experience as a result of their treatments may be perceived positively as a sign that the cancer treatment is working. Conversely,

symptoms such pain and fatigue can be interpreted negatively as it may be a persistent reminder of their vulnerability and cancer diagnosis. Also, a symptom that may be considered the most distressing may not be the most meaningful symptom for that individual (Armstrong; McDaniel & Rhodes, 1995).

Patients with cancer experience many symptoms related to their tumor or its treatment. Symptoms rarely occur in isolation. According to Lenz et al. (1997), when symptoms occur simultaneously, their impact is multiplicative rather than additive. For instance, it has been reported that pain tends to be much more severe when nausea and fatigue are concurrently experienced (Armstrong, 2003; Lenz et al.). Symptoms can manifest in clusters or they may operate as catalysts for other symptoms (Armstrong). *Symptom clusters* are considered to be three or more concurrent symptoms which are related to each other. Symptoms within a cluster are not required to share the same etiology; for example, pain may be caused by the tumor, fatigue may be caused by the cancer treatment, and sleep disturbance may be a result of anxiety (Dodd, Miaskowski & Paul, 2001). Consequently, the identification of all symptoms and their etiology is complex but necessary to ease the impact on a person's quality of life (Cleeland et al., 2000). A careful assessment of the interaction between symptoms is also important. Assessing multiple symptoms can easily become complicated due to the multidimensional nature of each individual symptom (Ingham & Portenoy, 1996).

Age is a variable which may have significance in the way in which symptoms are perceived (Lenz et al., 1997; Fu et al., 2004; Rhodes & Watson, 1987). Results from various studies examining the relationship between age on symptom experience however have been mixed (Cooley, Short & Moriarty, 2003). Kurtz, Kurtz, Stommel, Given, and

Given (1999) studied women over the age of sixty-five with cancer (n=229) and found that more advanced age corresponded to greater symptom severity. Conversely, McMillan (1989) found that older patients reported lower levels of pain, nausea, and vomiting than younger patients. A study by Given, Given, Azzouz, Kozachik, and Stommel (2001) which examined the predictors of pain and fatigue in elderly cancer patients found no relationship between age and pain and /or fatigue. Similarly, Walker and Sofaer (1998) found no significant relationship between age and pain intensity and frequency in patients who attended pain clinics (n=124). Older adults however, were much less likely to feel control over their pain than younger adults (Walker & Sofaer).

The presence of one or more co-morbid conditions can also impact the perception of symptom experience. Kurtz et al. (1999) found that symptom severity was positively correlated (low) with co-morbidity ($r = 0.15, p < 0.009$) and negatively correlated with physical functioning ($r = -0.486, p < 0.001$). Given and colleagues (2001) found that patients with three or more co-morbidities were more likely to report pain, fatigue, or both than when compared to patients less co-morbidity. It is conceivable that pain and fatigue may be a result of or is compounded by other health conditions (Given et al.).

Consequences of Symptom Experience

The consequence of one's symptom experience has the potential to impact many aspects of a person's life. Symptom distress has been linked to decreased functional status, disease progression, and even survival (Armstrong, 2003; Degner & Sloan, 1995). Symptom experience can also negatively affect psychological health status, quality of life, and adjustment to illness (Armstrong; Cooley et al., 2003; Ingham & Portenoy, 1996).

Symptom occurrence, severity, and distress can influence health status and consequently decrease patient independence. Certain cancer therapies can produce many debilitating and potentially life-threatening symptoms that result in a patient's inability to care for oneself and increase dependence on health care providers and family members (Pasacreta, 1997). Patients with various co-morbidities, multiple or severe symptoms, experience an overall lower functional health status, cognitive functioning, physical performance capacity, and engage in less effective role performance (Armstrong, 2003; Ingham & Portenoy, 1998). For instance, a natural response to fatigue is to decrease physical activity and get more rest in an attempt to alleviate or manage this experience. Over time this can lead to a decreased functional ability and reduced ability to tolerate exercise and normal activity (Mock, Dow, Meares, Grimm, Dienenmann, Haisfield-Wolfe, et al., 1997). Furthermore, diminished stamina can also create difficulty in meeting personal and /or work obligations (Pasacreta, 1997).

Symptom experience has the capacity to have a negative impact on a person's health status. There is some evidence in health-related literature which suggests that the presence of multiple symptoms in patients with cancer is linked to decreased wound healing, immune suppression, and progression of metastasis (Armstrong, 2003; DeKeyser et al., 1998; Kiecolt-Glaser, Page, Marucha, MacCallum, & Glaser, 1998). For example, the presence of general symptom distress and pain has been linked to decreased immune function in patients with cancer (DeKeyser et al., 1998).

Symptom experience is also correlated to physical functioning. A longitudinal study of cancer patients revealed that loss of physical functioning was primarily related to multiple symptoms, and to a lesser degree, age (Kurtz, Kurtz, Given & Given, 1993).

Loss of physical functioning also varies according to tumor site. Patients with lung cancer have a higher loss of physical functioning than patients with breast or colorectal cancer (Kurtz et al.). In fact, Tanaka, Akechi, Okuyama, Nishiwaki, and Uchitomi (2002) measured the impact of dyspnea, pain, and fatigue on activities of daily living in lung cancer patients (n=171) and found that all three symptoms had a significantly negative impact on walking, normal work, general activities, and sleep. Hodgson and Given (2004) found that high levels symptom severity in older adults recovering from cancer surgery (n=172) were linked to decreased functional recovery.

Unrelieved symptoms are associated with increased levels of distress and diminished quality of life (Cooley, Short & Moriarty, 2003; Ingham & Portenoy, 1996). Among patients with lung and colon cancer (Cooley et al.; Kurtz, Kurtz, Stommel, Given & Given, 2000; Tishelman et al., 2000), the most distressing symptom experienced was fatigue. Pain, sleep disturbance, and decreased appetite were also frequently reported as physical symptoms that induce distress in cancer patients (Kurtz et al., 2000).

Conversely, distress resulting from other symptoms such as nausea can create or exacerbate a sleep or appetite disturbance. Symptom-related distress may also intensify pain sensitivity (Kiecolt-Glaser et al., 1998). Treatment of cancer (e.g., surgery) can ease or eliminate symptoms caused directly by the tumor; however, the treatment itself can be another source of physical symptom distress in patients with cancer (Kuo & Ma, 2002).

Uncontrolled or severe symptoms may interrupt cancer treatment and have a negative influence on the treatment's effectiveness (Cleeland et al., 2000). For example, chemotherapy-induced diarrhea is a major dose limiting toxicity that is a common side effect in patients taking Irinotecan®, an adjuvant chemotherapy, for CRC. Severe

diarrhea can result in dose modifications, delays, or discontinuation of chemotherapy; all of which may result in a suboptimal therapeutic dose (Engelking, 2004). In addition, it has been documented that symptom severity is a critical determinant in a patient's surgical recovery. Higher levels of symptom severity among older adults undergoing surgery for cancer resulted in an increased delay in recovery (Hodgson & Given, 2004).

Symptom Assessment Tools

Comprehensive and accurate assessment of symptoms and their experience are important for patient care and health-related research. In patient care, it is imperative to understand not only the etiology of the symptoms but the way in which they manifest so that patient needs are being met and appropriate interventions can be implemented quickly and effectively (Samarel, Leddy, Greco, Cooley, Torres, Tulman et al., 1996). In research, a comprehensive symptom measurement tool provides valuable insight into the patient experience and where new or existing interventions need to be targeted.

Several symptom-related measurement tools exist which have acceptable reliability and validity. Many of these tools however, only measure only one or two dimensions of the symptom experience. The Symptom Distress Scale (SDS; McCorkle & Young, 1978) is a tool that is frequently used in health-related research and in clinical practice for patient assessment of symptom distress and symptom occurrence. The SDS is a scale which is based on the assumption that symptom frequency and intensity can be equated with distress; however, the most frequently occurring symptom may not be the most distressing (Larsen, Nordstrom, Ljungman & Gardulf, 2004; McClement et al., 1997). Although other valid symptom measurement tools exist, they do not capture complex multidimensional nature of the symptom experience (Portenoy, Thaler,

Kornblith, McCarthy Lepore, Friedlander-Klar, Coyle, et al., 1994). As a result, several multidimensional symptom assessment scales have recently been developed. The *Memorial Symptom Assessment Scale* (MSAS; Portenoy et al. 1994); the *Edmonton Symptom Assessment Scale* (ESAS; Bruera, Kuehn, Miller, Selmser & Macmillan, 1994); the *Symptom Experience Scale* (SES; Sameral et al., 1996); the *Adapted Symptom Distress Scale* (ASDS-2; Rhodes et al., 2000); the *M. D. Anderson Symptom Inventory* (Cleeland et al., 2000); and the *Symptom Frequency Intensity, and Distress Questionnaire* (Larsen et al., 2004) are some of the newest and most commonly used instruments which try to capture multiple dimensions of symptom experience.

Symptom Management

Management of cancer-related symptoms is an essential element to cancer care across the illness trajectory of diagnosis, treatment, and palliation (Fu et al., 2004). The goal of symptom management is to provide relief from symptoms, prevent symptom occurrence, and reduce the level of symptom distress. Effective management of one or more symptoms is essential to ensure that a patient maintains optimal quality of life (Fu et al).

Appropriate management of the cancer-related symptom experience is imperative not only for maintaining a patient's quality of life, but also the easing the burden on the health care system. Uncontrolled or poorly managed symptoms can put a tremendous strain on the health care budget. Complicated recovery times due to poor symptom control can result in prolonged length of hospital stay, higher rates of institutionalization, increased need for home care; and therefore, increased overall health care expenditures (Carlson & Bultz, 2003; Hodgson & Given, 2004).

There are many different symptom management options available for patients with cancer. Once the etiology of the symptom is determined through a comprehensive patient assessment, a variety of treatment options may be utilized. Pharmaceutical management of various cancer-related symptoms is often a first-line treatment modality for effective symptom management (Berg, 2003). Non-pharmaceutical interventions should also be incorporated into the care plan whenever possible. Psycho-educational care such as health information giving, skills teaching, and psycho-social support have found to be effective in symptom management. A meta-analysis of 191 studies that examined the effects of psycho-educational care on adult surgical patients found significant beneficial effects on post-operative recovery, pain, and distress levels (Berg; Devine, 1992). Forester, Kornfeld, Fleiss, and Thompson (1993) looked at the effects of group psychotherapy in 24 patients receiving radiotherapy. The group randomly selected for psychotherapy had enhanced quality of life and reduced levels of distress when compared with the group that did not receive psychotherapy (Forester et al.). Even if the frequency or intensity of symptoms is not relieved by support group therapy, participation often minimizes the distress experienced as a result of symptoms (Samarel et al., 1996). Other treatment effects such as relaxation, imagery, and meditation can also be useful in relieving symptom severity and distress alone or in combination with other therapies (Carlson & Bultz, 2002; Cheung, Molassiotis & Chang, 2003; Fu et al., 2004).

Summary of Symptoms

Many unpleasant symptoms result from cancer or cancer-related treatments. Symptom experience is a subjective perception of the frequency, severity, and distress as symptoms are produced and expressed (Armstrong, 2003; McDaniel & Rhodes, 1995). It

is a multidimensional and dynamic experience which interacts with the perception of the symptom(s), evaluation of the meaning of a symptom(s), and response to the experience (Fu, et al., 2004; McDaniel & Rhodes). Symptom management in the cancer population is essential to ensure that the best quality of life can be maintained. Effective management of one or more symptoms should lead to symptom relief, reduced symptom distress, and / or the prevention of symptom occurrence (Fu et al., NCCN, 2004).

Psychological Distress

Psychological distress is a significant problem for patients with cancer at every stage of their disease. Although the concept of psychological distress is frequently used in health research, it is seldom conceptually defined. There are many different manifestations of distress with anxiety and depression being the most common (Bodurka-Bervers, Basen-Engquist, Carmack, Fitzgerald, Wolf, de Moor et al., 2000; Mock et al., 1997; Walker & Sofaer, 1998). In addition there are many manifestations of distress which can in turn negatively impact a patient's health status. Assessment and management of psychological distress is imperative to ease the burden on patients and help them cope with their diagnosis and treatment (NCCN, 2004; Nordin et al., 2001).

Prevalence of Psychological Distress

A recent study measuring the prevalence of psychological distress in a large group of cancer patients (n=4496), revealed that 35.1% of the total sample had significant psychological distress as a result of cancer or cancer-related treatments (Zabora et al., 2001). In this study the rates varied from 43.4% in patients with lung cancer to 29.6% in patients with gynecological cancers, with an overall average of 35.1% for all tumor site groups (Zabora et al.). Reported prevalence rates of psychological distress also vary

widely in research. Rates of less than 5% to over 50% have been cited in the literature. There are many possible explanations for this. Prevalence rates vary according to tumor site and extent of disease. In addition, prevalence rates will vary and will be reported differently depending on which empirical tools were used to measure psychological distress (Sellick & Crooks, 1999; Zabora et al.). Carlson and Bultz (2002) reported that psychological distress is most frequent and severe among patients with a poorer prognosis and greater patient burden. The rates of psychological distress also vary as the concept is dynamic and levels of distress often change at various stages in the illness trajectory and treatment phase (NCCN, 2004).

Although prevalence rates as high as 50% have been reported, fewer than 10% of all cancer patients are actually referred for psychosocial help by a mental health professional (NCCN, 2004). Physicians are often too busy in oncology clinics to adequately assess patient distress. Furthermore, patients are hesitant to report distress because of the stigmatizing nature of the words *psychological* or *psychiatric*. As a result, many patients are reluctant to relay information about their distress to health care professionals (Hoffman, Zevon, D'Arrigo & Cecchini, 2004; NCCN). If this is true, then it is likely that the prevalence rates of psychological distress among the cancer population may be even greater than reported.

Prevalence of Psychological Distress in Colorectal Cancer Patients

Several studies have examined the psychological status of CRC patients. One of the earliest studies documenting the prevalence of psychological distress in CRC reported that nearly two-thirds of patients were depressed during immediate recovery from surgery (Druss, O'Connor & Stern, 1968). These numbers need to be interpreted with caution as

surgery has since improved and stoma care has also dramatically improved with more supports available to patients. More recently, Klemm, Miller, and Fernsler (2000) have reported that as high as 90% of patients being treated for CRC had psycho-social or existential concerns related to their disease. Zabora et al. (2001) however, reported that the overall prevalence of psychological distress was 31.6% in patients with CRC. Nordin and Glimelius (1997) examined the psychological reactions in patients newly diagnosed with gastrointestinal cancer and found lower levels of psychological distress, between 17 to 21%, in colon and rectal cancer patients. Prevalence rates of anxiety and depression at time of CRC diagnosis have been also reported at 25% and 26% respectively (Wasteson, Nordin, Hoffman, Glimelius & Sjoden, 2002). Northouse, Mood, Templin, Mellon, and George (2000) evaluated the psychological status of patients with colon cancer and their spouses (n=56) one-week post diagnosis, 60 days post-surgically, and one year post-surgically and found that the prevalence of distress significantly lessened over time. In contrast, Yan and Sellick (2004) reported that levels of depression increased significantly over time among colorectal cancer patients.

Many studies have also examined the effect of stoma surgery on a patients' psychological status. Wade (1990) interviewed 250 patients ten weeks and one year after stoma surgery and found that overall 25% of persons were anxious or depressed, six percent were severely depressed, and five percent had contemplated suicide. The prevalence of anxiety and depression increased to 34% in districts in which patients did not have access to a stoma care nurse (Wade, 1990). Thomas, Madden, and Jehu (1984) measured psychological morbidity following the first three months after stoma surgery and found that more than one-half of the patients experienced some psychiatric

disturbance. Sprangers, de Velde, Aaronson, and Taal's (1993) literature review revealed that psychological distress tends to be higher among stoma patients than non-stoma patients, younger patients and patients who are female. MacDonald and Anderson (1985) examined the psychological well-being of in long-term survivors of rectal cancer patients (n=420). The results indicate that 25% were severely depressed and 26% were severely anxious. Although the presence of colostomy was not associated with overall distress, significantly more patients with colostomy were severely depressed (MacDonald & Anderson).

Peak Periods of Psychological Distress

According to the NCIC (2002), common periods of crisis for cancer patients across the illness trajectory exist which can lead to significant psychological distress. These critical periods of vulnerability include: while finding a suspicious symptom, during workup, at time of diagnosis, while awaiting the start of treatment; and during changes in treatment, post-treatment, medical follow-up, remission, time of recurrence, disease progression, and the transition to palliative care (NCCN, 1999; NCCN, 2004; NCIC). Each of period of vulnerability along the illness continuum provokes unique existential questions, requires the use of different coping mechanisms, and presents specific obstacles (Brennan, 2001; NCIC; Spencer, Carver & Price, 1998).

Carlson and Bultz (2002) however, disputed the assertion that distress has many peaks and valleys. These authors maintained that psychological distress remains at a relatively stable level throughout the cancer diagnosis and treatment phase and is only disrupted at the terminal stage of disease when there is a marked increase in quality of life issues. Brown, Levy, Rosberger, and Edgar (2003) examined the effects of distress

on survival among cancer patients from various tumor site groups (n=207) and also found that levels of distress remained stable over time. Waligora-Serafin, McMahon, Pruitt, and Davenport (1992) studied the relationship between psychological distress and psychological concerns in newly diagnosed cancer outpatients at time of diagnosis, and at 3 and 6 month intervals. They determined that distress was major issue in newly diagnosed cancer patients particularly after the first 3 months post-diagnosis. Other reports support this finding and indicate that initial high levels of distress will gradually diminish over time (Nordin & Glimelius, 1998).

A normal adjustment to these periods of crisis can encompass a wide array of reactions and emotions such as shock, disbelief, denial, and a period of distress (Nordin, Berglund, Glimelius & Sjoden, 2001; Nordin, Wasteson, Hoffman, Glimelius & Sjoden, 2001). Normal adjustment often involves frequent periods of tearfulness, anger at God, social isolation, and the feeling of giving up hope. An initial reaction of distress as a result of a cancer diagnosis is common and this reaction usually dissipates over time after a period of adjustment. It may be exacerbated by another crisis such as the initiation of chemotherapy. It is important to note that although the severity of distress symptoms may be acute, this does not necessarily indicate psychopathology as the frequency and duration of symptoms tends to be self-limiting (Curbow, Somerfield & Baker, 1993; NCIC, 2002; Northouse et al., 2002).

Conceptual Clarification

The concept of psychological distress is significant as many patients with cancer experience some degree of emotional disturbance related to their diagnosis or treatment. Despite the fact that psychological distress is an important issue in the cancer population

and is widely investigated in cancer research, the concept remains vague and not well defined. Psychological distress is often defined only by its empirical measurement tools. According to Ream and Richardson (1996), if a concept is unclear then any work on which it is based is also unclear. The lack of conceptual clarity may result in unsuitable methodology that could threaten the internal validity of research and perhaps more importantly, negatively impact patient care.

The term psychological distress is a concept that is frequently communicated in both lay and professional language, but seldom defined as a distinct concept (Ridner, 2004). According to *Taber's Cyclopedic Medical Dictionary* (Thomas, 1993), the term *psychological* refers to a broad encompassing term: the study of the mind in all of its relationships. A definition of *distress* in the context of health and social sciences is referred to as "... a subjective response to internal or external stimuli that are threatening or perceived as threatening to the self" (Fortinash & Holiday-Worret, 2000, pp. 804). Jones and Johnston (2000) defined the concept of psychological distress as too much or not enough arousal resulting in harm to the mind. Stimuli become distressing only when perceived as such. The authors further conceptualized psychological distress by describing it as an outcome of ongoing negative situational transactions (Jones & Johnston).

Masse (2000), a medical anthropologist, described the concept of psychological distress as a subjective experience. Each manifestation of distress has varied meanings and these meanings are context and person dependent. Psychological distress is not a static condition, but rather a lived experience and a dynamic process that has different levels of severity and changes throughout a person's distress episode. Distress is a crisis

of one's self. This crisis is derived from a person's perceived capacity or incapacity to control one's life as in the case with a major life stressor such as cancer. Symptoms of emotional distress can be interpreted through language. It is the language of distress that allows people to socially experience mental suffering and enables them to enact their suffering according to his or her individual experience. The qualitative approach taken by Masse to describe psychological distress is unique. Health-related literature predominantly quantifies emotional distress and its operational definitions are derived from measurement tools. According to Masse, qualitative research captures the essence of psychological distress and any empirical measures de-contextualize the individual's experienced manifestations of distress.

The *National Comprehensive Cancer Network* (NCCN; 1999) developed its own conceptual definition of psychological distress with the intention of accurately depicting the concept without using stigmatizing rhetoric. Psychological distress has been defined as:

An unpleasant experience of an emotional, psychological, social or spiritual nature that interferes with the ability to cope with cancer treatment. It extends along a continuum, common normal feelings of vulnerability, sadness, and fears, to problems that are disabling such as true anxiety, depression, panic and feelings of isolation or in a spiritual crisis (NCCN, 1999, pp, 10).

The NCIC (2002) has placed psychological distress on a continuum which is based on *The Diagnostic and statistical Manual of Mental Disorders (DSM-IV) Adjustment Disorder*. This continuum of psychological distress ranges from normal adjustment to a more severe psychological distress (Appendix A). The severe type of distress on the

continuum meets the full diagnostic criteria of a mental disorder. Although most cancer patients do not necessarily meet the criteria for a major mental disorder, the continuum is helpful to address the unique needs of individual clients who experience a wide range of emotional responses to the diagnosis and treatment of cancer (NCIC). The magnitude and severity of the symptoms of psychological distress can depend on the severity of illness (Kelly, Ghazi & Caldwell, 2002; Mast, 1998; Mock et al., 1997). The magnitude and severity of distress a person experiences, is based on a person's ability to balance the ratio between the perception of the demands that a situation places on them (e.g., surgery), with the perception of resources they possess to manage these demands (e.g., analgesics for post-operative pain) (NCIC).

Manifestations of Psychological Distress

Psychological distress can manifest itself in many different ways. Masse (2000) described expressions of psychological distress in terms of six idioms. These idioms are: demoralization and pessimism towards the future, anguish and stress, self-deprecation, social withdraw, somatization, and withdrawing into one's self (Masse). These idioms are believed to be the primary expressions of distress. The first idiom, demoralization and pessimism towards the future, encompasses feelings of despair and disillusionment that may lead to decreased motivation and disengagement in an individual's social or professional activities. Anguish and stress may be manifested as an internal suffering through anxiety, nervous tension, or strain and excessive worry. The next idiom, self-deprecation, involves blaming thy self and doubting self-worth. The fourth idiom manifests itself through the process of withdrawing and isolating oneself from social encounters. Somatization, another idiom, is linked to fatigue, loss of energy and / or

apathy. The final idiom describes the process of an individual withdrawing into one's self (Masse; Ridner, 2004).

Van Servellen et al. (1996) utilized the concept of emotional distress as a reflection of a negative affective state capable of altering a patient's quality of life. According to these authors, emotional distress manifests itself in behavioral, cognitive, and somatic features that can impact a person's health status and the ability to cope or comply with medical instructions (1996). Patients can exhibit symptoms such as irritability, decreased energy or lethargy, disrupted sleep patterns, feelings of helplessness, and loss of hope. Other manifestations of psychological distress described in the literature include self-accusatory evaluations, pervasive fear and worry, anxiety, hostility, sadness or depression, and altered physical and /or cognitive responses (Bodurka-Bevers et al., 2000; Mock et al., 1997; Van Servellen et al., 1996; Walker & Sofaer, 1998). The two most common manifestations of psychological distress described and measured in the literature are anxiety and depression (Baider, Andrisch, Uziely, Goldzweig, Ever-Hadani, Hofman et al., 2003; Bisson, Chubbs, Bennett, Mason, Jones & Kynatson, 2002; Bodurka-Bevers et al., 2000; Montazeri, Jarvandi, Haghightat, Vahdani, Sajadian, Ebrahimi, et al., 2001; Nordin, Berglund, Glimelius & Sjoden, 2001; Nordin et al., 2001).

The defining attributes of a concept are characteristics of a concept which appear repeatedly in the literature that describes the concept. This process allows a concept to be differentiated from other related concepts (Walker & Avant, 1995). A review of the literature of psychological distress in the cancer population has revealed several defining characteristics. Psychological distress is an internal state of suffering which an individual

experiences that has a negative impact on quality of life for the individual and family. This negative affect or mood state has varying degrees of severity which may fluctuate over time. The more pre-existing stressors present, the greater likelihood of severity and/or duration of psychological distress. It has the capacity to affect the cognitive and physical dimensions of self. Emotional distress may manifest itself in several ways such as through anxiety or fear, depression or sadness, fatigue or exhaustion, hostility, pessimism, social withdrawal, and sleep disturbances. These symptoms interact with one another in a dynamic process. Finally, it is a context rich variable that is often measured on a continuum via quantitative measures.

Risk Factors for Psychological Distress

There are many sources of risk that can be predictive of the development of psychological distress in the cancer population. Often, these risk factors do not occur in isolation. A person with multiple risk factors is at higher risk for developing significant psychological distress. Some of the most common predictive risk factors will be examined. They include age, gender (Baider et al., 2003; Compas et al., 1999; Nordin et al., 2001; Sammarco, 2001; Walker & Sofaer, 1998), coping style (Baider et al.; Kuo & Ma, 2002), limited social support ((Koopman et al., 2001; Kurtz et al., 2002), and pre-existing illness or co-morbidity(Kurtz et al.; Nordin et al., 2001; Thomas et al., 1987).

Age at cancer diagnosis is considered to be an important predictor of psychological distress in cancer. Younger cancer patients tend to have a higher incidence of psychological distress when compared to older patients. For example, younger women with breast cancer are more likely to have a decreased ability to cope with treatment-related side effects and to maintain a positive attitude than older women with breast

cancer. Women less than 50 years of age were more distressed over body-image disfigurement and fear of recurrence (Baider et al., 2003; Bodurka-Bervers et al., 2000; Compas et al., 1999; Nordin et al., 2001; Sammarco, 2001; Trief & Khan, 1997; Walker & Sofaer, 1998). Higher levels of distress associated with younger age may be a result of a larger disruption in social and familiar roles at earlier stages, such as establishing careers and raising a family. Additional distress may be caused by the belief that it is less fair for a younger person to be struck with cancer (Carlson, Angen, Cullum, Goodey, Koopmans, Lamont et al., 2004). It has also been hypothesized that older patients have experience managing symptoms for other chronic illnesses; therefore, they have more life experience and have learned effective coping skills to deal with illness and associated symptom burden (Kurtz, Kurtz, Stommel, Given & Given, 2001).

Gender is another variable that has been linked to psychological distress. Women are at higher risk for developing significant levels of psychological distress related to cancer than men (Carlson et al., 2004; Kurtz et al., 2001). Studies which examined the psychological impact of cancer on both patient and their spouses found similar results. Women with cancer and women who are caregivers of their spouses with cancer experience greater psychological distress than men who have cancer or men who are caregivers (Bisson et al., 2002; Hagedorn, Buunk, Kuijer, Wobbes & Sanderman, 2000; Matthews, 2003; Northouse et al., 2000; Oberst & Scott, 1988).

Another major risk factor for psychological distress is coping style. The type of coping style an individual uses to adjust to cancer is a major determining factor that can lead to or prevent psychological distress. Less effective problem solving ability is a predictive factor for higher anxiety, depression, and overall distress levels (Maguth Nezu,

Nezu, Friedman, Houts, DelliCarpini, Bildner et al., 1999). Lazarus and Folkman (1984) classified coping style into two categories: *problem-focused coping* and *emotion-focused coping*. A person engaging in *problem-focused coping* is actively solving problems, setting goals, altering expectations, seeking information, and adopting techniques to increase self-control. Conversely, people with cancer who engage in *emotion-focused coping* are not directed towards problem solving; rather, they subjectively change their thoughts. This type of coping includes hopeful thinking, escape, repression, denial, or acceptance (Kuo & Ma, 2002). Although it has been stated that neither of these two coping styles are superior, many studies have shown that individuals who engage in emotion-focused coping score consistently higher on psychological distress scales than individuals who engage in problem-focused coping (Baider et al, 2003; Brennan, 2001; Compas et al., 1999; Kuo & Ma, 2002; Wasteson et al., 2002).

A person with a limited social support network is also at higher risk for developing psychological distress. Hence, a person who has a large social support system of friends and family is less likely to experience significant cancer-related psychological distress for an extended period of time (Koopman et al., 2001; Kurtz et al., 2002; Nordin et al., 2001; Northouse & Glimelius, 1995; Trief & Khan, 1997; Van Servellen, 1996). Good family functioning has been correlated with lower levels of depression, anxiety, and overall distress (Edwards & Clarke, 2003); while inadequate supports, problems in relationships, unsupportive environments, and social isolation have all been associated with increased levels of depression (Raveis & Karus, 1999). Nordin et al.'s study which focused on predicting anxiety and depression in cancer patients identified three different types of social support as emotional support, informational

support, and instrumental support. Emotional support encompasses all verbal and non-verbal communication the patient is engaged in. The second type of support, informational support, pertains to the information and advice offered by family, friends, and health care professionals. Instrumental support entails the provision of items such as money or food. Patients preferred emotional support to be given by family and friends and informational support be provided by health care providers (Nordin et al.).

Psychological and physical co-morbidities are also important risk factors for the development of psychological distress in patients with cancer. Patients with a history of psychological morbidity (e.g., anxiety disorder or depression) prior to the diagnosis of cancer are at greater risk for experiencing moderate to severe levels of psychological distress after diagnosis (Bodurka-Bervers et al., 2000; Kurtz, Kurtz, Stommel, Given & Given, 2002; Nordin et al., 2001, Pascoe, Edelman & Kidman, 2000; Trief & Khan, 1997; Van Servellen et al., 1996). Elderly cancer patients who have multiple physical co-morbidity experience more psychological distress than those without (Kurtz et al.). Cancer-related pain may also be predictive of symptoms of depression (Atesci, Baltarli, Oguzhanoglu, Karada, Ozdel & Karagoz, 2004). Furthermore, a poor prognosis, advanced disease, or severe functional impairment are all factors which leave a person vulnerable to developing significant distress levels (Bodurka-Bervers et al; Carlson & Bultz, 2002; Pascoe, Edelman & Kidman, 2000).

Consequences

There are many potential consequences of psychological distress in the cancer population. If psychological distress remains untreated, several problems may result.

Distress may adversely affect a patient's physical and mental health status and have a negative impact on overall quality of life (Kurtz et al., 2002; NCCN, 2004).

Psychological distress affects the social relationships of cancer patients. Cancer has the ability to stigmatize individuals and subsequently put pressure on pre-existing relationships (Flanagan & Holmes, 2000). Patients with cancer often worry about being a burden to their family and experience feelings of guilt. Distress can immobilize patients from participating in social relationships which can result in feelings of isolation. Isolation from friends and family can potentially deepen the emotional impact. In turn, family and friends may unknowingly perpetuate strained relationships. They may feel helpless and do not know how to ease the suffering of the patient. Also, excessive fear of cancer and the possibility of losing a loved one, compounded with a lack of knowledge, may cause family and friends to exhibit avoidance or overprotective behaviors to the person with cancer (Kuo & Ma).

Psychological distress is also positively correlated with increased morbidity and mortality (Kurtz et al. 2002). Psychological well-being is an important predictor of post-operative recovery regardless of age, co-morbidity, symptom severity, and type of cancer (Hodgson & Given, 2004). It can have a negative impact on immune function and wound healing, both of which are key variables in post-operative recovery (Kiecolt & Marucha, 1995). This has the potential to significantly reduce a patient's quality of life and even reduces overall survival time (Kurtz et al.). In one study the effects of psychological distress on cancer survival in patients from various tumor site groups (n=205) were examined and results indicated that the presence of depressive symptomology is

significantly correlated with reduced survival time (Brown, Levy, Rosberger & Edgar, 2003).

Psychological distress can adversely affect a patient with cancer in many other ways. Distress can impact one's ability to cope with cancer treatments, maintain treatment compliance, and reduce one's ability for self-care (Engelking, 2004; Mock et al, 1997; Redeker et al., 2000). The physical impact of psychological distress in cancer is often difficult to detect or isolate because many symptoms of psychological distress can mimic or overlap with symptoms arising from cancer and cancer-related treatments (Mock, Dow, Meares, Grimm, Dienemann, Haisfield-Wolfe, Quitasol, Mitchell, Chakravarthy & Gage, 1997; NCIC, 2002).

Unmanaged psychological distress can also be very costly to both the patient and the health care system. Distressed patients may have increased difficulty making decisions about treatment plans and maintaining treatment compliance. This may lead to dissatisfaction with the health care team and the medical care provided. All of these factors may in turn increase length of hospital stay, emergency room visits and hospital re-admission rates (Hoffman et al., 2004; NCCN, 2004).

Measurement Tools for Psychological Distress

Although Masse's (2000) depiction of psychological distress focuses on its subjective and context dependent nature, many empirical measures of psychological distress exist and are widely used in health research. These empirical instruments are useful screening tools that can be used by nurses and other members of the oncology health care team to facilitate the assessment and identification of patients at risk for significant levels of psychological distress. Although these tools are useful for screening

purposes, it is important to note that they are not sufficient for a diagnosis of a psychiatric disorder (Sellick & Crooks, 1999). The *Brief Symptom Inventory* (BSI; Derogatis & Melisaratos, 1983), the *General Health Questionnaire* (GHQ; Goldberg & Williams, 1998), the *Profile of Mood States* (POMS; McNair, Lorr & Droppleman, 1971), and the *Psychological Distress Inventory* (PDI; Morasso, Costantini, Baracco, Borreani & Capelli, 1996) have all been frequently used to measure overall distress in patients with cancer. The *Hospital Anxiety and Depression Scale* (HADS; Zigmond & Snaith, 1983) is perhaps one of the most common empirical tools used in this type of cancer research. This scale can be used to measure anxiety, depression, and overall distress.

Management of Psychological Distress

As stated previously, up to 50% of cancer patients can experience significant psychological distress, but fewer than 10% get referred for psycho-social intervention (Hoffman et al., 2004). To ensure that psychological distress in patients with cancer is recognized, all patients should be assessed in hospital and in oncology clinics using a brief screening tool (NCCN, 2004). Standardized screening tools are helpful in identifying patients at risk for developing all levels of psychological distress and can be the impetus for further inquiry. These tools can also be used to track patients over time. Unfortunately, routine screening of cancer patients for psychological distress is not the norm. Frequently, patients with cancer are either self-referred or referred by the oncology team who becomes aware of the patient's distress during the course of care (Carlson et. al., 2004). This can result in missing many patients in need of distress management who are either too distressed to seek help or are unable to navigate through the medical system to reach appropriate psychosocial care. In addition, patients with

cancer maybe so preoccupied with their physical needs that they may not have the ability to recognize the severity of their distress. In these instances, the most disadvantaged patients may be the least likely to receive psychological intervention (Carlson et al.).

Once psychological distress has been identified in patients it can be treated. The oncology team has a responsibility to provide the best possible interventions targeted at acknowledging, minimizing, and alleviating this distress (Hoffman et al., 2004). Recently, the imperative need for such interventions has been recognized and several options are widely available for patients. Interventions aimed at treating distress are standardized and highly effective (Carlson & Bultz, 2002). The availability of multiple treatment modalities is helpful, as the unique needs of individual patients may be better suited toward a certain type of intervention.

Mild levels of psychological distress can be managed by the primary oncology health care team. The primary oncology team is typically comprised of an oncologist, nurse, and social worker. Mild levels of cancer-related distress should be anticipated and treated as a part of a normal human response to illness. It is imperative that the health care team acknowledges these feelings as normal to the patient and encourages discussion and expression of emotion. It is essential that all the necessary social supports are in place for patients and their families and that they are informed of where to access educational information and community resources (NCCN, 2004). Severe psychological distress as recognized by the patient or the oncology team should trigger an immediate referral to a mental health professional, social worker or spiritual counselor. For instance, a psychiatric nurse, psychologist, or psychiatrist may be consulted for mental health services. Oncology social work would be consulted with practical or social

concerns. Likewise, pastoral care would be consulted in cases where patients have existential concerns or problems of a spiritual nature (NCCN).

Individual therapy. Individual therapy is often beneficial in alleviating a patient's psychological distress. However, individual psychotherapy for patients with cancer is most effective once a trusting relationship between therapist and client is established. Therapy can focus on areas such as exploring personal meaning of cancer and developing skills such as coping mechanisms, reappraisal of negative thoughts, and improved problem-solving techniques. This often entails interventions such as open communication, role-playing, and relaxation techniques. The duration of therapy is patient dependent and can range from one session to several sessions over many weeks or months. Individual therapy can result in increasing a patient's self-efficacy, perception of control over environment, hope, and overall quality of life (Sellick & Crooks, 1999).

Group therapy. Group therapy, in lieu of individual therapy, is a growing trend that is gaining momentum (Pascoe et al., 2000). Group therapy can be advantageous over individual therapy as it provides a significant cost-benefit to the Canadian health care system as many individuals are treated at once. Active problem solving skills and social support gained through group therapy eases the adaptation of patients with cancer, thereby alleviating psychological distress (Golant, Altman & Martin, 2003). There are numerous types of group therapies available for many types of cancer such as supportive expressive therapy, meditation-based stress reduction therapy, and group psycho-educational programs (Carlson & Bultz, 2002).

Supportive group therapy places emphasis on open and honest expression of thoughts and emotions, receiving, and offering support and learning new ways to cope

with cancer. A therapist guides the discussion and educates the group about important themes such as fear of recurrence (Fobair, Koopman, Dimiceli, O'Hanilan, Butler & Classen, 2002; NCIC, 2002). Fobair et al., (2002) studied the effects of a supportive-expressive group therapy intervention offered to lesbians with breast cancer (n=29). After the 12-week intervention, the women in therapy reported significantly reduced emotional distress ($p < 0.02$) and reported improved coping abilities at three, six, and 12 months post-intervention. Support groups therapy can also provide a supportive atmosphere where individuals with cancer can feel comfortable to express emotions. Expressing emotions through this route can decrease anxiety and depression resulting in an overall improvement of mood and long term quality of life (Compas et al., 1999; Trief & Khan, 1997). Group therapy can also improve interpersonal relationships, foster better coping skills, and decrease symptom distress related to cancer and its related treatments (Golant et al., 2003).

Standardized group behavioral psycho-educational programs are also beneficial to patients with various types of cancer. Psycho-educational programs reduce psychological distress offering support and information about cancer and its treatments. Psycho-educational programs are aimed at using the mechanism of active problem solving and social support to reduce the psychological suffering in cancer patients. Patients who were actively involved in their illness tended to show increased optimism and engage in positive behavioral and cognitive responses to the management of their illness (Golant et al., 2003). A psycho-educational program allows health care professionals to provide patients with accurate and thorough information that is pertinent to their cancer diagnosis and subsequent treatment. Meeting patient's educational needs has been effective in

reducing uncertainty about illness and results in more effective symptom management (Baider et al, 2003; Golant et al, 2003; Montazeri et al., 2001).

It is important to note that although therapy is beneficial to many cancer patients; it is certainly not indicated for all patients with cancer who have psychological distress. It may not be warranted for patients who experience only mild to moderate symptoms of distress that can naturally dissipate over time. Furthermore, patients often rely on their friends, family, and community for social support, and this type of support can be just as effective in reducing distress (Baider et al., 2002; Nordin et al., 2001; Sellick & Crooks, 1999). Patients also may find other interventions other than therapy useful in the management of their distress. Exercise programs, such as walking or yoga, can be helpful in alleviating the burden of distress (Mock et al., 1997). For patients with more severe forms of distress, a form of pharmacotherapy may be indicated alone or in combination with therapy (NCIC, 2002).

Not only do various treatment modalities improve quality of life, they also offer some positive physical health benefits. Carlson and Bultz (2002) reported that psychosocial interventions that improve quality of life have also been linked to positive responses in immune and hormonal functioning and even may improve survival rates. For instance, a study by Spiegel, Bloom, Draemer, and Gottheil (1989) examined the effects of group therapy on survival rates for women with metastatic breast cancer and showed an 18-month survival advantage over those who did not participate in group therapy. Eldman, Craig, and Kidman (2000) however, reviewed several studies that looked at the effects of psychotherapy and survival time, and determined that there were no statistically significant survival benefits gained through therapy.

Health care professionals must be sensitive to their patients' needs and continually assess patients for varying levels of psychological distress. It is imperative that their assessments be thorough and client-centered; that is, informing patients, listening to patients, taking time to answer questions, having the ability to provide psychological support, and directing them to appropriate resources for assistance (Sellick & Crooks, 1999).

Summary of Psychological Distress

Cancer is a potentially life threatening illness that can impose a serious psychological burden on clients. The prevalence of psychological distress after a diagnosis of cancer is well recognized (Bisson et al., 2002). As a result of a thorough exploration, the concept of psychological distress in the cancer population has been clarified. Psychological distress is a negative mood state that can have a fluctuating or variable symptom presentation. In particular, cancer patients often suffer from considerable psychological distress such as anxiety and depression at time of diagnosis, initiation of cancer treatments, and with symptom exacerbation (NCCN, 2004; NCIC, 2002).

Many risk factors such as age, gender, poor coping strategies, lack of social support, and pre-existing physical and psychological morbidity all can contribute to and magnify an individual's level of psychological distress (Baider et al., 2003; Bodurka-Bevers et al., 2000; Carlson et al., 2004; Kuo & Ma, 2002; Kurtz et al., 2002; Oberst & Scott, 1988). Unresolved psychological distress can significantly decrease an individual's and family's quality of life.

Many empirical measurement tools to assess psychological distress are available for use in research and are also useful screening instruments for clinical practice (NCIC). Fortunately, many effective standardized interventions such as group therapy are widely available to patients experiencing psychological distress (Golant et al., 2003). Nurses and other members of the oncology team play a pivotal role in the screening and assessment of their clients' psychological status. Therefore, it is essential that nurses be vigilant in the assessment of psychological distress in patients with cancer through open communication and the use of applicable screening tools to ensure that patients receive appropriate care and interventions targeted at alleviating psychological distress.

Psychological Distress and Symptom Experience

The relationship between psychological distress and symptom experience in patients with cancer maybe a logical assumption, but there is a paucity of literature to support this claim. There are no studies to date, that directly measure the relationship between psychological distress and physical symptom experience in patients with cancer. Evidence that does support this relationship is fragmented. Many inferences are derived from health-related quality of life research. Inferences about psychological distress and the physical symptom experience are also made from studies which measure one physical symptom (e.g. pain or fatigue) in relation to one aspect of psychological distress (e.g., depression). In addition, many inquiries into symptoms such as pain or fatigue fail to capture the multidimensional symptom experience. Some of the reasons for this are that each of these concepts has lacked conceptual clarity and wide variation in assessment methodology (Chen, Chang & Yeh, 2000). This makes comparison difficult and drawing inferences about different tumor site groups even more challenging. The current state of

the literature will be explored and existing evidence of the relationship between psychological distress and physical symptom experience will be presented.

Psychological distress and negative physical symptom experience have a reciprocal relationship. Psychological distress has the capacity to exacerbate a patient's pre-existing symptoms from cancer and cancer-related treatments. Pain, fatigue, nausea, and vomiting can be interpreted as more severe and bothersome in patients with high versus low levels of psychological distress (Gupta, Nayak, Khoursheed, & Roy, 1999; Kuo & Ma, 2002; Mock et al., 1997; Redeker et al., 2000; Van Servellen, 1996; Waterman, Leatherborrow, Slater & Waterman, 1999). Likewise, a high degree of symptom severity is correlated with an increased level of psychological distress (Kurtz et al.; Mock et al.; Nordin et al., 2001; Van Servellen). The number of symptoms is also linked to psychological distress. The more symptoms reported by patients with cancer, the more likely they are to experience heightened levels psychological distress and decreased quality of life (Fowler, Carpenter, Gupta, Golden-Kreutz & Anderson, 2004; Portenoy et al., 1994).

Psychological distress and symptom distress is another important relationship. Pasacrete (1997) examined the relationship between depression and physical distress in patients with breast cancer and found that women with higher levels of depression had more physical distress than those without depression. DeKeyser et al. (1998) also investigated the relationship between psychological distress and physical symptom distress and its effects on immune function in women with suspected breast cancer (n=35) and the results revealed a significant correlation between psychological and physical symptom distress.

The relationship between pain and psychological distress in patients with cancer has been frequently reported (Raveis & Karus, 1999). Anxiety, depression, and overall psychological distress have all been correlated with cancer-related pain. Anxiety and depression is significantly higher in patients experiencing pain than those who are not (Knotkova, Clark, Mokrejs, Padour & Kuhl, 2004; Tanaka et al., 2002; Zimmerman et al., 1996). It has been reported that cancer patients experiencing pain are twice as likely to develop psychiatric morbidity as patients without pain (Derogatis, Morrow, Fetting, Penman, Piasetsky, Schmale et al. 1983). A review of the literature by Zaza and Baine (2002) also found strong evidence to support the relationship between psychological distress and cancer pain. Patients with significant psychological distress reported increased levels of and more intense pain than patients with no distress (Zaza & Baine).

The relationship between fatigue and psychological distress has also been explored. In a recent study, women treated for breast cancer (n=109) who reported the greatest amount of fatigue also had concurrent psychological symptoms such as anxiety and / or depression (Bennett, Goldstein, Lloyd, Davenport & Hickie, 2004). Similar results were found in lung cancer patients with anemia (n=250). Improvements in cancer-related fatigue were significantly correlated with reductions in anxiety and depression (Tchekmedyan et al., 2003). Ahlberg, Ekman, Wallgren, and Gaston-Johansson (2004) also reported significant correlations between fatigue and psychological distress in patients with uterine cancer (n=60). In particular, correlations were detected between general fatigue and anxiety and general fatigue and depression (Ahlberg et al.).

Anxiety and depression have both been correlated with common cancer symptom clusters such as pain, fatigue, and insomnia. Mock and colleagues (1997) found that fatigue, difficulty sleeping, anxiety, and depression were the most frequent and intense symptoms experienced by women with breast cancer treated with radiation. Redeker et al. (2000) studied insomnia, fatigue, anxiety, and depression in cancer patients being treated with chemotherapy (n=263). Both insomnia and fatigue demonstrated a moderate positive correlation with anxiety and depression. The relationship between these psychological and physical symptoms is complex since many of the symptoms of depression are similar to those of cancer such as weight-loss, fatigue, and insomnia (Given, Given, Rahbar, Jeon, McCorkle, Cimprich, et al., 2004).

Symptom experience and psychological distress have also been noted in post-surgical cancer patients. The total magnitude of symptoms after radical cystectomy is an important determinant of anxiety and depression in bladder cancer survivors (Henningsohn, Wijkstrom, Pedersen, Ahlstrand, Aus, Bergmark, et al., 2003). Multiple, frequent, and intense post-operative symptoms are associated with decreased levels of well-being (Henningsohn et al.). Pain, fatigue, and depression were determined to be significantly correlated in post-surgical elderly patients (Zalon, 2004). Surgery and its associated symptoms during recovery are associated with greater risk developing depressive symptoms. Post-operatively, patients experiencing multiple symptoms stated they felt "...overwhelmed and captured by the disease" (Olsson et al., 2002, pp.54).

Psychological Distress, Symptom Experience, and Colorectal Cancer

Evidence to support the relationship between psychological and physical symptom experience in patients with CRC has been for the most part, incomplete. Overlapping symptoms, use of different empirical measurement tools, and a lack of conceptual clarity perpetuate the difficulty in gaining an accurate depiction of colorectal cancer patients operatively. Although there has been research done that looks at the relationship between certain symptoms that are common to colorectal cancer and the effects of cancer-related treatments on psychological distress, no study to date has specifically examined the total symptom experience and psychological distress in patients with colorectal cancer in the immediate post-operative recovery phase.

There have been a few studies that have examined the relationship between psychological morbidity and symptoms in colorectal cancer. A significant finding in the study conducted by Kurtz et al. (1999) was the correlation between symptom severity, physical functioning, and mental health. Women with lung, colon, and breast cancer (n=299) who reported greater symptom severity, tended to be older and reported greater losses in physical functioning and poorer mental health (Kurtz et al., 1999). Similar findings were reported in a more recent study by Kurtz et al. (2002), which examined predictors of depression in geriatric patients with CRC (n=234). Females, African-Americans, and patients with co-morbidities had the highest levels of depressive symptoms. Also, the more symptoms a patient reported, the higher the patient's level of depressive symptoms (Given et al., 1994; Kurtz et al., 2002).

The primary treatment for CRC is surgery. Research that examines the effects of pre-operative psychological intervention shows that patients benefit post-surgically in

relation to their psychological and physical health status (Kiecolt-Glaser et al., 1998). Patients who are not psychologically distressed pre-operatively are less likely to report severe pain, use less analgesic, and experience faster physical recovery post-operatively. Conversely, patients experiencing psychological morbidity are more likely to have significantly more serious physical symptoms three months and one year post-operatively (Thomas et al., 1987). Also, patients who are more anxious are more likely to experience greater post-operative pain than non-anxious patients. Psychological distress can result in decreased immune function, delayed wound healing, decreased treatment compliance, and increased post-operative complications (Kiecolt-Glaser et al., 1998). Distressed post-operative patients who are in greater pain may be more cautious about ambulation, and deep breathing and coughing; thereby, increasing the risk for post-operative complications such as deep vein thrombosis and pneumonia (Kiecolt-Glaser et al.).

Post-operative recovery for CRC is a critical period in which psychological health and symptom management is crucial for optimal well-being and survival. Wade (1990) studied psychological adjustment after stoma surgery for CRC (n=215) and found a strong association between a patient's physical state and psychological adjustment. Wade found that of the 25% of colostomy patients who were either anxious or depressed at ten weeks post-operatively were among those who died the subsequent year; whereas, only 13% of colostomy patients with low levels of psychological distress died during this time. It was not reported however, if these results were statistically significant. Bekkers, Van Knippenberg, Van Dulmen, Van Den Borne, and Van Berge-Henegouwen (1997) results were similar; poor psychological adjustment to stoma surgery and non-stoma

bowel resection appeared to be a predictor of death and terminal status after demographic variables such as age were controlled for (Bekkers et al.).

Although there are studies which include some aspects of psychological morbidity and symptom experience in colorectal cancer patients, it is important to note their limitations in relation to this current research project. In all of the studies cited, only frequency, severity, or distress was measured. None of the studies measured total symptom experience (i.e., symptom frequency, severity and distress); and therefore did not illustrate the multidimensional nature of the concept. In addition, the studies presented did not adequately capture the complexity of the concepts of psychological distress and symptom experience; rather, these concepts were defined only by their measurement scales.

Chapter III

Theoretical Framework

Introduction

The *Theory of Unpleasant Symptoms* (TUS) is a middle-range nursing theory developed by Lenz, Pugh, Milligan, Gift, and Suppe (1995) that will be used to guide this pilot study. This theory was updated by Lenz and colleagues in 1997 who maintain that the development of this theory is ongoing. The TUS was chosen because of its parsimonious nature and relevance to the concepts that will be measured within this study. Due to the fact that this theory is relatively new and has only been used in a select group of cancer patients, a thorough analysis will be provided to enhance the understanding and applicability of the theory to this pilot project.

One of the most important benefits of middle-range nursing theories is their applicability and relevance to clinical nursing practice (Lenz & Gift, 1998). A recent trend in the profession of nursing is to create, use, and carry out research-based care. A goal which is inherent to this trend is to develop and use nursing theory. A critical appraisal of theory is an essential element required to determine whether or not the theory is being used appropriately in practice or research (Dudley-Brown, 1997). The systematic analysis and evaluation process is imperative and can lead to a deeper understanding of theory and can propel the development of a theory forward. Fawcett's (2000) framework for analysis and evaluation of nursing theory will be utilized to analyze the TUS (Lenz et al. 1995). This framework is a two-phase process; theory analysis and evaluation. Each phase has several steps that enhance the appraisal process (Fawcett).

Theory Analysis

The first aspect to the critical appraisal of the TUS (Lenz et al., 1995, Lenz et al., 1997) is theory analysis. The analysis component of Fawcett (2000)'s framework is used to systematically analyze the content, structure, and function of a theory (Fawcett, 2000). It is a non-judgmental, detailed examination of a theory with the purpose of developing a deeper understanding of that theory (McEwen, 2002).

Theory scope

Nursing theory has several levels of theory that range in scope. Tomey and Alligood (1998) differentiated between three ranges of nursing theory: grand theory, micro-theory, and middle-range theory. The first range of theory, grand theory, is the broadest in scope (Tomey & Alligood). Grand theories consist of concepts and propositions which attempt to reveal all aspects of the human experience and response. These theories are the most abstract, as a result, are difficult to link with reality and test empirically (McEwen, 2002). A micro-theory, or practice theory, is the least abstract and most specific type of theory (Tomey & Alligood). These theories have few concepts and each is operationally defined and is used to test and/or explain a small aspect of reality (McEwen).

The TUS is described as a middle-range nursing theory (Lenz et al., 1995). A middle-range theory is less abstract and narrower in focus than a grand-theory but more abstract and broader in focus than a practice theory (Tomey & Alligood, 1998). The scope of a middle-range theory allows some level of generalization across nursing specialties and practice environments. Propositions of middle-range theories are testable (McEwen, 2002). Fawcett (2000) classified middle-range theory as descriptive,

explanatory or predictive. The TUS (Lenz et al.) is based on the assumption that this theory can be used to explain and guide research and nursing practice. Its purpose is to describe, explain, and predict an individual's symptom experience; factors which influence symptoms; and the outcomes on an individual's performance (Lenz, 1997).

Theory Context

A metaparadigm is the most abstract level of nursing knowledge in its structural hierarchy. A metaparadigm functions to provide a summary of intellectual and social missions of a discipline (Fawcett, 2000). There are four essential elements of a metaparadigm: it must be distinctive from other disciplines, encompass all phenomena of interest to the discipline, is perspective neutral, and is international in scope and substance. According to Fawcett, the four central metaparadigm concepts to nursing are person, environment, health, and nursing. Despite the fact that the metaparadigm concepts and propositions are not explicitly outlined in the TUS, inferences can be made about them.

Person. The person is central to this middle-range theory as its focus is on the individual patient or client. This theory is not applicable to families, groups of individuals, or communities. The TUS depicts the individual as multidimensional and dynamic. It looks at an individual in parts, but takes into account the person as a whole. An individual is affected by physiologic, psychologic, and situational factors which influence how an individual perceives symptoms and this perception affects an individual's functional and cognitive performance (Lenz et al., 1995; Lenz et al., 1997).

Environment. Environment is also addressed by the TUS. The environment, as described in the TUS, is not limited to physical environment. Environment can include a

variety of situational factors. Social support from family and friends, marital support, and job satisfaction are all considered antecedents to a person's symptom experience. The theory also has the capacity to account for a person's economic, cultural, and political aspects of the concept of environment. The authors described many potential physical environmental factors that could influence an individual's symptom experience. Some examples include heat, humidity, air quality, noise, and light (Lenz et al., 1995; Lenz et al., 1997).

Health. The metaparadigm concept of health is another key element of the TUS. The theory focuses on an individual's health as a multidimensional process. One element of health is the symptom experience. Symptoms are the perceived indicators of change in normal physiological functioning. Physiologic, psychologic, and situational factors all impact the health of an individual, particularly in relation to the symptom experience. Performance outcomes are also based on health, functional status, cognitive status, and physical performance (Lenz et al., 1997).

Although this theory is very useful for nursing, the model does not include any specific references to nurses' practice or nursing actions. Nursing actions geared toward improved patient outcomes however, can be targeted at virtually all aspects within the theory. The TUS can be used by nurses to identify preventive interventions to modify factors that produce symptoms, or it can be used to develop nursing interventions to reduce the patient's symptom experience and enhance performance outcomes (Lenz et al., 1995).

Metaparadigm propositions can also be inferred from the TUS. The TUS deals with life processes as a reciprocal process of illness and well-being. The metaparadigm

proposition that is related to the processes that affect health is also addressed. The original theory by Lenz and colleagues (1995) proposed that the physiologic, psychological, and situational factors; that is, health and environment, were non-relational. In 1997, Lenz et al. adapted their theory and the propositions became relational. Health is directly related to the person and the environment has a bi-directional relationship with health and person.

According to Polifroni and Welch (1999), philosophy is a pursuit of the truth, nature of the universe, and the meaning of the human experience. The authors of the TUS cite a post-positivist perspective as their philosophic view of middle-range nursing theory (Lenz et al., 1995). Post-positivism, also referred to as contemporary empiricism, recognizes a subjective nature of inquiry; however, it favors objective, rigorous methods of investigation through quantitative research methods. This philosophy seeks to explain and predict phenomena while recognizing contextual variables (McEwen, 2000). Lenz et al. asserted that descriptive data (qualitative) can be measured quantitatively through the process of objectively coding qualitative data. Post-positivist research does not exclude qualitative research and research methods should be based on the nature of the research question (Clark, 1998).

According to McEwen (2002), philosophy attempts to ascertain knowledge and truth and tries to recognize what is important and essential. Lenz and colleagues (1995) maintained that a shift in nursing theory development from grand to middle-range theory is necessary and important to guide research and bridge the theory/practice/research gap. The authors of the TUS believed the role of grand-theories in the legitimization of the nursing profession has been for the most part achieved and that middle-range theories are

more apt to guide research and provide the basis for more effective interventions. Middle-range theories strengthen the theory-research, theory-practice linkages (Lenz et al.). These beliefs are congruent with a post-positivist or contemporary empirical philosophy.

The authors of the TUS; Lenz, Suppe, Gift, Pugh, and Milligan (1995), all shared a similar world view as stated in their original theory paper. Although the worldview was not specifically named in the paper, the authors did mention that their worldview was similar as they had several socializing elements in common. All authors lived in the same geographical location, had the same doctoral training, continue to practice clinically, and were open to sharing ideas and collegial input (Lenz et al.).

After analyzing the TUS and comparing various paradigms, the authors' world view emerged; *Interactive-Integrative or Reciprocal Interaction* (Fawcett, 1993; Fawcett, 2000). According to this world view, reality is multidimensional and contextual. Entities are context-dependent and relative. People are seen as holistic and active beings. Interactions between other people and environment are reciprocal. Certain aspects or parts of a human being are seen in context of the whole person (Fawcett, 2000). Change is considered a result of various antecedent factors and probabilistic relationships. The *Interactive-Integrative* world view purports that both objective and subjective phenomena can be researched; however, objectivity, control, and prediction are stressed (Fawcett, 1993). This approach is evidenced in the TUS as there are multiple dimensions to the theory and each symptom is dependent on a variety of influencing factors which provide context to the symptom experience. The TUS supports empirical research and also could be used for descriptive, exploratory research endeavors.

The development of the TUS was based on antecedent knowledge from nursing and other disciplines. All research utilized in the theory development was cited in the reference list. The first article about the TUS (Lenz et al, 1995), discussed the theory's development process. The process of theory development was not preplanned. It was through communication with colleagues and substantial individual and paired work the idea to collaborate to develop a theory originated. The TUS was developed out of a perceived need to integrate existing information about various symptoms. Lenz et al. used Walker and Avant's *Strategies for Theory Construction* as a framework for their theory development.

A deductive and inductive approach for theory development that was grounded in research and clinical practice was used. The TUS was not developed from a conceptual model or grand theory. Rather, the theory development process started from the most specific (research) to the more general (middle-range theory). Lenz et al. (1995) used a strategy of analysis, derivation and synthesis at the single concept level and then at the theory level. The single concept level included: fatigue during postpartum, fatigue during intrapartum, and dyspnea in chronic obstructive pulmonary disease (COPD). These concepts were based on the individual authors' work (Pugh & Milligan, 1993; Gift & Cahill, 1990; Gift, 1990). The initial concepts were developed through extensive practice-research observations, thorough literature reviews and concept analyses. The authors then collaborated and after repeated discussions and analogical reasoning combined their ideas through an integrating and synthesizing process to develop a multiple concept level. It included: a framework for study of fatigue during childbearing and dyspnea/fatigue.

Once it was established that the authors were conceptualizing the symptoms in a similar way, the mid-range theory was developed so that the model could be extended to different clinical populations with multiple symptoms (Lenz et al., 1995). The assumption behind the TUS is that there are enough commonalities between symptoms to justify a theory that is not limited to one symptom, but rather, it can guide nursing research and practice which can consider an assortment of different symptoms (Lenz et al., 1995; Lenz et al., 1997). An update to the TUS was published in 1997 and the authors stress that the theory development is a continual process.

Theory Content

The final step in theory analysis requires a thorough examination of the content of the theory. The content of a theory includes the subject matter of the theory and is stated in terms of concepts and propositions. Concepts of a theory may be defined as:

words or groups of words that express a mental image of some phenomenon.

They represent the special vocabulary of a theory. Furthermore, the concepts give meaning to what can be imagined or observed through the senses. They enable the theorist to categorize, interpret, and structure the phenomena encompassed by the theory. Concepts can be uni-dimensional, or they can have more than one dimension. (Fawcett, 2000, pp. 503).

Propositions are declarative statements about one or more concepts within a theory and tell the reader about what ought to be. Non-relational statements describe concepts by stating their constitutive definitions. Relational propositions describe the relationships between the concepts within a theory (Fawcett).

There are several concepts within the TUS. The central concept in the TUS is symptoms. Other concepts discussed in the theory include the physiologic, psychologic, and situational components grouped together as influencing factors. Finally, the consequences of the symptom experience as described in terms of cognitive and functional performance outcomes are addressed (Lenz et al, 1995 and Lenz et al., 1997). A description of the original theory will be provided along with the updated version.

Symptom experience. The symptom(s) that an individual experiences are the central focus of the TUS. In the original model, only one symptom was depicted (Lenz et al., 1995). The updated model stated that although one symptom can occur in isolation, it is more common that multiple symptoms can occur simultaneously or one symptom can precede another. Often, an individual who has several symptoms has an experience which is multiplicative versus additive; that is, two or more symptoms occurring simultaneously can catalyze each other. The authors used the example of pain and fatigue. They posited that pain is much worse when one is experiencing severe fatigue and perhaps even worse if nausea is also present (Lenz et al., 1997).

Each symptom is conceptualized to be a multidimensional experience. The four dimensions proposed by Lenz and colleagues (1995) are: *intensity*, *level of distress*, *timing*, and *quality*. The dimensions of each symptom can be separated; however, they are interrelated. Each dimension can be conceptualized and measured separately or in combination with other symptoms (Lenz et al., 1997). The symptom dimension of intensity relates to the severity or strength of the symptom experienced by the individual. The level of distress refers to how much an individual is bothered by the symptom(s). Level of distress is person-specific; that is, one individual may be very distressed over the

symptom of fatigue, and another may find fatigue to be the least bothersome of symptoms experienced. Time is another dimension of a symptom. Timing is usually characterized by duration and frequency of occurrence of the symptom. The last dimension of a symptom is quality. Quality is described as what the symptom feels like; for instance, a dull ache or a stabbing pain. Quality attributes of a symptom tend to be specific to a given symptom; but, it is often difficult for people to be able to differentiate the quality of a symptom when multiple symptoms are occurring (Lenz et al., 1997).

Influencing factors. The TUS describes three categories of variables that are conceptualized as antecedents to, or *influencing factors* of, an individual's symptom experience. The first influencing factor is the *physiologic* antecedent. This component takes into account a person's normal physiologic status, the existence of pathology, and an energy substrate.

The second factor, *psychologic*, includes a person's mental or mood state. This may be related to reaction to illness, level of uncertainty, and knowledge about the symptoms and their meaning.

The third influencing factor is *situational*. These may be characterized by a person's physical and social environment. This includes social support, lifestyle behaviors, employment status, and availability or access to health care (Lenz et al., 1995; Lenz et al., 1997). In the original model, the propositions discussed were non-relational. However, this was acknowledged as a limitation and the updated TUS changed these non-relational propositional statements to relational propositions. All three factors can now interact with one another in a bi-directional manner (Lenz et al., 1997).

Performance outcomes. The last component of the TUS is the performance outcomes of the symptom experience. Performance is referred to as the outcome or effect of a person's symptom experience. It is conceptualized to include functional status and cognitive status. Functional status is defined broadly to include physical functioning, role performance in activities of daily living, and social activities and interactions. Cognitive status refers to one's ability to think, problem solve, and /or concentrate (Lenz et al., 1997).

Relational propositions. The three components of the TUS-influencing factors, symptoms, and performance, have various relationships (relational propositions) with each other. In the original TUS, the relationship between the three categories of influencing factors and symptoms experience was unidirectional as illustrated in Appendix C (Lenz et al., 1995). The updated version asserted that these relationships may be reciprocal and it is reflected in the new model (Appendix D; Lenz et al., 1997). The original model depicted a unidirectional relationship of symptoms on performance. A feedback loop was added to the updated TUS, so that performance can affect the influencing factors (Lenz et al., 1997). The authors also added that the symptom experience can have a moderating influence on the relationship between physiologic or psychological status, and performance (Lenz et al., 1997). The authors believed that these relational propositions more accurately depicted the multidimensional and complex nature of the symptom experience, thereby making the TUS more clinically relevant.

Theory Evaluation

Theory evaluation involves making judgments about whether or not a theory has met certain criteria such as significance, internal consistency, parsimony, testability,

empirical and pragmatic adequacy (Fawcett, 2000). The evaluation is based on the evidence provided in the theory analysis and on a review of existing theory critiques and reports of practical application of the theory. Its purpose is to assess the theory's potential contribution to a discipline's knowledge base (McEwen, 2002).

Significance

To meet the requirements of significance, a justification of the importance of the theory to nursing is necessary. The requirements are met when the metaparadigmatic, philosophical, and conceptual origins are clear and antecedent nursing knowledge is addressed and cited (Fawcett, 2000). The metaparadigm concepts and propositions were not explicitly acknowledged. The philosophical claim was stated; post-positivism. The conceptual model from which the theory was derived was not stated. Due to the fact that some of the criteria required for a theory's significance were not explicit and had to be inferred, the significance of the theory may be questioned. However, one must take into account that the origin of the TUS was not an abstract conceptual model; rather, it was developed inductively from a research-to-theory approach and this is congruent with the authors' philosophical perspective. The philosophical perspective of the authors, contemporary empiricism, is compatible with the TUS. The metaparadigmatic concepts and propositions (if inferred in accordance with the authors) are also congruent with the authors' philosophical perspective. The antecedent knowledge is generally explicit. Previous research was cited in the reference list as were conceptual frameworks from which the original single concepts were derived.

Internal Consistency

Internal consistency, the next step in the evaluation process, centers on the context and content of the theory. Internal consistency should have congruency in respect to the authors' philosophical claims, conceptual model, theory concepts, and propositions (Fawcett, 2000). As mentioned above, the authors' philosophical perspective is harmonious with their post-positivist philosophy and a reciprocal interaction world view. Furthermore, it is also congruent with the concepts and propositions in the TUS. According to the TUS, symptoms are context dependent and a change in the experience of one or more symptoms is based on multiple antecedent factors. In the TUS, these antecedent factors include the physiologic, psychologic, and situational influences. Individuals are portrayed in parts (Appendix C; Appendix D) but the parts are considered in the context of the whole person. The TUS can be used to guide quantitative and qualitative research, with a primary emphasis on the latter. This is congruent with the author's philosophy and world view.

Semantic clarity and consistency are also necessary components for internal consistency of a theory (Fawcett, 2000). The TUS is both semantically clear and consistent. All major concepts; symptoms, influencing factors, and performance are defined. The definitions are clear and explicit. Excessive verbiage which could hinder clarity was not used in the theory description. The same terms were used throughout the theory so there was no confusion regarding which concept was being discussed. The same meaning was consistently attached to each concept. Diagrams in both versions of the TUS were simple and easy to understand. Both contribute to a further clarification of the theory (Appendix C and D). The propositions, relational and non-relational, reflect

structural consistency. No contradictions were found within the relational propositions. The concepts of the TUS are used consistently with their definition. All concepts and definitions presented in the TUS are accompanied with a concrete, practical example thereby contributing significantly to its semantic clarity and consistency. For example, the definition of situational factors was followed with a variety of examples such as marital satisfaction, employment status, and social support (Lenz et al., 1997).

Parsimony

The next step in theory evaluation is to assess the level of parsimony. This criterion requires a theory to be clearly and concisely stated. The theory should be presented in the most economical way possible without losing meaning of the theory through oversimplification (Fawcett, 2000). The content of the theory is clearly and concisely stated throughout its description: the TUS is parsimonious. In fact, the original theory was perhaps too parsimonious (Appendix C) as the theory was updated in 1997 to more accurately depict the complex nature of an individual's symptom experience (Hutchinson & Wilson, 1998). Parsimony remains evident in the updated version and is further enhanced by the use of a diagram (Appendix D). Both diagrams clearly illustrate the different dimensions of one or more symptoms, the depth of the three influencing factors, and the performance outcomes. The parsimonious nature of the theory does not underscore the complex nature of the theory. The updated version published by Lenz and colleagues in 1997, changed the model by adding in reciprocal influences on factor of symptom groups. This version also clearly depicts the potential interaction between influencing factors as well as between symptoms (Lenz et al., 1997).

The parsimonious nature has been questioned in a research study aimed at evaluating the TUS and its fit with Alzheimer's (AD) patients. Hutchinson and Wilson (1998) found that the boundaries of the components of the symptoms, influencing factors, and performance outcomes are blurred and overlap. For example, in AD patients, it was difficult to determine whether or not dehydration was a symptom or physiologic factor or if anxiety was indeed a psychologic factor or a symptom. This study suggested that the components of the TUS should not be mutually exclusive and that they should be depicted as fluid and even interchangeable depending on their context (Hutchinson & Wilson).

Testability: Middle-Range Theories

Testability is often considered a significant characteristic of a useful scientific theory. The ultimate goal of theory development in nursing is the ability to empirically test nursing interventions. Traditional empiricism is used to evaluate the testability of middle-range theories (Fawcett, 2000). The research methodology is congruent and reflects the nature of middle-range nursing theory. The concepts and propositions of the TUS can be operationally defined and lends to empirical testing. The TUS however, can be used to underpin research that is both quantitative and qualitative. Due to the fact that the TUS is a theory which is not well-established and its development ongoing, specific measurement tools derived from the TUS have yet to be created for this theory.

Fawcett's (2000) framework for evaluation is therefore not applicable in this section of theory appraisal and will not be specifically followed. Lenz and colleagues (1997) did however provide an adequate discussion regarding the way in which the development of measurement tools should progress. The discussion is initiated by comparing the TUS

with the *North Atlantic Nursing Diagnosis Association* (NANDA) and the University of Iowa's *Nursing interventions Classification* (NIC). Lenz et al. maintained that both the NANDA and the NIC classifications of symptoms are less abstract than the TUS. The NIC and NANDA classifications may be more specific because they focus on one diagnosis at a time and do not take into account the interactive effects which are evident in the TUS (Lenz et al.).

According to Lenz et al. (1997), the development of theoretically derived measurement tools are necessary to guide nursing research in practical and useful ways. The work-in-progress of the TUS provides a starting point for development process of a measurement tool and the conceptual mapping of various symptoms. The updated version of the theory provides a sound conceptual basis for measurement. The authors added that to restrict measurement of a symptom to one dimension would be insufficient and a more sophisticated standard is more appropriate. For this reason, research methodology for symptoms should reflect the four dimensions of a person's symptom experience: intensity, distress, quality, and timing. Middle-range theories by their nature require broadened scope of measurement to better approximate clinical reality. This lends well to objective measures and qualitative coding schemes. Until a multidimensional tool that can measure a multitude of symptoms is developed, the authors recommend measuring each symptom separately (Lenz et al., 1995). Since the publication of this theory, several multi-dimensional symptom assessment tools have been developed and can be adapted to fit the TUS. The MSAS (Portenoy et al., 1994) for instance, measures the symptom frequency, severity, and distress dimensions of the symptom experience.

Empirical Adequacy: Middle-Range Theories

Empirical adequacy of a theory is the fifth step in the theory evaluation process. A theory is considered empirically adequate if the assertions made by the theory are consistent with the empirical evidence. A middle-range theory is evaluated based on the theory's testability (Fawcett, 2000). The TUS has been used to guide only a handful of research studies, most likely related to its relatively recent debut and ongoing evolution. A summary of each study will be provided so that one can gain insight to the research methodology driven by the TUS. The summary will include: sample and population, measurement tools, and concepts tested. All of the studies below have supported the use of the TUS and their results are congruent with the theory's concepts and propositions.

The first study that evaluated the TUS and its fit with symptoms common in Alzheimer's patients (n=29) was conducted by Hutchinson and Wilson (1998). A qualitative approach was used to observe the range and diversity of behavioral symptoms in patients with Alzheimer's disease (AD). The data analysis revealed that AD symptoms occur in multiples. It was determined that confusion exists within the TUS; the differentiation between a symptom and a psychologic factor is not clear because the boundaries of the concepts are blurred and overlap (Hutchinson & Wilson).

The TUS was the framework utilized by Redeker et al. (2000) in their study which looked at the relationship between the symptoms nausea and fatigue and the psychological factors anxiety and depression in cancer patients undergoing chemotherapy (n=263). The study also examined the relationship between these variables and with quality of life. This study used a descriptive, correlative research design. Symptoms were measured using the *Symptom Distress Scale* (McCorkle & Young, 1978) and anxiety and

depression were measured with the Profile of Mood States (McNair et al., 1981). Quality of life was measured by the Functional Assessment of Cancer Treatment (FACT-G; Cella, 1993). Redeker et al. (2000), stated that despite confusion related to the nature of the psychologic influencing factors, the TUS was a useful framework for their study.

The TUS has also guided a study by McCann and Boore (2000) which focused on fatigue in persons with renal failure who required hemodialysis (n=39). This study used a descriptive correlational design which inductively examined fatigue while considering the influencing factors proposed by the TUS. Fatigue was measured using the *Multidimensional Fatigue Inventory* (MFI-20; Smets, Garssen, Bonke & de Haes, 1995) and the *Hospital Anxiety and Depression Scale* (Zigmond & Snaith, 1983) was used to measure the psychologic factors. Physiologic data consisted of lab data such as hemoglobin. This study used the original version of the TUS and as a result, a modification was necessary to show reciprocal relationships between symptoms and influencing factors and between influencing factors (McCann & Boore). This modification was similar to the reciprocal nature depicted in the updated version of the TUS.

Another study, conducted by Spector, Hicks, and Pickleman (2002), used the TUS as the conceptual framework to guide their pilot research project. This study focused on post-operative symptoms from gastroesophageal cancer surgery and quality of life. Data was gathered from a retrospective chart review and a mailed survey (n=27). Symptoms and quality of life were assessed using the Gastroenterology Quality of Life Index (Spector et al.).

Finally, the most recent study to use the TUS as a theoretical framework examined fatigue in healthy young smoking and non-smoking adults and its relationship to the physiologic, psychologic, and situational factors (Corwin, Klein & Rickelman, 2003). A self-report questionnaire was used to measure fatigue. The results of this study support the TUS and suggested that psychological and situational factors are significant contributors to fatigue in young adults (Corwin et al.).

Pragmatic Adequacy

The final step in the evaluation phase of theory appraisal is to determine its pragmatic adequacy, that is, is to determine how applicable the theory is for clinical practice (Fawcett, 2000). The authors of the TUS discussed how research has used the theory to guide clinical practice. The TUS has been used to guide multidimensional symptom assessment and evaluation in a variety of clinical settings such as: emergency departments, outpatient clinics, and medical and surgical units (Lenz et al., 1995; 1997). A multidimensional assessment was based a patient's symptoms and on physiologic parameters, psychologic influences, and situational factors (Lenz et al., 1997).

The TUS has been used in to guide clinical nursing practice. Pugh and Mulligan (1997), two of the authors of the TUS, used this theory to guide their own practice. Both have used the TUS to identify mothers who were having difficulty breastfeeding. Nursing interventions were targeted at altering the influencing factors. For example, a mother's anxiety (*psychological factor*) was addressed through an educational intervention to enhance the mother's knowledge base about breastfeeding and changes associated with the post-partum period. Other interventions targeted physical symptoms; for instance, warm compresses were applied to reduce nipple pain (Lenz et al., 1997).

Although the TUS is practical and parsimonious, an individual clinical nurse would require special training before the theory could be applied to his /her clinical practice. The nurse could find it difficult to implement this theory if it is not congruent with the existing theories within the institution in which he or she practices. The clinical nurse may not have the legal authority to alter practice without organizational support. Perhaps the institution or clinical unit would first need to incorporate the TUS into policy and procedures surrounding symptom management. An integration of TUS into nursing protocols is feasible due to its clinical applicability. This would facilitate a nurse's ability to guide their practice according to the theory.

One may speculate based on the evidence provided in the preceding discussion that the TUS is significant and a theory-based practice would lead to favorable patient outcomes. Nursing interventions can be targeted at all stages within the TUS. Nurses who are aware of the multidimensional nature of an individual's symptom experience are better equipped to intervene to alleviate symptoms and increase positive functional, cognitive, and physical performance outcomes. Interventions could be created aimed at lessening any negative effects of antecedents and at easing multiple symptoms. Furthermore, the TUS allows nurses to tailor their nursing care to the unique and complex needs of individual patients and their symptom experience.

Summary

Fawcett's (2000) framework for theory analysis and evaluation was useful in the critical appraisal of the TUS. The TUS was derived from the concepts of dyspnea and fatigue; however, the theory development process has been successful in its ability to be applicable to a multitude of symptoms. The TUS addresses the complex nature of the

symptom experience and takes into account physiologic, psychological and situational factors as well as the performance outcomes that can be affected by the symptom experience. Although Lenz and colleagues did address their philosophical view, post-positivism, the analysis would have been facilitated if the metaparadigm concepts and propositions had been explicit. Inferences had to be made that may not accurately depict the authors' perspective(s). The TUS's internal consistency and significance is weakened for this reason. A trademark of middle-range nursing theory is its ability to be applicable and relevant to nursing practice (Lenz & Gift, 1998). The TUS is a promising new middle-range theory. Its updated version has even greater clinical relevance than the original model. This theory is useful to guide nursing practice and can be applicable to a variety of clinical settings such as medical/surgical units, mother-baby units, and oncology units. The development of reliable and valid measurement tools that are specific to the theory's concepts would increase this theory's empirical adequacy and facilitate its use in research and clinical practice. Further research that specifically tests the TUS is needed to propel this theory forward so that it may become a mainstay of middle-range nursing theory.

The focus of this research study is on the relationship between the *psychologic* influencing factors and the physical symptom experience. Colorectal cancer will be the main *physiologic* factor and psychological distress (i.e., anxiety and depression) will be the focus of the *psychologic* factor. Psychological distress will be measured by the *Hospital Anxiety and Depression Scale* (Zigmond & Snaith, 1983). The symptom

experience will be measured with the *Memorial Symptom Assessment Scale* (MSAS; Portenoy et al., 1994). The MSAS measures the distress, frequency, and severity components of the symptom experience.

Chapter IV

Methodology

Introduction

This chapter describes the research design and methodology used in this study. Information regarding the research design, sample, setting, and data collection methods and procedures will be provided. A description of the data collection tools will also be included. In addition, a brief discussion regarding the ethical implications of this study is provided.

Design

This pilot research project utilized a descriptive correlative research design. The purpose of a descriptive correlative design is to describe the relationship among variables (Polit & Hungler, 1999). The dependent variables for this study are psychological distress (i.e., anxiety and depression) and symptom experience (i.e., frequency, severity, and distress). The characteristics of the socio-demographics, diagnosis, and treatment variables are the independent variables. The purpose of piloting this study was to determine the feasibility of conducting this project at tertiary hospital in Winnipeg, Manitoba. A pilot study was chosen to obtain information regarding the target population including the feasibility of the data collection methods and whether the empirical measurement tools were appropriate for the targeted patient sample.

Setting

The setting for this pilot study was at the St. Boniface General Hospital, a tertiary hospital in Winnipeg, Manitoba, Canada. Two general surgery units, 7ASouth and 7AWest, were selected. These units were chosen because they have the highest

volume of colorectal surgeries for cancer in Manitoba. This was important as the data collection period was limited. Interviews with patients took place in patients' rooms or in a private conference room on the seventh floor. Choice of location was based on participant preference.

Sample

The target population for this study was patients diagnosed with colon or rectal cancer recovering from surgical resection of their tumor. A non-probability, convenience sample of adult men and women who were in the acute post-operative recovery phase for colon or rectal cancer were recruited from the two general surgery units at the St. Boniface General Hospital.

Inclusion Criteria

Several inclusion criteria were selected for eligibility for this study. The criteria for inclusion in this study included (1) patients between 40-80 years of age, (2) diagnosed with colon or rectal cancer, (3) recovering on 7ASouth or 7AWest from surgical resection of their tumor, (4) within 24 hours of hospital discharge, (5) able to speak, read and write English, and (6) were cognitively and physically able to complete the questionnaires. An amendment was made during the first two weeks of data collection with the intent of increasing the sample size. Patients with recurrent colon or rectal cancer were added to the inclusion criteria. This amendment was approved by the *Education and Nursing Research Ethics Board* (Appendix E).

Exclusion Criteria

Exclusion criteria included patients who had (1) a bowel resection for palliation purposes, and (2) patients in hospital for more than 14 days post-operatively due to

complications such as wound infection, wound dehiscence, ileus, deep-vein thrombosis, or due to other medical conditions such as cardiac or respiratory problems. The exclusion criteria related to post-operative complications and medical conditions was added as these patients may have had a much different or more severe symptom experience which could have skewed the results of the study.

Due to the fact that this was a feasibility/pilot study, the sample size was originally determined by the data collection phase of three months. All patients who met the criteria for the study within the data collection phase who agreed to participate in the study were included. The data collection phase was extended by one month due to the lower than expected number of cancer surgeries. Reasons for less than average surgical volume include surgeon vacation, paternal leave, bereavement leave, and hospital bed closure. One month into data collection, 7AW closed two beds and cut nursing staff; while 7ASouth's general surgery service was combined with the ear, nose and throat (ENT) surgical service. The extension of data collection resulted in approximately 11 extra participants.

A total of 35 participants were obtained during the data collection period from January 30 to June 5, 2004. Three participants gave verbal consent to participate in the study but were missed due to unanticipated early discharge. Two eligible patients refused to participate in the study. The reasons for refusal were not obtained.

Method

Procedure

Data collection was initiated after ethical approval was obtained from the *Education and Nursing Ethics Review Board* at the University of Manitoba, and site

access was obtained from the St. Boniface General *Hospital Research Review Committee*. Meetings with two enterostomal therapy nurses (ETNs) and two clinical resource nurses (CRNs) on 7ASouth and 7AWest were scheduled in an attempt to clarify the purpose of the pilot project and their role in recruitment. The ETNs were chosen because they are consulted to see all patients pre-operatively whether or not they will require a stoma formation. The CRNs were also chosen as they have access to the operative slates and admission records so that potential participants could be identified. In accordance with *Personal Health Information Act* (PHIA), the CRNs and ETNs referred to patient's medical records to determine eligibility. On the third or fourth post-operative day, the nurses approached the patients and requested permission of the release of their names so that the investigator could approach them for potential participation in the study. Eligible subjects were given an *Invitation to Participate* (Appendix F) and either signed the form or gave verbal consent to the ETNs or the CRNs. Once the patients agreed to have the investigator approach them (verbally or written), the nurses then informed the investigator of such. The investigator then met with patients within 24 hours prior to hospital discharge. At this time the investigator introduced self and discussed informed consent in accordance with the policies and procedures at the St. Boniface General Hospital as outlined by the *Research Review Board*. Two copies of the informed consent letter (Appendix G) were part of the participant package. One signed copy of the consent letter was kept for the investigator's records and one copy was left for the participants. At this time the Medical Information Form (Appendix H) was completed.

Once informed consent was obtained (Appendix G), three surveys (Appendix I, J, and K) were given to the patients to complete. The estimated time of completion of the three surveys was approximately 20 to 25 minutes. While the subjects completed the surveys, the investigator remained with the patients to answer any potential questions. After the subjects completed the surveys, the investigator interviewed them using five open-ended questions (Appendix L). Answers were summarized and recorded by the investigator to allow the participants the opportunity to focus on their verbal responses. The interview took approximately 10 minutes to complete. Every effort was taken to ensure privacy of the subject's responses. The hospital door was closed and the curtain was drawn for additional privacy. The investigator allotted extra time after the interview for debriefing if deemed necessary by the participant or the investigator. A copy of the consent form and a list of community resources for psychological support (Appendix M) were left for the participants.

Instruments

The first survey (Appendix I) was a brief demographic questionnaire included to obtain information about the sample. The second survey, the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983), provided detailed description of the level of anxiety, depression, and overall psychological distress patients had prior to hospital discharge (Appendix J). The third survey, the Memorial Symptom Assessment Scale (MSAS; Portenoy et al., 1994), was used to gather data about the patients' symptom experience prior to hospital discharge (Appendix K). Finally, the semi-structured interview used five open-ended questions to supplement the information obtained in the surveys.

Patient demographic questionnaire. The first instrument given to the participating subjects was a demographic questionnaire which was developed by the investigator (Appendix I). The questionnaire generated demographic data including; age, gender, race / ethnicity, level of education, type of admission (i.e., elective versus emergency surgery), and type of surgery (i.e., stoma versus non-stoma). This information was collected for the purpose of describing the sample.

Hospital Anxiety and Depression Scale. The second instrument utilized in this study was the Hospital Anxiety and Depression Scale (HADS: Zigmond & Snaith, 1983). This tool was used to measure the dependent variable, psychological distress. This scale (Appendix J) was originally designed for medical or surgical patients, as it excludes physical symptoms, and relies only on the emotional symptoms of anxiety and depression (Bisson et al., 2002; Porcelli, Leoci & Guerra, 1996).

The HADS is a 14 item self-report scale with two subscales, one assessing anxiety (HADS-A; seven items) and the other, depression (HADS-D; seven items). Each item is rated on a four point Likert scale and each item is given a score between zero and three. Responses relate to feelings experienced by patients during the past week. This scale takes approximately five to ten minutes to complete (Ahlberg et al., 2004). Subscale scores range between zero (no distress) to 21(maximum distress) (Nordin & Glimelius, 1997; Zigmond & Snaith, 1983). Zigmond and Snaith suggested a score of seven or less as a '*normal or a non-case*', eight-10 as a '*doubtful or borderline case*', and a score of 11 or greater as a '*clinically significant case*' for each subscale. The HADS can also be used as a uni-dimensional scale assessing general or total

psychological distress by totaling the subscale scores (Skarstein, Aass, Fossa, Skovlund & Dahl, 2000).

This scale has been frequently used to measure psychological distress within the cancer population (Bjelland, Dahl, Haug & Neckelmann, 2002; Montazeri et al, 2001; Nordin et al., 2001). The brevity of the scale, and its acceptability for patients has made it a particularly useful screening tool in oncology patients. The HADS has been used in cancer site groups such as breast (Fobair et al., 2001; Fulton, 1997; Montazeri et al., 2001), lung (Pascoe et al., 2000), gastrointestinal (Nordin & Glimelius, 1998; Nordin & Glimelius, 1999; Nordin et al., 1996; Nordin et al.; Pascoe et al.), prostate (Bisson et al., 2002), head and neck (Pascoe et al.), hematological (Smith, Selby, Velikova, Stark, Wright, Gould et al., 2002.; Skarstein, Aass, Fossa, Skovlund & Dahl, 2000), and genitor-urinary (Ahlberg et al., 2004; Smith et al.).

The reliability and validity of the HADS scale has been consistently reported in the oncology literature. Generally, a Cronbach's alpha coefficient should be at least 0.60 for a self-report scale to be reliable. In a sample of breast cancer patients, the Cronbach's alpha was 0.94 for the HADS total score, 0.90 for the HADS-A subscale, and 0.90 for the HADS-D subscale (Fobair et al., 2002). In another study using HADS, the internal consistency (coefficient alpha) was 0.93 and 0.90 for anxiety and depression respectively (Pasacreta, 1997). The item-to-subscale reliability correlations have been reported to range from 0.41-0.76 for the HADS-A subscale and 0.30-0.60 for the HADS-D subscale (Ahlberg et al., 2004). A recent literature review by Bjelland et al. (2002) which examined the validity of the HADS revealed that the Cronbach's alpha coefficient of internal consistency for 15 studies varied

from 0.68 to 0.93 (mean 0.83) for the HADS-A, and for the HADS-D from 0.67 to 0.90 (mean 0.82).

Although the scale is used frequently among oncology patients, its scoring has raised some concerns. Often the prevalence rate of psychological distress is lower when compared other scales (e.g., the Brief Symptom Inventory) used in the same tumor site group. Love, Kissane, Bloch, and Clarke (2002) did not recommend using the HADS as a screening instrument and assert that the recommended cut-off scores by Zigmond and Snaith (1983) may be too high, thereby missing a significant number of patients experiencing psychological distress. However, when an attempt was made to reduce the cut-off scores and increase sensitivity, the instrument's specificity was reduced (Kissane et al.). Other attempts have been made, reducing combined cut-off scores to 19 and 14 (Hall, A'Hern & Fallowfield, 1999; Love et al.). Ramirez, Richards, Jarrett and Fentiman (1995) found adequate accuracy by reducing the anxiety cut-off score to six and five.

Many studies authored Nordin et al (1996; 1999; 2001; 2002) use the HADS scale to measure anxiety and depression in gastrointestinal cancer patients. Scores of eight and above are included in reported prevalence rates of psychological distress (i.e., anxiety and depression). They group the *borderline cases* and *clinical cases* into one group. For this present study, *borderline cases* will also be included in the prevalence of psychological distress. Although, patients who score as *borderline cases* may not be experiencing clinically significant psychiatric morbidity, they may be experiencing a moderate level of psychological distress which may benefit from psycho-social intervention.

Memorial Symptom Assessment Scale. The third instrument, the Memorial Symptom Assessment Scale (MSAS; Portenoy et al., 1994), is used in this study to measure symptom experiences in post-surgical colorectal cancer patients. The MSAS (Appendix K) is a patient-rated instrument that provides a comprehensive, multidimensional assessment of symptoms commonly associated with cancer. The scale is a 32-item questionnaire that evaluates physical and psychological symptoms in terms of symptom presence, severity, frequency, and distress. The MSAS was originally developed in a heterogeneous group of cancer patients. Each of the 32 symptoms which are commonly associated with cancer was chosen from an extensive literature review. Lobchuk and Degner (2002) reported that patients with lung cancer and their caregivers took approximately 15-20 minutes to finish the MSAS, and found the tool to be generally acceptable to complete.

The MSAS evaluates each symptom with four or five item Likert scales that assess each of three dimensions of the symptom experience separately (Portenoy et al., 1994; Yan & Sellick, 2004). Three dimensions (i.e., frequency, severity, and distress) are used for 24 of the items (e.g., pain, nausea, and vomiting) and two dimensions (i.e., severity and distress) are used for the remaining eight items on the scale. Only two dimensions are assessed when assessing the frequency dimension is not relevant (e.g., weight loss and hair loss). In the MSAS, a patient indicates whether a symptom is present, and if present, the patient then rates the symptom frequency, severity, and distress for each symptom which is present. Symptom frequency is rated on a four-point Likert scale with categories of *rarely*, *occasionally*, *frequently*, and *almost constantly*, and is scaled from one to four. Symptom severity

is also rated on a four-point scale with categories consisting of *mild*, *moderate*, *severe*, and *very severe* and again, is scaled from one to four. Symptom distress is rated on a five-point scale ranging from *not at all*, *a little bit*, *somewhat*, *quite a bit*, and *very much*; and its scale is statistically adjusted from 0.8-4.0 (Chang, Hwang, Feuerman & Kasimis, 2000; Portenoy et al.).

Originally, the symptoms score of the MSAS was an average of the three dimensions for each scale. However, health care professionals are often interested in severe symptoms. A moderate individual symptom score has been defined as greater than or equal to two. Therefore, symptom frequency would be classified as at least *occasionally*, severity was at least *moderate*, and distress was at least *somewhat* (Chang et al., 2000). Similarly, a severe score was defined as greater than or equal to three. Hence, symptom frequency was classified as at least *frequently*, severity was at least *severe*, and distress was at least *quite a bit* (Chang et al.).

Within the MSAS, there are three valid subscales. The Global Distress Index (MSAS-GDI) is a 10 item measure of global symptom distress. The MSAS-GDI is the average of the frequency of four prevalent psychological symptoms (feeling sad, worrying, feeling irritable, and feeling nervous) and the distress associated with six prevalent physical symptoms (Chang, Thaler, Polyak, Kornblith, Lepore & Portenoy, 1998). A psychological symptom subscale (MSAS-PSYCH) consists of six items and measures global psychological distress. This score is the average of the frequency, severity, and distress associated with six prevalent psychological symptoms which include feeling sad, feeling nervous, feeling irritable, worrying, difficulty sleeping, and difficulty concentrating (Chang et al., Portenoy et al., 1994). Finally, a physical

symptom subscale (MSAS-PHYS) has 12 items and reflects overall physical symptomatology (Portenoy et al.). This subscale is determined by averaging the frequency, severity, and distress associated with 12 prevalent symptoms which include lack of appetite, lack of energy, feeling drowsy, feeling bloated, constipation, pain, nausea, vomiting, dizziness, dry mouth, change in the way food tastes, and weight loss (Chang et al.; Portenoy et al.).

The reliability and validity of the MSAS was evaluated by Portenoy et al. (1994) from a randomly selected sample of patients with prostate, ovarian, colon, and breast cancer (n= 246). A factor analysis revealed three major symptom groups: psychological symptoms (PSYCH), high prevalence physical symptoms (PHYS H), and low prevalence physical symptoms (PHYS L) (Portenoy et al., 1994). Internal consistency was high in the PSYCH subscale (Cronbach's alpha coefficient of 0.83) and in the PHYS H subscale (Cronbach's alpha coefficient of 0.88). The internal consistency was moderate (Cronbach's alpha coefficient of 0.58) in the PHYS L group (Portenoy et al., 1994). Tranmer, Heyland, Dudgeon, Groll, Squires-Graham, and Coulson (2003) compared the symptom experience of seriously ill, hospitalized cancer and non-cancer patients and found high internal consistency in the PSYCH subscale (Cronbach's alpha coefficient = 0.85 in the cancer group and 0.77 in the non-cancer group), and in the PHYS H and L subscales (Cronbach's alpha coefficients ranged between 0.78 to 0.87).

Open-ended questionnaire. Finally, the last instrument used in this study is an open-ended questionnaire. There are five open-ended questions that were developed to guide the semi-structured interview (Appendix L). The questions were constructed

based on the literature review and from input provided by the thesis committee. These questions were generated to capture patient perspectives that could not be identified with the quantitative instruments. The questions were designed with the intent to produce qualitative data which expands on colorectal cancer patients' psychological and physical symptom experiences recovering from surgical resection of their tumor prior to hospital discharge. These questions were also included with the intent of generating hypotheses for future areas of research investigation.

Ethical Implications

This study was reviewed by three committees prior to the commencement of data collection. The thesis committee first approved the thesis in its proposal stage (October, 2003). Ethical approval was then obtained through the *Education and Nursing Ethics Board* at the University of Manitoba and also, research and site access was gained through the St. Boniface General Hospital's *Research Review Committee*.

Informed Consent and Confidentiality

All participants received verbal and written information through informed consent letters about the nature of the study and the confidentiality of their responses. The participants in the study had the ability to withdraw from the study at any point without prejudice or repercussion. Informed consent from all research subjects was mandatory and was evident by their signature and date on the informed consent letter (Appendix G). The consent letter provided contact information of the investigator, thesis supervisor, and Human Ethics Secretariat. A copy of the consent form was also given to participants for their records.

Every attempt has been made to ensure the participant packages including the surveys are secure. All surveys have been numerically coded and locked in cabinets at the researcher's home. The informed consent forms with their corresponding numerical codes will be stored separately from the surveys. Only the investigator has access to the subject's identifying data. Data will be stored for a maximum of seven years, at which time it will be destroyed via a confidential paper shredder.

Participant Involvement and Potential Risks

There was no deception or coercion associated with any of the procedures. Patients were not compensated in any way for their participation in the study. Time was the primary investment required by the research participants. There were no perceived legal or social risks for the research subjects, nor were there any major harmful effects of the study. Most patients felt the surveys were cathartic in nature; however, it was conceivable that an emotional response may have resulted from exploring one's feelings about having cancer and surgery. This risk was considered minimal. Every effort was made to provide the research participants with appropriate support and information. The investigator allowed time to debrief after the completion of the surveys and all patients were given a sheet of community resources (Appendix M) for any additional psychological support needed after discharge. Support was also made available from the nursing staff on the general surgery units as required.

In one participant interview, the participant informed the researcher that suicidal thoughts had been contemplated. This raised an ethical dilemma as the patient interview was confidential. This issue was resolved by investigator requesting

permission from the participant to tell another health care professional about these feelings so that appropriate interventions could be initiated. The participant verbally consented to this release of this information and the charge nurse and attending physician were informed. Subsequently, a psychiatric consult was made.

Data Analysis

Data were analyzed using various statistical tests appropriate to the aforementioned research questions. The SPSS 11.0 version computer software program was used for data analysis. A reliability analysis (Cronbach's alpha) was conducted on the HADS (Zigmond & Snaith, 1983) and the MSAS (Portenoy et al., 1994). Demographic information collected included age, gender, race/ethnicity, marital status, socioeconomic status, level of education, presence of ostomy, and whether surgery was emergent or elective. Descriptive statistics were also used to generate information regarding the demographics of the sample obtained. Two tailed, independent t-tests were used to test for significant differences between mean scores in such groups as age, gender, marital status, diagnosis, type of surgery, and presence of ostomy.

Clinical questions 1) and 2) were analyzed using descriptive statistics. Frequency distributions, means and standard deviations were calculated to determine the prevalence rates of the psychological distress and symptom experience. Clinical question 3) used a Pearson's r correlational test for a relationship between psychological distress and symptom experience. All statistical tests had significance levels set at $p=0.05$, unless otherwise indicated. And finally, content analysis was conducted on the five open-ended questions to detect themes within subject

responses. Many of the participants provided only short responses. The analysis of the interviews involved categorizing participant responses according to similarities in responses.

Chapter V

Results

Introduction

In this chapter, the results of this descriptive correlational pilot study are reported. The characteristics of the demographic data are first provided; then the findings for each clinical question are presented. The results of the open-ended questions will also be highlighted at the end of this chapter.

Demographic Data

The non-probability, convenience sample consisted of a total of 35 participants from the St. Boniface General Hospital. The demographic information about the participants in this study is presented in Table 5.1.

Table 5.1 Demographic Profile of Participants

Characteristics	Total Sample (n=35)
Age Range	
40-50 years of age	2 (5.7%)
51-60 years of age	5 (14.3%)
61-70 years of age	12 (34.3%)
71-80+ years of age	16 (45.7%)
Gender	
Male	20 (57.1%)
Female	15 (42.9%)

Characteristics	Total Sample (n=35)
Marital Status	
Single	0 (0.0%)
Married/Common Law	22 (62.9%)
Divorced/Separated	4 (11.4%)
Widowed	9 (25.7%)
Highest Level of Education	
Completed	
Elementary School	13 (37.1%)
High School	6 (17.1%)
Community/Technical College	7 (20.0%)
University	9 (25.7%)
Current Occupational Status	
Full-time	9 (25.7%)
Part-time	1 (2.9%)
Retired	21 (60.0%)
Unemployed/Don't work	1 (2.9%)
Medical Leave	3 (8.6%)
Ethnic Background	
Canadian	12 (34.3%)
European	19 (54.3%)
Aboriginal/First Nations/Inuit	2 (5.7%)
Asia & Pacific Islands	2 (5.7%)

Characteristics	Total Sample (n=35)
Religious Affiliation	
Anglican	8 (22.9%)
Roman/Ukrainian Catholic	15 (42.9%)
United Church	6 (17.1%)
Mennonite	3 (8.6%)
Lutheran	1 (2.9%)
Jewish	1 (2.9%)
Other	1 (2.9%)
Current Diagnosis	
Right Colon Cancer	8 (22.9%)
Transverse Colon Cancer	1 (2.9%)
Left Colon Cancer	5 (14.3%)
Rectal Cancer	20 (57.1%)
Missing Data	1 (2.9%)
Additional Diagnoses	
Arthritis	6 (17.1%)
Diabetes	7 (20.0%)
Inflammatory Bowel Disease	4 (11.4%)
Heart Disease (IHD or PVD)	6 (17.1%)
Hypertension	13 (37.1%)
Depression	2 (5.7%)
Other	8 (22.9%)
<p data-bbox="212 1640 1040 1675">* Note: Adds up to more than 100%</p> <p data-bbox="212 1692 1040 1732">May have multiple co-morbidities</p>	

Characteristics	Total Sample (n=35)
Type of Surgery	
Right Hemi-colectomy	8 (22.9%)
Left Hemi-colectomy	1 (2.9%)
Sigmoid Colectomy	2 (5.7%)
Anterior Resection	11 (31.4%)
Abdominal Perineal Resection	9 (25.7%)
Sub-total Colectomy	3 (8.6%)
Total proctocolectomy	1 (2.9%)
Elective Versus Emergency Surgery	
Elective Surgery	32 (91.4%)
Emergent Surgery	3 (8.6%)
Presence of Ostomy	
Yes	18 (51.4%)
No	17 (48.6%)

Almost half of the participants in this study were over the age of seventy. There were slightly more males than female patients. Participants in this study were predominantly married or widowed and over half were retired. The level of education was variable; ranging from the completion of elementary school to the completion of one or more university degrees. The majority of patients were of Canadian or European decent and were of the Christian faith.

Over half of the participants in this pilot study had rectal cancer, and therefore the low anterior resection and abdominal perineal resection were also the most common type of surgeries performed. An overwhelming majority (91%) of the surgical cases were elective and just over half (51%) of the participants had colostomy formation. The average post-operative hospital stay was 8.5 days. The most common co-morbidities included hypertension and diabetes.

Reliability of the HADS and MSAS

A reliability analysis of the two instruments was conducted for this research study. According to Polit and Hungler (1999), higher reliability coefficients are indicative of a more stable measure. In general, reliability coefficients above 0.70 are considered satisfactory (Polit & Hungler). The reliability coefficient, Cronbach's alpha, for the items on the overall HADS score and its subscales was 0.833. For the MSAS, the Cronbach's alpha in this study was 0.878.

Research Question One: Prevalence of Psychological Distress

The first question was answered through an analysis of the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983). The HADS-A and HADS-D subscales and overall psychological distress was totaled according to the recommendations by Zigmond and Snaith. Nordin and colleagues (1996; 1999; 2001; 2002) included both the *borderline cases* as well as the *clinical cases* when reporting distress in gastrointestinal cancer patients. Similarly, *borderline cases* were also included in these results. In addition, *borderline cases* have been categorized as *moderate* levels of anxiety, depression, or overall psychological distress.

Table 5.2 summarizes the results of the HADS (Zigmond & Snaith, 1983). The mean psychological distress score for colorectal cancer patients was 14.3 (SD \pm 5.7). The mean scores for the HADS-A, and the HADS-D subscales was 7.8 (SD \pm 3.1) and 6.5 (SD \pm 3.9) respectively. Age, gender, type of cancer, or presence of ostomy had no statistically significantly impact on the mean scores of psychological distress, anxiety, or depression.

Table 5.2 Results from the Hospital Anxiety and Depression Scale

Each Item	Frequency	Mean & Standard Deviation (SD)
HADS-A Subscale		Range of score: 0-3
1. I feel tense or 'wound-up':		1.2 (SD \pm 0.9)
-Most of the time (3)	4 (11.4%)	
-A lot of the time (2)	5 (14.3%)	
-From time to time, occasionally (1)	20 (57.1%)	
-Not at all (0)	6 (17.1%)	
2. I get a sort of frightened feeling as if something awful is about to happen:		1.3 (SD \pm 1.0)
-Very definitely & quite badly (3)	4 (11.4%)	
-Yes, but not too badly (2)	12 (34.3%)	
-A little, but it doesn't worry me (1)	9 (25.7%)	
-Not at all (0)	10 (28.6%)	

<p>3. Worrying thoughts go through my mind:</p> <ul style="list-style-type: none"> -A great deal of the time (3) -A lot of the time (2) -From time to time but not too often (1) -Only occasionally (0) <p>4. I can sit at ease & feel relaxed:</p> <ul style="list-style-type: none"> -Definitely (0) -Usually (1) -Not often (2) -Not at all (3) 	<p>5 (14.3%)</p> <p>6 (17.1%)</p> <p>17 (48.6%)</p> <p>7 (20.0%)</p> <p>6 (17.1%)</p> <p>18 (51.4%)</p> <p>11 (31.4%)</p> <p>0</p>	<p>Range of score: 0-3</p> <p>1.3 (SD ± 1.0)</p> <p>1.1 (SD ± 0.7)</p>
<p>5. I get a sort of frightened feeling like 'butterflies' in the stomach:</p> <ul style="list-style-type: none"> -Not at all (0) -Occasionally (1) -Quite Often (2) -Very Often (3) <p>6. I feel restless as if I have to be on the move:</p> <ul style="list-style-type: none"> -Very much indeed (3) -Quite a lot (2) -Not very much (1) -Not at all (0) <p>7. I get sudden feelings of panic:</p> <ul style="list-style-type: none"> -Very often indeed (3) -Quite often (2) -Not very often (1) -Not at all (0) 	<p>16 (45.7%)</p> <p>18 (51.4%)</p> <p>1 (2.9%)</p> <p>0</p> <p>3 (8.6%)</p> <p>12 (34.3%)</p> <p>14 (40.0%)</p> <p>6 (17.1%)</p> <p>1 (2.9%)</p> <p>6 (17.1%)</p> <p>17 (48.6%)</p> <p>11 (31.4%)</p>	<p>0.6 (SD ± 0.6)</p> <p>1.3 (SD ± 0.9)</p> <p>0.9 (SD ± 0.8)</p>

Overall HADS-A Score		Range of score: 0-21
-No Anxiety	15 (42.9%)	7.8 (SD ± 3.1)
-Borderline (moderate) anxiety cases	11 (31.4%)	
-Clinical cases of anxiety	9 (25.7%)	
- <i>Borderline and Clinical cases combined</i>	20 (57.1%)	

Each Item	Frequency	Mean (SD)
HADS-D Subscale		Range of score: 0-3
1. I still enjoy the things I used to enjoy:		0.9 (SD ± 0.8)
-Definitely as much (0)	12 (34.3%)	
-Not quite as much (1)	16 (45.7%)	
-Only a little (2)	4 (11.4%)	
-Hardly at all (3)	2 (5.9%)	
2. I can laugh & see the funny side of things:		0.6 (SD ± 0.7)
-As much as I always could (0)	18 (51.4%)	
-Not quite so much now (1)	12 (34.3%)	
-Definitely not so much now (2)	5 (14.3%)	
-Not at all (3)	0	
3. I feel cheerful:		0.7 (SD ± 0.8)
-Not at all (3)	1 (2.9%)	
-Not often (2)	3 (8.6%)	
-Sometimes (1)	14 (40.0%)	
-Most of the time (0)	17 (48.6%)	

<p>4. I feel as if I am slowed down:</p> <ul style="list-style-type: none"> -Nearly all the time (3) -Very often (2) -Sometimes (1) -Not at all (0) <p>5. I have lost interest in my appearance:</p> <ul style="list-style-type: none"> -Definitely (3) -I don't take so much care as I should (2) -I may not take quite as much care (1) -I take just as much care as ever (0) 	<p>12 (34.3%)</p> <p>11 (31.4%)</p> <p>11 (31.4%)</p> <p>1 (2.9%)</p> <p>2 (5.7%)</p> <p>10 (28.6%)</p> <p>9 (25.7%)</p> <p>14 (40%)</p>	<p>Range of score: 0-3</p> <p>2.0 (SD ± 0.9)</p> <p>1.0 (SD ± 1.0)</p>
HADS-D Subscale		
<p>6. I look forward with enjoyment to things:</p> <ul style="list-style-type: none"> -As much as I ever did (0) -Rather less than I used to (1) -Definitely less than I used to (2) -Hardly at all (3) <p>7. I can enjoy a good book or radio or TV program:</p> <ul style="list-style-type: none"> -Often (0) -Sometimes (1) -Not often (2) -Very seldom (3) 	<p>17 (48.6%)</p> <p>11 (31.4%)</p> <p>5 (14.3%)</p> <p>2 (5.7%)</p> <p>20 (57.1%)</p> <p>7 (20.0%)</p> <p>6 (17.1%)</p> <p>2 (5.7%)</p>	<p>0.8 (SD ± 0.9)</p> <p>0.7 (SD ± 1.0)</p>

Overall HADS-D Score		Range of score: 0-21 6.5 (SD ± 3.9)
-No depression	22 (62.9%)	
-Borderline (moderate) Depression cases	7 (20.0%)	
-Clinical Depression cases	6 (17.1%)	
- <i>Borderline & Clinical cases combined</i>	13 (37.1%)	
Global Psychological Distress (PD) Score		Range of score: 0-42 14.3 (SD ± 5.6)
-No PD	18 (51.4%)	
-Borderline (moderate) PD	12 (28.6%)	
-Clinical PD cases	5 (14.3%)	
- <i>Borderline & Clinical PD cases combined</i>	17 (42.9%)	

Research Question Two: Prevalence of Symptom Experience

The purpose of the second research question was to determine the prevalence of symptom experience in post-surgical CRC patients prior to hospital discharge. The MSAS (Portenoy et al., 1994) provided a rich data set that illustrated the presence of and most frequent, severe, and distressing symptoms.

Table 5.3 summarizes the prevalence of symptoms as reported by post-surgical CRC patients prior to hospital discharge. The mean number of patient symptoms was 13.3 (SD ± 3.4), and the range was five to 19. The median number of symptoms in this patient population was 13.5. The most prevalent symptoms (> 50%) included lack of energy, pain, dry mouth, difficulty concentrating, lack of appetite, feeling sad, feeling drowsy, weight loss, worrying, nausea, difficulty sleeping, and sweats. The least

prevalent symptoms (< 10%) included problems with urination, mouth sores, hair loss, constipation, and problems with sexual interest or activity. Although not the most prevalent of psychological symptoms, feeling irritable and feeling nervous was experienced in 31% and 46% of patients respectively.

Table 5.3 Prevalence of Symptoms in Post-Surgical CRC Patients

Symptoms	Prevalence (Percent)
Lack of energy	31/35 (88.6%)
Pain	29/35 (82.9%)
Dry mouth	29/35 (82.9%)
Difficulty concentrating	23/35 (65.7%)
Lack of appetite	22/34 (64.7%)
Feeling sad	22/35 (62.9%)
Feeling drowsy	22/35 (62.9%)
Weight loss	22/35 (62.9%)
Worrying	21/35 (60.0%)
Nausea	19/35 (54.3%)
Difficulty sleeping	18/35 (51.4%)
Sweats	18/35 (51.4%)
Feeling nervous	16/35 (45.7%)
Feeling bloated	14/35 (40.0%)
Vomiting	14/35 (40.0%)
Cough	12/35 (34.3%)
Feeling irritable	11/35 (31.4%)
Diarrhea	10/35 (28.6%)
"I don't look like myself"	9/35 (25.7%)
Itching	8/34 (23.5%)
Shortness of breath	8/35 (22.9%)

Dizziness	8/35 (22.9%)
Numbness/tingling in hands/feet	7/35 (20.0%)
Change in the way food tastes	7/35 (20.0%)
Swelling in the arms or legs	7/35 (20.0%)
Difficulty swallowing	4/35 (11.4%)
Changes in skin	4/35 (11.4%)
Problems with urination	3/35 (8.6%)
Mouth sores	2/35 (5.7%)
Hair loss	2/35 (5.7%)
Constipation	1/35 (2.9%)
Problems with sexual interest or activity	0/35 (0.0%)

Table 5.4 presents the percentage ratings for symptom frequency (MSAS ratings ≥ 3), severity (MSAS ratings ≥ 2), and distress (MSAS ratings ≥ 3). The most frequently occurring prevalent symptoms reported by CRC patients were feeling drowsy, difficulty sleeping, dry mouth, lack of energy, lack of appetite, and pain. Lack of appetite was the most severe of the frequently occurring symptoms, followed by worry, pain, nausea, drowsiness, and feeling sad. Of the most prevalent symptoms, difficulty sleeping and nausea were the two most distressing symptoms. Worrying, pain, feeling sad, and lack of energy were also moderately distressing to patients. The two least distressing prevalent symptoms experienced was lack of appetite and sweats.

Some symptoms, although not the most prevalent, had a significant impact on patient's symptom experience. For instance, difficulty swallowing was noted in only four participants; however, three out of the four rated this as a highly distressing symptom. Most of the patients who experienced swollen hands or feet, change in food taste, dizziness, shortness of breath, itchiness, or feeling irritable, rated it as moderate to very

severe, but less than one-third rated them as symptoms which caused them significant distress. About three-quarters of patients, who reported feeling bloated, felt bloated frequently or almost constantly; and about half found this symptom to cause distress.

Table 5.4 Characteristics of the MSAS Symptoms

Symptom	Frequency (Freq-Con) Score 3-4	Severity (Mod-VSev) Score 2-4	Distress (QB-VM) Score 3-4
Lack of energy	20/31 (64.5%)	23/31 (74.2%)	10/31 (32.3%)
Pain	17/29 (58.6%)	26/29 (89.7%)	11/29 (37.9%)
Dry Mouth	19/29 (65.5%)	23/29 (79.3%)	7/29 (24.1%)
Difficulty concentrating	11/23 (47.8%)	17/23 (73.9%)	7/23 (30.4%)
Lack of appetite	13/22 (59.1%)	21/22 (95.5%)	3/22 (13.6%)
Feeling sad	5/22 (22.7%)	18/22 (81.8%)	8/22 (36.4%)
Feeling drowsy	16/22 (72.7%)	19/22 (86.4%)	6/22 (27.3%)
Weight loss	n/a	15/22 (68.2%)	4/22 (18.2%)
Worrying	10/21 (47.6%)	20/21 (95.2%)	8/21 (38.1%)
Nausea	8/19 (42.1%)	17/19 (89.5%)	9/19 (47.4%)
Difficulty Sleeping	12/18 (66.7%)	14/18 (77.8%)	9/18 (50.0%)
Sweats	8/18 (44.4%)	12/18 (66.7%)	2/18 (11.1%)
Feeling nervous	7/16 (43.8%)	11/16 (68.9%)	3/16 (18.8%)
Feeling bloated	11/14 (78.6%)	12/14 (85.7%)	6/14 (42.9%)
Vomiting	2/14 (14.3%)	11/14 (78.6%)	6/13 (46.2%)
Cough	1/12 (8.3%)	6/12 (50.0%)	3/12 (25.0%)
Feeling irritable	6/11 (54.5%)	11/11 (100%)	3/11 (27.3%)
Diarrhea	7/10 (70.0%)	9/10 (90.0%)	4/10 (40%)
"I don't look like myself"	n/a	8/9 (88.9%)	2/9 (22.2%)
Itching	4/8 (50.0%)	7/8 (87.5%)	2/8 (25.0%)
Shortness of breath	3/8 (37.5%)	8/8 (100%)	2/8 (25.0%)

Dizziness	4/8 (50.0%)	5/8 (62.5%)	1/8 (12.5%)
Numbness of the hands/feet	3/7 (42.9%)	2/7 (28.6%)	1/7 (14.3%)
Change in the way food tastes	n/a	6/7 (85.7%)	2/7 (28.6%)
Swelling in the arms or legs	n/a	6/8 (75.0%)	1/8 (12.5%)
Difficulty swallowing	1/4 (25.0%)	3/4 (75.0%)	3/4 (75.0%)
Changes in skin	n/a	2/4 (50.0%)	0/4 (0%)
Problems with urination	2/3 (66.7%)	3/3 (100%)	0/3 (0%)
Mouth sores	n/a	1/2 (50.0%)	1/2 (50.0%)
Hair loss	n/a	1/2 (50.0%)	0/2 (0%)
Constipation	n/a	1/1 (100%)	1/1 (100%)
Problems with sexual interest or activity	-	-	-

Abbreviations: Freq-Con, frequently to constantly; Mod-VSev, moderate to very severe; QB-VM, quite a bit to very much; n/a, not applicable.

Tables 5.5 summarizes the mean MSAS symptom scores and standard deviation. The mean of each symptom's frequency, severity, and distress is displayed. The order of symptoms begins with the most prevalent among the sample and ends with the least prevalent symptom. In reference to the most prevalent physical symptoms, the most frequent, and severe symptoms (i.e., lack of energy, pain, dry mouth) were also distressing for patients. Lack of appetite and feeling drowsy however occurred more frequently but caused less distress to patients. In addition, weight loss, although prevalent (22/35 or 62.9%), was less severe and caused less distress than the other more prevalent symptoms. Of the physical symptoms which were less prevalent; difficulty swallowing, constipation, and feeling bloated were both moderate to severe, and caused quite a bit of distress for CRC patients. Patients rated the frequency, severity, and

amount of distress of the psychological symptoms; feeling sad, irritable, nervous, and worrying, at similar levels. That is, frequent and severe symptom ratings corresponded with comparable ratings of distress.

The mean scores for the three MSAS subscales were calculated. The range of scores for the subscales are as follows; MSAS-PHYS (range 0-132), MSAS-PSYCH (range 0-72), and the MSAS-GDI (range 0-40). The mean MSAS-PHYS subscale score was 51.3 (SD \pm 18.4), and the mean score for the MSAS-PYSCH was 22.5 (SD \pm 13.7). The mean MDAS-GDI score was 13.0 (SD \pm 5.5). Several t-tests (2-tailed) revealed no significant difference in the mean scores of the each of the three subscales by age, gender, type of surgery, or presence of ostomy.

Table 5.5 Mean Scores of the MSAS

Symptom	Mean Patient Score	Standard Deviation (SD)
Lack of energy		
Frequency	2.84	0.97
Severity	2.20	0.95
Distress	2.22	0.98
Pain		
Frequency	2.69	0.85
Severity	2.21	0.62
Distress	2.30	0.97
Dry mouth		
Frequency	2.93	0.96
Severity	2.45	1.01
Distress	2.17	1.04
Difficulty concentrating		
Frequency	2.65	0.98
Severity	2.26	0.96
Distress	2.19	1.06

Lack of appetite		
Frequency	2.82	1.01
Severity	2.48	0.85
Distress	1.78	0.78
Feeling drowsy		
Frequency	2.73	0.98
Severity	2.18	0.80
Distress	1.85	1.00
Feeling sad		
Frequency	2.32	0.78
Severity	2.23	0.87
Distress	2.51	0.79
Weight loss		
Frequency	n/a	n/a
Severity	1.95	0.79
Distress	1.78	0.95
Worrying		
Frequency	2.52	0.87
Severity	2.24	0.53
Distress	2.06	0.73
Nausea		
Frequency	2.37	0.90
Severity	2.58	0.90
Distress	2.69	0.85
Difficulty sleeping		
Frequency	2.89	0.90
Severity	2.17	0.86
Distress	2.62	0.86
Sweats		
Frequency	2.28	0.75
Severity	2.06	1.00
Distress	1.91	0.56
Feeling nervous		
Frequency	2.38	1.09
Severity	1.81	0.66
Distress	1.95	0.82
Feeling bloated		
Frequency	3.14	0.77
Severity	2.50	0.94
Distress	2.57	1.10
Vomiting		
Frequency	1.79	0.70
Severity	2.43	1.02
Distress	2.52	0.72

Cough		
Frequency	1.92	0.51
Severity	1.83	1.03
Distress	1.93	1.05
Feeling irritable		
Frequency	2.58	0.90
Severity	2.45	0.69
Distress	2.47	0.56
Diarrhea		
Frequency	2.90	0.99
Severity	2.40	0.70
Distress	2.32	1.22
"I don't look like myself"		
Frequency	n/a	n/a
Severity	2.44	0.88
Distress	2.22	0.96
Itchiness		
Frequency	2.38	0.74
Severity	2.38	0.92
Distress	2.20	1.03
Shortness of breath		
Frequency	2.50	0.76
Severity	2.25	0.46
Distress	2.10	0.85
Dizziness		
Frequency	2.38	0.74
Severity	1.88	0.83
Distress	1.70	0.79
Numbness of the hands/feet		
Frequency	2.43	1.27
Severity	1.57	1.13
Distress	1.60	1.13
Change in the way food tastes		
Frequency	n/a	n/a
Severity	2.43	0.98
Distress	2.17	1.00
Swelling of the arms or legs		
Frequency	n/a	n/a
Severity	2.38	1.19
Distress	1.49	0.86
Difficulty swallowing		
Frequency	2.50	1.00
Severity	3.00	1.41
Distress	3.00	1.01

Changes in skin		
Frequency	n/a	n/a
Severity	1.75	0.96
Distress	1.40	0.77
Problems with urination		
Frequency	2.67	0.58
Severity	2.00	0.00
Distress	2.13	0.46
Mouth sores		
Frequency	n/a	n/a
Severity	2.00	1.41
Distress	2.00	1.70
Hair loss		
Frequency	n/a	n/a
Severity	1.50	0.71
Distress	1.20	0.57
Constipation		
Frequency	n/a	n/a
Severity	3.00	0.00
Distress	3.02	0.00
Problems with sexual interest or activity		
Frequency	n/a	n/a
Severity	n/a	n/a
Distress	n/a	n/a

*Higher values on the symptom items indicate higher frequency with which the symptom occurred, severity of the symptom, and the more distress that the symptom produced. Scores range: 1-4, n/a; not applicable

*Research Question Three: Relationship Between Psychological
Distress and Symptom Experience*

The third research question examines the relationship between the physical symptoms and psychological symptoms in post-surgical CRC patients. The Pearson r correlation test was used to test for relationships between the physical symptoms (MSAS-PHYS Subscale) and psychological symptoms (HADS, HADS-A, HADS-D, and the MSAS-PSYCH Subscale). The Global Distress Index (MSAS-GDI), an overall symptom distress score, has also been tested with the above MSAS-PSYCH and HADS subscales.

Table 5.6 MSAS-PHYS Subscale and the HADS Correlation Matrix

Pearson Correlation (2-tailed test) N=35		MSAS-PHYS Subscale	HADS Psychological Distress	HADS-A Subscale	HADS-D Subscale
MSAS-PHYS Subscale	r	1	0.326	0.076	0.413*
HADS Psychological Distress	r	0.326	1	0.755**	0.846**
HADS-A Subscale	r	0.076	0.755**	1	0.289
HADS-D Subscale	r	0.413*	1	0.289	1

r = correlation coefficient

* Correlation is significant at the 0.05 level (2-tailed)

** Correlation is significant at the 0.01 level (2-tailed)

Table 5.6 illustrates a significant positive relationship between the HADS-D subscale and the MSAS-PHYS subscale ($r = 0.413$, $p = 0.014$). No significant relationships were detected between MSAS-PHYS subscale and the HADS overall psychological distress score or the MSAS-PHYS subscale and the HADS-A subscale.

5.7 MSAS-GDI and the HADS Correlation Matrix

Pearson Correlation (2-tailed) N=35	MSAS-GDI	HADS Psychological Distress	HADS-A	HADS-D
MSAS-GDI r	1	0.490**	0.484**	0.326
HADS Psychological Distress r	0.490**	1	0.755**	0.846**
HADS-A r	0.484**	0.755**	1	0.289
HADS-D r	0.326	0.846**	0.289	1

r=Correlation coefficient

**Correlation significant at the 0.01 level (2-tailed).

Table 5.7 shows that the MSAS-GDI and the HADS overall psychological distress measure were significantly correlated ($r = + 0.49$, $p = 0.004$). The MSAS-GDI is also correlated with the HADS-A subscale ($r = + 0.48$, $p = 0.004$). No significant correlation was noted in the HADS-D subscale ($r = + 0.33$, $p = 0.064$).

5.8 MSAS-PHYS, MSAS-PSYCH, and the MSAS-GDI Correlation Matrix

Pearson Correlation (2-tailed) N=35	MSAS-PHYS	MSAS-PSYCH	MSAS-GDI
MSAS-PHYS r	1	0.573**	0.581**
MSAS-PSYCH r	0.573**	1	0.812**
MSAS-GDI r	0.581**	0.812**	1

r = Correlation coefficient

** Correlation significant at the 0.01 level (2-tailed)

The three MSAS subscales were all tested for significant relationships in Table 5.8. The results of the Pearson r correlation analysis revealed that a significant relationship exists between the MSAS-PHYS and the MSAS-PSYCH ($r = + 0.573$, $p < 0.001$). The MSAS-PHYS was also significantly correlated with the MSAS-GDI ($r = + 0.581$, $p < 0.001$). Furthermore, the MSAS-GDI had a highly positive correlation with the MSAS-PSYCH ($r = + 0.812$, $p < 0.001$). Of the individual physical symptoms reported, a patient's overall pain experience was positively correlated with the MSAS-PYSCH subscale ($r = + 0.374$, $p = 0.027$).

The HADS and its subscales have also been correlated with various individual symptoms. Overall psychological distress was significantly correlated with the following symptoms: difficulty concentrating ($r = + 0.362$, $p = 0.05$) and difficulty sleeping ($r = 0.397$, $p = 0.018$). The total symptom experience (i.e., frequency, severity, and distress) of difficulty concentrating and difficulty sleeping was also significantly correlated with the HADS-D subscale ($r = + 0.524$, $p = 0.001$; $r = 0.413$, $p = 0.014$). HADS-D was also correlated with overall lack of energy ($r = + 0.399$, $p = 0.018$). Finally, the HADS-A subscale was significantly correlated with the total symptom experience of pain ($r = 0.347$, $p = 0.041$).

Open-Ended Questions

Five open-ended questions that guided the semi-structured interviewed were analyzed through content analysis. Several themes emerged and the results of each of the five questions are presented individually.

Question One: What was the purpose of your surgery?

The first question asked participants about the nature or purpose of their surgery. This question was posed to get a sense about whether or not the patients knew or acknowledged they had colorectal cancer. When asked about the purpose of their surgery, 26 of 35 (74%) answered the question directly indicating an awareness of cancer present in either the colon or rectum. Three patients (9%) stated the purpose of their surgery was to save their life and two other patients (6%) stated it was to remove a blockage in the bowel. Two more patients (6%) stated the purpose of the surgery was to stop the bleeding from their bowel and the final patient (3%) stated the reason for surgery was related to the fact that he “lost control over his bowels”.

Question Two: How ready do you feel to go home?

The second question posed to the participants was aimed at determining a patient’s level of readiness for hospital discharge. Eighteen patients (51%) stated that they were ready to go home. Seven others (20%) felt almost ready for hospital discharge and another seven (20%) felt they were not yet ready to go home. In addition, four patients (11%) answered by stating they were scared, anxious, or uncertain about going home.

Question Three: Do you have any concerns about going home?

The third open-ended question gave patients a chance to explore any concerns they had about going home. The majority of patients (20/35 or 57%) responded by saying that they had no concerns about going home. Other patients (5/35 or 14%) initially responded no, but then elaborated about concerns about looking after the colostomy bag and about having to come back to hospital for further treatment.

Approximately 23% of patients (11/35) had concerns about going home. These concerns were related to their functional status in relation to caring for themselves and their capacity to carry out activities of daily living. None of the participants commented about concerns related to their psychological status or symptom experience.

Question Four: How do you think things will go in the long-term?

When respondents were asked about the future, over half (54%) were hopeful or optimistic about the future. However, almost one-third of the patients (31%) stated they were uncertain about the future. Uncertainty was related to hearing the results of the biopsy and about the possibility of tumor recurrence. This question often elicited worry within many patients surrounding upcoming adjuvant treatment (i.e., chemotherapy) and results of pathology reports. Other patients however, frequently used the word 'hopeful' in their response, despite feelings of uncertainty.

Question Five: What advice would you give regarding what to expect after surgery to another person going for the same type of surgery?

The final open-ended question asked participants to give advice to help other patients going through the same type of surgery. Content analysis revealed six themes. Faith or belief in God was one of the most prevalent themes noted in participant response (12/35 or 34%). This faith or trust was described as comforting or peaceful. Timely medical intervention was cited with the same frequency (12/35 or 34%). This theme refers to advice related to seeking medical intervention early, early detection through screening, and urging others to get the cancer surgery as soon as possible. Family support was another theme which emerged from 9 of 35 participants (26%). Family support included spouses, children, other relatives, and close friends. Another common

theme was positive thinking and this type of advice was offered by 6 of 35 participants (17%). Positive thinking was cited as a coping mechanism which was helpful in getting through both the cancer diagnosis and the post-operative recovery period. Conversely, four of the 35 patients (11%) stated they would recommend to other patients not to go through with the surgery. They felt that surgery was not worth it and they felt worse than they did pre-operatively. And finally, three participants (9%) advised patients to 'take it one day at a time' in reference to coping with cancer and recovery from surgery.

Many patients reported multiple themes within their responses. Anger or frustrations with doctors related to untimely diagnosis were noted in six participants (17%). Seven of the respondents became tearful during the response of this question. It appeared that this line of questioning made them reflect back on their cancer experience, what was important to life, and who or what they relied upon for support.

Summary

The analysis of data has produced several important results. The first important finding was a high rate (43%) of psychological distress among post-surgical CRC patients. Second, the most prevalent physical symptoms reported included: lack of energy, pain, dry mouth, difficulty concentrating, lack of appetite, feeling drowsy, weight loss, difficulty sleeping, and sweating. Three prevalent symptoms had significant relationships with depression and overall psychological distress – difficulty concentrating, lack of energy, and difficulty sleeping. Pain was positively correlated with anxiety. And finally the results indicate that over half of the participants had no concerns about hospital discharge and /or the transition home.

Chapter VI

Discussion

Introduction

The results of this study provide an increased understanding of colorectal cancer patients. It has captured both the psychological and physical symptom experiences of post-surgical CRC patients prior to hospital discharge. The use of the TUS (Lenz et al., 1997) as a theoretical framework will be briefly discussed. The demographic data of the patient sample will be then be addressed, followed by a discussion regarding each clinical question. The discussion will incorporate the prominent findings from this project with a comparative analysis of relevant literature. Limitations of the study will also be explored. In addition, recommendations for areas of future research are provided. Finally, the chapter closes with a summary of how the research results will be disseminated.

Theoretical Framework

The TUS (Lenz et al., 1997) was the theoretical framework used to guide this study. Chapter III provided a detailed analysis of the theory. The benefit of using a middle range theory is its benefit to both research and clinical practice. The parsimonious nature of the theory makes its use in the clinical setting appealing. Overall, the theory was useful in describing the reciprocal relationship between psychological distress (*psychologic factor*) and the symptom experience. The way the TUS conceptualized the multidimensional nature of symptom experience served as an appropriate framework for this study. Although the MSAS (Portenoy et al., 1994) did not capture the *quality* of symptom experience, it did however capture the other dimensions of frequency, severity, and distress of a symptom. The TUS was also appropriate for this

study as it acknowledged that multiple symptoms can co-occur and interact with each other.

As first pointed out by Redeker et al. (2000), further inquiry into the nature of *psychologic influencing factors* is needed. In this pilot study, *psychologic factors* were conceptualized as psychological distress (i.e., anxiety and depression) and measured by the HADS (Zigmond & Snaith, 1983). A causal relationship suggests that the *influencing factors* precede the symptom experience in time (Redeker et al.). It is difficult to make inferences about the causal nature of the relationship among the variables in this study. For instance, difficulty sleeping and concentrating may be manifestations of depression. Depression is a symptom and not an influencing factor. Overall psychological distress, depression, and anxiety may in fact be a result or part of the total symptom experience. Further clarification and refinement of the TUS is needed to become a more useful framework describing the relationship between psychological and physical symptoms. Perhaps another theory, such as the Self-Regulation Theory (Johnson, 1999), could prove valuable by providing a framework which lends itself to further understanding of the relationships between psychological distress and physical symptom experiences. Furthermore, this theory which emphasizes the use information as a means of regulating emotional and functional responses to illness could also be useful in guiding intervention-based research between distress and the physical symptom experience (1999).

Demographic Data

According to the NCIC (2003), the highest incidence of CRC occurs in the seventh decade and the median age of diagnosis is 67 years of age. This sample corresponds with the national average as 34% of patients were between the ages of 61- 70

and 46% of patients were over the age of seventy. The NCIC has also reported that males have a slightly higher incidence of CRC than females in Canada. Again, this sample seems to correspond with national averages as 57% of the sample was male and 43% were female. This sample however, was overrepresented by Caucasian participants (31 of 35 or 89%). Another bias of the sample is that over 95% of the participants were Christian; therefore, the ability to generalize between diverse religions is limited.

More than half of the participants (57%) had rectal tumors. These results are similar to Berg (2003) who reported an average of 56% of cases; however, this percentage also included tumors of the descending and sigmoid colon. It was not surprising that low anterior resection and abdominal perineal resections were most the most frequent surgeries performed. However, it was surprising that in light of the trend toward sphincter preserving surgery, over half of the elective cases resulted in colostomy formation. Clearly, these rates require further investigation with a larger sample size and more rigorous methodology.

Research Question One: Prevalence of Psychological Distress

The overall prevalence for moderate to severe psychological distress in post-surgical colorectal cancer patients was about 43%. This rate was higher than expected and higher than other studies using the HADS scale. Prevalence of anxiety scores was higher than overall psychological distress and depression scores. It is important to note however, that lower psychological distress and depression scores still affected more than a third of patients.

Other studies using the HADS with CRC patients did not yield such high scores. Overall anxiety and depression scores have generally been low, even when *borderline*

and *clinical cases* were combined. Mean HADS scores at diagnosis were 4.0 for anxiety and 4.4 for depression among patients with gastrointestinal (GI) cancer (Nordin & Glimelius, 1999). Mean HADS scores among post-operative GI cancer patients at follow-up were also low; 4.2 for anxiety and 4.3 for depression (Wasteson et al., 2002). Timing may be an important factor to consider regarding differences in HADS scores. The mean HADS scores post-diagnosis and surgery were 7.77 for anxiety and 6.54 for depression. The higher anxiety scores may indicate that there is more anxiety after surgery associated with cancer, post-operative recovery, discharge, or uncertainty about the future. This supports the notion that CRC patients are affected by a double or even triple threat of a cancer diagnosis, major surgery, and possibly a new colostomy.

There were no differences in the mean scores for psychological distress, anxiety, and depression according to age, gender, marital status, religion, type of surgery, or presence of ostomy. These results do not substantiate a growing body of literature that has shown that younger age, female gender, and presence of ostomy is associated with more psychological distress than those who are older, male, and do not have an ostomy (Sprangers et al., 1993). Rates of psychological distress in this study may be similar between stoma and non-stoma patients due to the extra support given to patients with a new colostomy by surgical nursing staff and the ETNs. Furthermore, the presence of colostomy may be relative. For instance, for non-stoma patients, a cancer diagnosis and major surgery is burdensome; a double threat unto itself. For stoma patients, a colostomy may be integrated into the entire cancer and surgical experience.

According to the NCIC (2004), less than ten percent of patients are referred on for psychological intervention. This implies that a significant proportion of patients with

CRC are discharged into the community with no formal psychological support in place. This is highly alarming, considering that there are several effective, standardized treatment options available such as psychoeducational care and counselling. The importance of alleviating psychological distress was made evident by Wade's (1990) research comparing psychological adjustment of post-operative colostomy patients who were visited by stoma-care nurses in the community. The results of this study indicated that 25% of patients who experienced psychological distress had died one year post-operatively compared with only 13% of patients who did not experience psychological distress. It is therefore crucial to routinely screen patients for psychological distress prior to hospital discharge so that the appropriate interventions can be arranged prior to discharge.

Research Question Two: Prevalence of Symptom Experience

The most prevalent physical symptoms (i.e., > 50%) reported by post-surgical CRC patients included lack of energy, pain, dry mouth, difficulty concentrating, lack of appetite, feeling drowsy, weight loss, difficulty sleeping, and sweating. These results are similar to the results obtained by Whynes and Neilson (1997). Whynes and Neilson however, used the Rotterdam Symptom Checklist to report the most prevalent symptoms three months post-operatively. They included: tiredness, lack of energy, lack of appetite, loss of weight, decreased sexual interest, and difficulty sleeping (Whynes & Neilson). Forsberg et al. (1996) identified several similar symptoms which were most prevalent after discharge using a symptom checklist - fatigue, pain, nutrition, difficulty sleeping, flatulence, and dry mouth were among the most prevalent physical symptoms. Perhaps an even better comparison for this pilot project's results is the recent study which also

used the MSAS to measure physical symptoms in newly diagnosed gastrointestinal cancer patients (Yan & Sellick, 2004). A comparison of results is illustrated in Table 6.1.

Table 6.1 Comparison of MSAS Physical Symptom Prevalence

Physical Symptoms	Prevalence; Current Results	Prevalence; (Yan & Sellick, 2004) Time 1
Lack of energy	88.6%	63.0%
Pain	82.9%	42.1%
Dry mouth	82.9%	38.4%
Lack of appetite	64.7%	35.6%
Weight Loss	62.9%	41.8%
Nausea	54.3%	17.1%
Difficulty sleeping	51.4%	24.7%
Sweats	51.4%	29.5%
Feeling bloated	40.0%	NR
Vomiting	40.0%	11.0%
Cough	34.3%	15.8%
Diarrhea	28.6%	19.2%
"I don't look like myself"	25.7%	NR
Itching	23.5%	18.5%
Shortness of breath	22.9%	15.8%
Dizziness	22.9%	29.5%
Numbness in hands/feet	20.0%	9.6%
Change in the way food tastes	20.0%	11.6%
Swelling in the arms or legs	20.0%	NR
Difficulty swallowing	11.4%	NR
Changes in skin	11.4%	8.9%
Problems with urination	8.6%	NR
Mouth sores	5.7%	6.2%
Constipation	2.9%	15.1%
Problems with sexual interest or activity	0.0%	NR

NR = not reported

The prevalence rates in all of the most frequent occurring symptoms are much higher when compared to the results of Yan and Sellick (2004). Although lack of energy, pain, dry mouth, and weight loss were the most prevalent in both groups, the

rates were much higher in this pilot study. Dizziness, constipation, and mouth sores were three physical symptoms that were more prevalent in Yan and Sellick's sample. Three factors may explain these differences: 1) sample, 2) timing of measurement, and 3) cultural influence. The sample in the pilot study ($n = 35$) is comprised of all CRC patients who were predominantly white and their symptoms were measured within 24 hours prior to discharge after surgical resection of their tumor. Conversely, tumor site groups varied in Yan and Sellick's patient sample ($n = 146$); only 36.3% of patients had CRC. Also, the timing of measurement (Time 1) was not well-defined by Yan and Sellick. All that can be inferred is that these patients were fairly, newly diagnosed with cancer. Another factor that may contribute to different prevalence rates is the cultural influence; all patients in Yan and Sellick's study were Chinese versus a pre-dominantly Caucasian sample obtained in this study.

There were no differences in the mean scores of physical symptom experience according to age, gender, type of surgery, or presence of ostomy. The literature on whether age and gender impacts the symptom experience is mixed. The results of this study are somewhat similar to those of Walker and Sofaer (1998) who also found no significant relationship between age and pain intensity. These results do however contradict literature that suggests patients with a new colostomy have more physical symptoms and associated distress than those patients who have undergone sphincter-preservation surgery (Renner, Rosen, Novi, Hobling & Schiessel, 1999).

Perhaps one of the most striking findings from the MSAS (Portenoy et al., 1994) is that all patients reported they had no problems with sexual interest or activity. These results are surprising considering almost half of the patients either had a low anterior

resection or abdominal perineal resection for rectal cancer, surgical procedures which have known risks associated with impaired sexual function (Gordon & Nivatvongs, 2000). Sprangers et al. (1995) has suggested that because CRC is a disease of the elderly, sexual capacity may already have been declining. There is also no way of knowing based on one self-report item whether or not they were informed of the possible sexual side effects from surgery. Again, timing of measurement may be an important factor in participant response. It may be that sexual functioning is not a top priority while in hospital. Patients may feel this line of questioning is not applicable as their focus is on physical recovery and discharge home. Measures related to sexual functioning weeks to months after discharge seem to support this notion as reports of sexual dysfunction in CRC patients are evident (Sprangers et al., 1995). Similarly, Yan and Sellick (2004) found that more patients revealed problems related to sexual functioning six months post-diagnosis rather than soon after diagnosis.

The mean number of physical symptoms reported by CRC patients was 13.31 (SD \pm 3.39). In a study by Lobchuk and Degner (2002), the mean number of symptoms reported in advanced stage cancer patients was 11.4 (SD \pm 6.06). This implies that CRC patients during the post-operative phase experience more symptoms than even advanced stage cancer patients. This reinforces the need for comprehensive symptom assessment during the post-operative recovery phase by all members of the health care team. Effective and efficient symptom management is paramount in this group of patients. Particular attention must be paid to ensure that patients are not going home without appropriate pharmaceutical and non-pharmaceutical interventions in place. Furthermore, immediate follow-up should be given to all CRC patients to ensure that patients are not

suffering unnecessarily at home. A nurse-led post-discharge telephone call may be a cost-effective option. There is growing evidence to suggest that telephone follow-up can reduce hospital readmission rates related to unmanaged symptoms, re-direct patients to appropriate resources, and provide physical and emotional comfort to patients in transition phases (Cox & Wilson, 2003).

*Research Question Three: Relationship between Psychological
Distress and Symptom Experience*

This is the first known research study that captures the relationship between psychological distress and the physical symptom experience using the HADS (Zigmond & Snaith, 1983) and the MSAS (Portenoy et al., 1994) in post-surgical CRC patients prior to hospital discharge. Three prevalent symptoms in particular had significant relationships with depression and overall psychological distress - difficulty concentrating, lack of energy, and difficulty sleeping. Pain, which was the second most prevalent symptom, was positively associated with anxiety.

Results suggest that higher overall physical symptom experience (i.e., frequency, severity, and distress) is associated with higher levels of depression, but not with anxiety or overall psychological distress. When the HADS scores were compared to the MSAS-GDI scores, all components of the HADS were significantly correlated to the MSAS-GDI. This implies that the greater the level of distress associated with common cancer symptoms, the greater chance patients will experience significant levels of anxiety, depression, or overall psychological distress. Furthermore, the MSAS-PSYCH had a significant positive relationship with the MSAS-PHYS, thereby reinforcing the association between physical symptoms and psychological distress. This supports

Portenoy et al. (1994) findings which have shown that the number of symptoms was closely associated with heightened psychological distress.

The relationship between the physical symptom experience and psychological distress is complex. These results provide further, more detailed evidence to the existing body of literature that supports this relationship. It is important for health care staff to recognize this relationship when making clinical decisions about symptom management. Alleviating psychological distress may diminish the severity or amount of distressed perceived by patients related to their physical symptoms. Similarly, effective symptom management for symptoms such as fatigue and pain may result in a better psychological adjustment and overall quality of life for patients with cancer.

Open-Ended Questions

The first open-ended question probed whether or not patients were informed and aware of their cancer diagnosis. The responses from participants indicate that patients are being told upfront about their cancer diagnosis and surgical intervention. Most of the responses included the words 'cancer, tumor, or malignancy'; while almost one-third of the responses did not use any cancer-related language to describe the purpose of their surgery. It is unclear from this line of questioning whether or not patients' avoidance of cancer-related language was purposeful.

The second and third open-ended questions focused on the hospital discharge. The majority of patients felt the timing of hospital discharge was appropriate. However, one of the most striking results of this pilot study was that few patients had concerns about the transition from hospital to home. When asked about concerns related to discharge, over half of the responses included a simple 'No, not really'. None of the participants'

responses focused on their psychological or physical symptom experience, which according to the HADS and the MSAS were moderately prevalent. Only eight of the participants had a few minor concerns related to their functional status and their ability to resume their activities of daily living (ADL's). Having family support or home care was cited as reasons for not being concerned about going home. It appears that going home was a common goal and one which was highly anticipated. One participant commented "Once I get home, I will recover really fast. I will be in my own environment; this [hospital] is no happy place".

Although anticipating discharge and being hopeful about the way the things will go once at home is an important positive attitude to possess, post-surgical patients may not have an accurate perception about the reality of hospital discharge. Further, patients may not have the ability to anticipate potential problems that may develop nor be realistic about the care needs they will have once at home (Henderson & Zernicke, 2001; LeClerc, Wells, Craig & Wilson, 2002). Problems that arise in a patient's home are different than problems encountered while in hospital when help is available 24 hours a day by nursing and medical staff (Pringle & Swan, 2001). The work of Mistiaen, Duijnhouwer, Wijkkel, de Bont, and Veeger (1997) revealed that almost 40% of elderly patients discharged from an acute care setting had some type of unmet need one week post-discharge. Discharge planning and subsequent home care typically focuses primarily on physical aspects of care and help with activities of daily living (ADLs). However, Hughes, Robinson, Cooley, Nuamah, Grobe, and McCorkle (2002) found that postsurgical care in the community focused primarily on education of patients and families and psychological support and encouragement. In fact, physical care activities were the least prevalent

nursing care activities documented (Hughes et al.). The importance of supporting the psychosocial needs of patients should be recognized as an essential component of the plan of care.

Feeling inadequately informed is a common post-discharge problem (Mistiaen, et al., 1997). Henderson and Zernicke (2001) examined the impact of discharge information for surgical patients (n = 116) and found that at discharge, 91% of patients stated that they were given sufficient discharge instruction. However, when interviewed one to two weeks post-discharge the number of satisfied patients dropped to 78%. One of the key functions of discharge information is to ensure patients have the necessary knowledge and instruction to perform self-care. Furthermore, unmet home care needs may contribute to poor patient outcomes (Henderson & Zernicke). According to Hughes, Hodgson, Muller, Robinson, and McCorkle (2000), information needs of elderly post-surgical cancer patients during the transition from hospital to home are extensive. Although patients are given discharge information in hospital, problems with recall and retention of new information during periods of stress have frequently cited (Hughes et al.). In addition, the information received in hospital may not be sufficient. This may be related to the fact nurses are perhaps ill-equipped to manage the complexities of surgical cancer patient discharge needs. In addition, large nurse-patient ratios and shortened length of hospital stay may also contribute to less opportunity for patient education and reinforcement (Mills & Sullivan, 1999). If nurses do not possess the knowledge base or do not have adequate time to address the complex needs of CRC patients, a CRC clinical nurse specialist (CNS) could support general duty nurses in patient education and provide patients and families with the expert patient care.

Participants in this study frequently mentioned a reliance on friends and family as a helpful coping mechanism, and this support system seemed to allay concerns about going home. According to Chan, Hen, Chien, and Lopez (2004), a large support network is an important contributor to successful coping in post-surgical cancer patients. In particular, functional support provided by spouses and adult children to elderly surgical patients often fills the gap of limited available home care services (LeClerc et al., 2002). Therefore, older adults with inadequate social supports are at risk for an inadequate post-operative transition from hospital to home and may fall through the cracks of the home care system. Given the fact that CRC is considered a disease of the elderly, this is of particular concern and needs to be further addressed in both research and clinical practice. For instance, the work of McCorkle, Strumph, Nuamah, Adler, Cooley, Jepson, et al., (2000) demonstrated a survival advantage in post-surgical cancer patients who received a specialized home care provided by advanced practice nurses when compared with patients who received usual follow-up care in the ambulatory clinic.

Faith and belief in God was another prevalent theme which emerged in patient responses. Current literature suggests that patients who possess a religious faith have less overall physical and mental illness and recover from illness more quickly. In cancer patients, spirituality contributes positively to quality of life, thereby increasing their ability to effectively cope with cancer and its treatments (McIllmurray, Francis, Harman, Morris, Soothill & Thomas, 2003; Soothill, Morris, Harman, Thomas, Francis & McIllmurray, 2002). In this present study, there were no differences in mean scores of the HADS and MSAS according to religious affiliation. This could be related to the fact that there was limited variation in responses, as over 90% were of the Christian faith.

Regardless of religious affiliation, the results of this study reinforce the importance of spirituality and hope in the recovery process.

Limitations

Sample

A non-probability convenience sample was utilized and is noted as a limitation of the study as the design is inherently weaker than a random sampling method (Polit & Hungler, 1999). Due to the fact that data collection was only be taken from one hospital and that the target population is very specific; hospitalized post-surgical colorectal cancer patients prior to discharge, the ability to generalize to a larger population may be a limiting factor. A multi-site study would be helpful in increasing the generalizability of this study.

Due to the time restraints of a four month data collection period, obtaining a large sample size was not possible as the number of surgical resections performed for the bowel or rectum was not sufficient. The statistical results must therefore be interpreted with caution. A longer data collection period which includes multiple sites would be helpful in obtaining a larger sample size.

Empirical Instruments; HADS

Although the HADS (Zigmond & Snaith, 1983) is a reliable and valid tool which has been used extensively in the cancer population, several limitations of its use have emerged. The scale was originally developed to measure anxiety and depression among hospitalized patients and its use to measure overall psychological distress has been well documented (Ahlberg et al., 2004; Bisson et al., 2002; Fobair et al., 2002; Pascoe et al., 2000; Porcelli et al., 1996). However, after conceptual clarification of psychological

distress in Chapter II, the HADS fails to capture the complex nature of the concept. Use of the scale perpetuates the belief that anxiety and depression are the only manifestations of psychological distress. Although these two symptoms are most common, other symptoms such as anger, hostility, pessimism, or social isolation which can also be manifestations of psychological distress (Masse, 2000, NCIC, 2004).

Empirical Instruments; MSAS

The MSAS was a useful tool in that it provided a rich data set. The tool captured the multidimensional nature of the concept of total symptom experience in that it measured the frequency, severity, and distress of 32 symptoms common in cancer. It also provided three meaningful subscales; the MSAS-PHYS, the MSAS-PSYCH, and the MSAS-GDI. The tool however was cumbersome. Patients were sometimes overwhelmed by its format and detail of questioning. Patients asked many questions about the pragmatics of filling out the questionnaire. These distractions may have impacted patient response. The MSAS was also complicated in scoring which does not make it a useful tool for clinical practice. Although it provides multidimensional data, its length and complexity would not be appropriate as a screening tool in busy hospital or clinic settings.

Open-Ended Questionnaire

The semi-structured interview focused predominantly on concerns related to discharge. According to Masse (2000), qualitative research captures the essence of psychological distress and empirical measures de-contextualize manifestations of distress. Therefore, a question regarding the patient's psychological symptom status would have been helpful to supplement and provide context to the empirical survey data.

Likewise, a question regarding a patient's physical symptom experience would serve a similar purpose, providing context to a patient's physical symptom experience.

Future Research

There are many directions future research can take as a result of this pilot study. First, a larger sample size is necessary to substantiate the result of this present study. This would require a longer data collection phase and multiple study sites. Gathering a sample that was not predominantly white, middle class, and Christian would also help make the results more culturally relevant. Comparing and contrasting different empirical measures for psychological distress and symptom experience would be useful to determine which measure is most acceptable to patients and captures the experiences the most accurately. Both psychological distress and symptom experience are dynamic variables that change over time. Therefore, measurement of psychological distress and symptom experience pre-operatively, post-operatively prior to hospital discharge, and at follow-up would produce results that would demonstrate how these variables fluctuate throughout the cancer illness trajectory.

Future research examining the surgical nursing staffs' knowledge base concerning the psychological needs of colorectal cancer is also imperative. One study which measured medical and surgical nurses' perceptions of their level of competence and educational needs in caring for patients with cancer identified several themes (McCaughan & Parahoo, 2000). Nurses were most competent in providing physical care for patients with cancer. Knowledge gaps were identified in the domains of psychosocial care and communication with patients and families surrounding the uncertainties of cancer. Lack of knowledge and time were also identified as two major barriers in

providing competent psychosocial care (McCaughan & Parahoo). If patients are to receive adequate psychological support and guidance in hospital, these barriers must be overcome. Staff nurses need to be equipped with the knowledge and tools to care for the unique needs of this patient cohort. Given the current staffing shortages and strained health care environment, the barrier of time seems like an insurmountable obstacle for surgical nurses. Therefore, innovative approaches, such as a CNS in colorectal cancer, need to be implemented to provide patients with expert care and time that staff nurses can not afford.

The use of assessment scales in hospital and home can yield structured and reliable data for decisions around patient care (Forsberg et al., 1996). Future research should also include the development of a psychological and physical symptom assessment tool developed specifically for post-surgical CRC patients. This tool could be designed with the purpose of being used pre-operatively and throughout the post-operative hospital stay so that their psychological and symptom experience can be monitored over time. A before-after research design would be an appropriate choice of methodology for this type of research. The challenge of developing such a tool is to capture the multidimensional nature of symptom experience which is easy to complete for patients and easy to score for health care professionals.

Research can also be targeted at developing a standardized discharge care package that would meet the needs of post-surgical CRC patients. Information packages need to be developed that include practical advice concerning activities of daily living, exercise, and nutrition. A list of community resources and local support organizations for patients to utilize for psychological support prior to their surgical follow-up visit or first visit to

the medical oncologist would be of benefit. A booklet of common cancer and post-surgical symptoms and their management should also be incorporated into the discharge package. This booklet can offer alternative therapies that may be helpful in alleviating symptoms such as relaxation or meditation (Goodman, 2000).

Further inquiry into the transition period of hospital to home is also indicated. The results of this study imply that patients are not aware of the potential problems that they may encounter once at home. The work of McCorkle et al. (2000) regarding the role of the advanced practice nurse in post-surgical care of the elderly needs to be replicated in this patient population. McCorkle et al. (2000)'s study of a specialized home care intervention for elderly post-surgical cancer patients was the first to provide empirical data that links advanced practice nursing with improved overall survival. The CNS in colorectal cancer could provide specialized education and support to patients pre and post-operatively. This role should extend into the community to ensure a successful transition home. Specialized care (i.e., informational support and follow-up provided by advanced practice nurses) in the community has shown to increase the speed of recovery, reduce complications rates, decrease psychological distress, improve symptom management, and decrease hospital readmission rates (Hughes et al., 2000; Hughes, Robinson, Cooley, Nuamah, Grobe & McCorkle, 2002; Pringle & Swan, 2001). Therefore, the development and implementation of this type of role needs to be further explored as a viable option to provide better care and improve patient outcomes for men and women with CRC in Manitoba.

Dissemination of Results

The results of this study will be shared with the healthcare providers at the St. Boniface General Hospital in the form of a written document and/or a presentation that summarizes the results of this pilot study. Participants of the study who indicated on their informed consent forms that they would like a summary of the research findings will be mailed a summarized document. The results of this research will be submitted for publication in appropriate nursing journals such as *Cancer Nursing*, or *Oncology Nursing Forum*. Abstracts will also be submitted for presentation of a research paper at local or national nursing conferences that highlight oncology-nursing research.

Summary

The purpose of this pilot study was to determine the prevalence rates of psychological distress and describe the physical symptom experience in post-surgical CRC patients prior to hospital discharge. Patients in this study reported numerous symptoms related to their diagnosis and /or treatment; lack of energy and pain being the most burdensome. A significant number of patients also reported moderate to severe levels of psychological distress prior to hospital discharge. In addition, a significant relationship between symptom experience and psychological distress was found. All of these results have important clinical implications. Patients are being discharged with many persisting physical and psychological symptoms. Health care professionals need to be aware of the importance of treating both the physical and psychological effects that CRC may provoke. Although nursing staff may be capable of providing the necessary education and support, the hectic climate of the health care system may not allow enough time to adequately prepare CRC patients for the transition home. Therefore, a CNS

specializing in the care of CRC patients is a viable option that could help meet the physical, psychological, and informational needs of patients and their families; and as a result, facilitate a successful transition from hospital to home.

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Appendix A

The NCIC's Psychological Distress Continuum



**Normal
Adjustment**

**Adjustment
Disorders**

**Sub-threshold to
Mental Disorders**

**Diagnosable
Disorder**

Appendix B

Theory Development (Lenz et al., 1995)

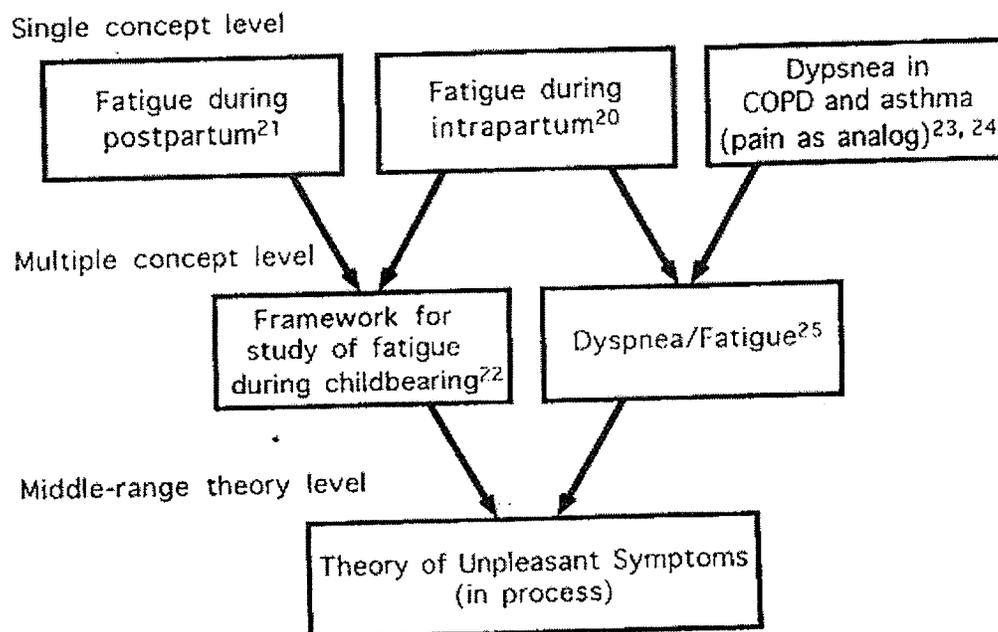
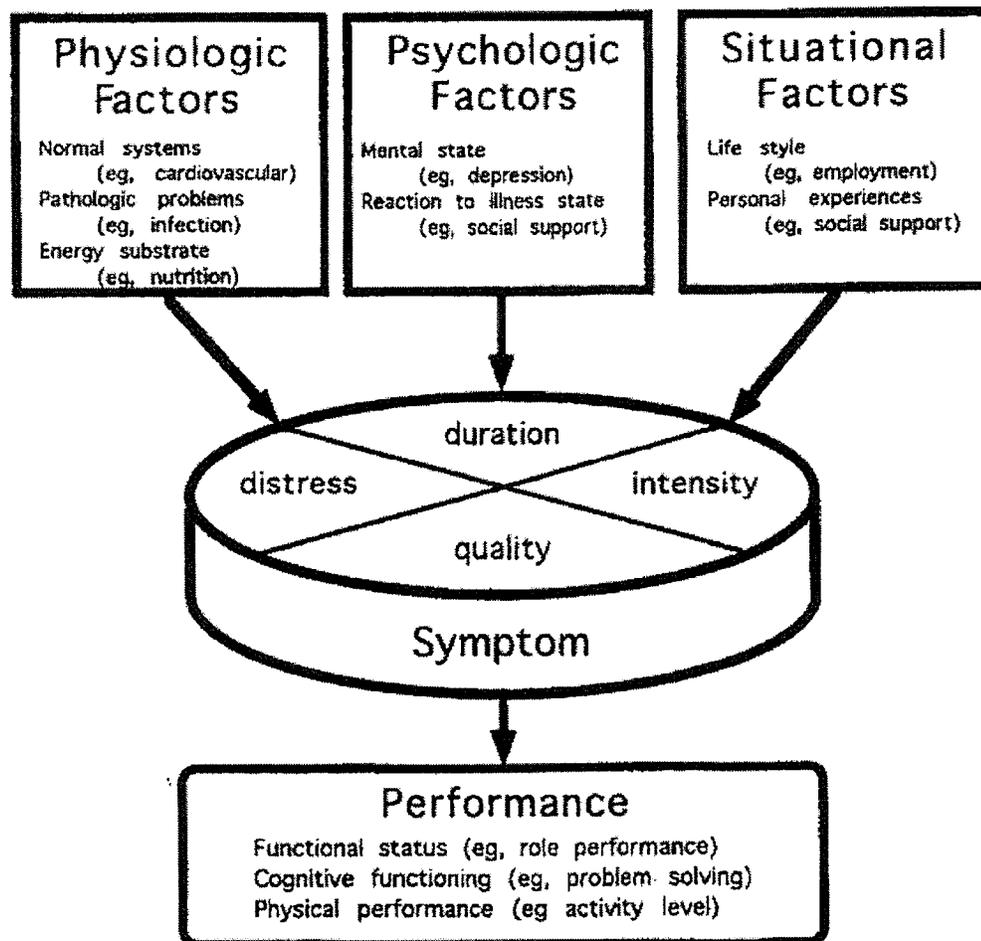


Fig 1. Overview of theory development process. COPD = chronic obstructive pulmonary disease.

Appendix C

Theory of Unpleasant Symptoms (Lenz et al., 1995)



Middle-range theory of unpleasant symptoms. → = influences.

Appendix D

Updated Theory of Unpleasant Symptoms (Lenz et al.,
1997)

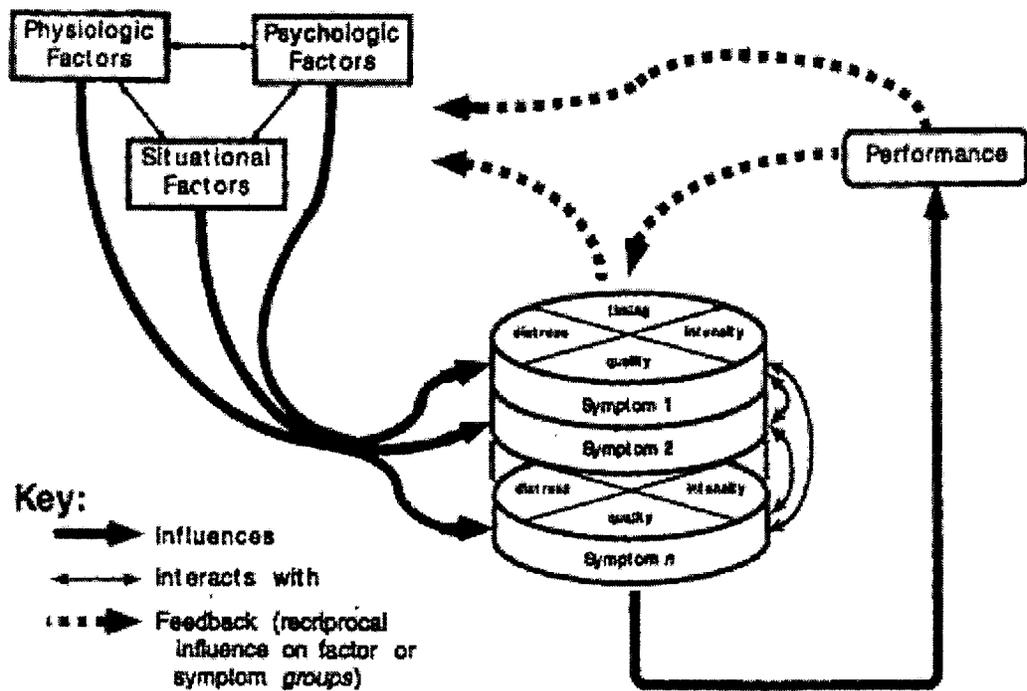


Fig 2. Updated version of the middle-range theory of unpleasant symptoms.

Appendix E**Research Review Committee****Amendment Request**

Psychological Distress and Symptom Experience in Post-Surgical Colorectal Cancer Patients

RRC Reference #: RRC/2003/0517
Approved January 08, 2004

University of Manitoba Education/Nursing Ethics Review Board (ENREB)
Protocol# E2003: 088
Original Approval: Nov 04 2003
Amendment Approval: Feb10/2003

Principal Investigator: Vanessa Wasio RN BN BA
Graduate Student
Faculty of Nursing
University of Manitoba

Research Review Committee
Room N1004-409 Tache Ave.
Berry St
Winnipeg, MB
R2H 2A6

Vanessa Wasio

RE: Amendment to Research Protocol, RRC Reference #: RRC/2003/0517

Date: February 10, 2004

Dr. Tetreault,

My name is Vanessa Wasio and I am the Principal Investigator for my study: Psychological Distress and Symptom Experience in Post-Surgical Colorectal Cancer Patients. I received RRC approval on January 8, 2004. I am hereby requesting an amendment to the protocol (RRC/2003/0517) related to the inclusion criteria for the study.

In order to acquire more patients, I wanted to open up inclusion criteria so that my intended sample size may be acquired. My original inclusion criterion was to include patients with a first time diagnosis of colon cancer. I would like to also include patients with recurrent colon or rectal tumors. Please see highlighted changes on St. Boniface Submission Form. I do not foresee any problems related to this change as the recommended change to the inclusion criteria was left out in the original due to an oversight. The amended change does not affect the informed consent letter, nor does it impact the instruments used in the study.

The University of Manitoba ethics committee (ENREB) has granted approval to this amendment on February 10, 2004. Please see attached.

If you require any further information about the proposed amendment, please feel free to phone me _____ or email me _____ your earliest convenience.

Thank-you,

Vanessa Wasio RN BN BA
Graduate Student
Faculty of Nursing
University of Manitoba

Appendix F

Invitation to Patients to Participate

Vanessa Wasio is a registered nurse and a graduate student at the Faculty of Graduate Studies, University of Manitoba. She is doing research here at the St. Boniface General Hospital about patients' emotional and physical symptoms after having surgery for the bowel or rectum. She is interested in learning about the thoughts and feeling patients may have about their symptoms after surgery before they are discharged home.

The information that you give will be kept strictly confidential. Whether or not you decide to participate will in no way influence the care that you receive.

Vanessa would like to talk to you about the study. Would you be willing to speak with Vanessa so that she can explain the study to you? You can let your nurse know about your decision to speak with Vanessa. Please indicate your decision on the bottom of this invitation and return it to your nurse. You can leave your name with the nurse so that Vanessa can contact you before you are discharged home about the study.

INVITATION TO PATIENTS
(A study by Vanessa Wasio, R.N., B.N., B.A., Faculty of Graduate Studies,
University of Manitoba)

_____ Yes, I agree to speak with Vanessa

NAME

_____ No, I do not agree to speak with Vanessa

Appendix G

RESEARCH SUBJECT INFORMATION AND CONSENT FORM

Research Project Title: **Psychological Distress and Physical Symptom
Experience in Post-Surgical Colorectal Cancer Patients**

Researcher: **Vanessa Wasio, R.N., B.N., B.A.
Graduate Student
Faculty of Nursing
University of Manitoba
Winnipeg, Manitoba**

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this information carefully and to understand any accompanying information.

Purpose

The purpose of this research is to describe psychological and physical symptoms after having surgery of the bowel or rectum. All participants will be recovering from surgery at the St. Boniface General Hospital. This research is being conducted to complete the requirements for a Master's of Nursing Degree at the University of Manitoba, under the supervision of Lesley Degner, R.N., Ph. D.

Procedure

You are requested to read and sign this consent form. Please remember to put your initials at the bottom of each page as an indicator that you have read and understood the information and/or questions on each page. Once your consent form is completed you will be given three short surveys to complete. The first survey will give the researcher general information (such as age or gender). The second survey will ask questions about some of the physical symptoms you may

have experienced in the last week. The third survey will ask questions about your current emotional state. Once you have completed the consent form and the surveys, you may then give them back to the interviewer/research nurse. Finally, the investigator will ask you five questions about your symptom experiences after your surgery. The investigator will take notes during the brief interview. Your answers will not be tape recorded. In total, your participation in the study will take about 30 minutes of your time.

Risks

There are no known risks associated with participation in this study, but being asked about your current feelings may cause you additional distress. If this happens to you, you may talk with the nurse to debrief. A list of health care resources in your community will be given to you with your surveys to provide additional support if necessary.

Benefits

Although this study has no direct benefit to you, your participation will be used to help expand our knowledge base about post-operative care issues and concerns. The information collected for this study will contribute to a better understanding of the physical and emotional experience patients undergo after bowel surgery. The information obtained from this study will be helpful to health care professionals (e.g. nurses) who would like to know how to improve the care they give patients.

Costs

There are no costs associated with participating in this study.

Payment for Participation

You will not be paid for your participation in this study.

Confidentiality

The potential names of participants have been obtained through the staff at St. Boniface General Hospital. The medical information from your chart will be collected in accordance with the *Personal Health Information Act (PHIA)* of Manitoba. Medical records that contain your

identity will be treated as confidential in accordance with PHIA. A patient number, rather than your name, will be used on all study surveys. To ensure confidentiality it is important that you **do not** put your name on any of the surveys. If you are a research subject at St. Boniface General Hospital, your research related records may be reviewed by St. Boniface General Hospital for quality assurance purposes. Information gathered from this study may be presented within the hospitals and/or published; however, your name and identifying data will never be revealed. Please know that during and after the research, all surveys will be securely locked up, and kept for seven to ten years, then destroyed.

Voluntary Participation/Withdrawal from the Study

Your decision to take part in this study is voluntary. If you choose not to participate or withdraw at any time, your decision will be respected. You may refuse to participate or you may withdraw from the study at any time without consequence. You may do so by letting the researcher know at any time. Your decision whether or not to participate will not affect the care you receive here at the St. Boniface General Hospital.

Consent

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. It also allows the research nurse to have access to your medical records. In no way does this waive your legal rights nor release the researchers or St. Boniface General Hospital from their legal and professional responsibilities. You are free to withdraw from the study at any time, and/or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

This research has been approved by the Education and Nursing Ethics Review Board at the University of Manitoba and the St. Boniface General Hospital Research Review Committee (RRC) to ensure that this research is in accordance with their ethical standards and regulations. If you have any concerns or complaints about this project you may contact the researcher, Vanessa Wasio or the study advisor, Dr. Lesley Degner, at 474-6767. If you wish you may also contact the Human Ethics Secretariat of the Education and Nursing Ethics Review Board at 474-7122. A copy of this consent form has been given to you to keep for your records and reference.

 Participant Printed Name

 Participant Signature

 Date

 Interviewer (Researcher) Printed Name

 Interviewer (Researcher) Signature

 Date

Thesis Committee:

Dr. Lesley Degner

Professor

Faculty of Nursing

University of Manitoba

Dr. Steve Latosinsky

Surgical Oncologist

Faculty of Medicine

University of Manitoba

Dr. Michelle Lobchuk

Assistant Professor

Faculty of Nursing

University of Manitoba

*I would like to receive a summary report of the results of this study: (Please check one)

Yes _____ No _____

If yes, please mail a summary of the report to:

Name: _____

Address: _____

Appendix H

Patient No. _____

Medical Record Information Form

Date of Admission: _____

Anticipated Date of Discharge: _____

Diagnosis: _____

Additional Medical Diagnoses:

Date of Surgery: _____

Type of Surgery: _____

Ostomy present? _____

Appendix I

Patient No. _____

Patient Demographic Data Form

*Please circle numbered item that is applicable to you. Please write down further information when indicated.

1. Age

- 01 41 - 50 years of age
- 02 51 - 60 years of age
- 03 61 - 70 years of age
- 04 71 - 80 years of age

2. Gender

- 01 Male
- 02 Female

3. Marital Status

- 01 Single/Never Married
- 02 Married/Common Law
*How long? Years _____ Months _____
- 03 Divorced/Separated
*How long? Years _____ Months _____
- 04 Widowed
*How long? Years _____ Months _____
- 05 Other (PLEASE SPECIFY) _____
*How long? Years _____ Months _____

4. What is your occupational status?

- 01 Full-time
- 02 Part-time
- 03 Retired
- 04 Unemployed/ Don't work
- 05 Medical Leave

Patient No. _____

Patient Demographic Data Form

5. Ethnic background

- 01 Canadian
- 02 USA
- 03 European
- 04 Aboriginal/First Nation/Inuit
- 05 Jewish
- 06 Asia & Pacific Islands (Chinese, Japanese, Pilipino, Vietnamese,
Korean...)
- 07 East Indian
- 08 African American
- 09 Middle Eastern
- 10 Other (SPECIFY) _____
- 11 Not sure

6. What is your religion?

- 01 No preference
- 02 Anglican
- 03 Roman Catholic/ Ukrainian Catholic
- 04 United Church
- 05 Mennonite
- 06 Lutheran
- 07 Hindu
- 08 Muslim
- 09 Jewish
- 10 Jehovah's Witness
- 11 Baptist
- 12 Greek Orthodox
- 13 Pentecostal
- 14 Presbyterian
- 15 Other (SPECIFY) _____

Patient No. _____

Patient Demographic Data Form

7. What is the highest level of schooling or education you have finished?
- 01 No formal schooling
 - 02 Elementary school
 - 03 High school
 - 04 Community/Technical college
 - 05 University
 - 06 Other (SPECIFY) _____
 - 07 Not sure
8. Did you know you were coming to hospital for bowel surgery? (Was it scheduled electively prior to your admission?)
- 01 No
 - 02 Yes
 - 03 Not sure
9. Do you have an ostomy (Do you now wear a bag on your stomach to collect your stool?)
- 01 No
 - 02 Yes

Appendix J

Patient No. _____

Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983)

Emotions play an important part in most illnesses. If the health care team is aware of these emotions they are better able to help you. This questionnaire is designed to help understand how you are feeling. Ignore the numbers on the left hand side of the page. Read each item and check the reply which comes closest to how you have been feeling in the past week. Try not to take too long over your replies; your immediate reaction to each item will probably be more accurate than a long thought out response.

A **I feel tense or 'wound up':**

- 3 ____ Most of the time
- 2 ____ A lot of the time
- 1 ____ From time to time, occasionally
- 0 ____ Not at all

D ***I still enjoy the things I used to enjoy:***

- 0 ____ Definitely as much
- 1 ____ Not quite as much
- 2 ____ Only a little
- 3 ____ Hardly at all

A **I get a sort of frightened feeling as if something awful is about to happen:**

- 3 ____ Very definitely and quite badly
- 2 ____ Yes, but not too badly
- 1 ____ A little, but it doesn't worry me
- 0 ____ Not at all

Patient No. _____

D *I can laugh and see the funny side of things:*

- 0 _____ As much as I always could
 1 _____ Not quite so much now
 2 _____ Definitely not so much now
 3 _____ Not at all

A **Worrying thoughts go through my mind:**

- 3 _____ A great deal of the time
 2 _____ A lot of the time
 1 _____ From time to time but not too often
 0 _____ Only occasionally

D *I feel cheerful:*

- 3 _____ Not at all
 2 _____ Not often
 1 _____ Sometimes
 0 _____ Most of the time

A **I can sit at ease and feel relaxed:**

- 0 _____ Definitely
 1 _____ Usually
 2 _____ Not often
 3 _____ Not at all

Patient No. _____

D *I feel as if I am slowed down:*

3 _____ Nearly all the time

2 _____ Very often

1 _____ Sometimes

0 _____ Not at all

A **I get a sort of frightened feeling like 'butterflies' in the stomach:**

0 _____ Not at all

1 _____ Occasionally

2 _____ Quite often

3 _____ Very Often

D *I have lost interest in my appearance:*

3 _____ Definitely

2 _____ I don't take so much care as I should

1 _____ I may not take quite as much care

0 _____ I take just as much care as ever

A **I feel restless as if I have to be on the move:**

3 _____ Very much indeed

2 _____ Quite a lot

1 _____ Not very much

0 _____ Not at all

Patient No. _____

D *I look forward with enjoyment to things:*

- 0** _____ As much as I ever did
- 1** _____ Rather less than I used to
- 2** _____ Definitely less than I used to
- 3** _____ Hardly at all

A *I get sudden feelings of panic:*

- 3** _____ Very often indeed
- 2** _____ Quite often
- 1** _____ Not very often
- 0** _____ Not at all

D *I can enjoy a good book or radio or TV programme:*

- 0** _____ Often
- 1** _____ Sometimes
- 2** _____ Not often
- 3** _____ Very seldom

*Please check to ensure that you have answered all questions. Thank-you.

For researcher use only: **D (8-10)** _____

A (8-10) _____

Appendix K

Patient No. _____

MEMORIAL SYMPTOM ASSESSMENT SCALE
(Portenoy et al., 1994)**INSTRUCTIONS:**

There are 32 symptoms listed below. Read each question carefully. If you HAD the symptom during the past week, please let tell us how OFTEN you had it, how SEVERE it was usually, and how much it DISTRESSES OR BOTHERED you by circling the appropriate number. If you DID NOT HAVE the symptom, make an "X" in the box marked "DID NOT HAVE".

Memorial Symptom Assessment Scale (Portenoy et al., 1994)

DURING THE PAST WEEK, Did you have any of the following symptoms?	D I D N O T H A V E	IF YES, How OFTEN did you have it?				IF YES, How SEVERE was it usually?				IF YES, How much did it DISTRESS or BOTHER you?				
		Rarely	Occas- ionally	Frequ- ently	Almost Cons- tantly	Slight	Moder- ate	Severe	Very Severe	Not At All	A Little Bit	Some- what	Quite A Bit	Very Much
Difficulty concentrating		1	2	3	4	1	2	3	4	0	1	2	3	4
Pain		1	2	3	4	1	2	3	4	0	1	2	3	4
Lack of energy		1	2	3	4	1	2	3	4	0	1	2	3	4
Cough		1	2	3	4	1	2	3	4	0	1	2	3	4
Feeling nervous		1	2	3	4	1	2	3	4	0	1	2	3	4
Dry mouth		1	2	3	4	1	2	3	4	0	1	2	3	4
Nausea		1	2	3	4	1	2	3	4	0	1	2	3	4
Feeling drowsy		1	2	3	4	1	2	3	4	0	1	2	3	4
Numbness / tingling in hands / feet		1	2	3	4	1	2	3	4	0	1	2	3	4
Difficulty sleeping		1	2	3	4	1	2	3	4	0	1	2	3	4
Feeling bloated		1	2	3	4	1	2	3	4	0	1	2	3	4
Problems with urination		1	2	3	4	1	2	3	4	0	1	2	3	4

(Continued on the next page)

Memorial Symptom Assessment Scale (Portenoy et al., 1994)

DURING THE PAST WEEK, Did you have any of the following symptoms?	D I D N O T H A V E	IF YES, How OFTEN did you have it?				IF YES, How SEVERE was it usually?				IF YES, How much did it DISTRESS or BOTHER you?				
		Rarely	Occas- ionally	Frequ- ently	Almost Const- antly	Slight	Moder- ate	Severe	Very Severe	Not At All	A Little Bit	Some- what	Quite A Bit	Very Much
Vomiting		1	2	3	4	1	2	3	4	0	1	2	3	4
Shortness of Breath		1	2	3	4	1	2	3	4	0	1	2	3	4
Diarrhea		1	2	3	4	1	2	3	4	0	1	2	3	4
Feeling sad		1	2	3	4	1	2	3	4	0	1	2	3	4
Sweats		1	2	3	4	1	2	3	4	0	1	2	3	4
Worrying		1	2	3	4	1	2	3	4	0	1	2	3	4
Problems with sexual interest or activity		1	2	3	4	1	2	3	4	0	1	2	3	4
Itching		1	2	3	4	1	2	3	4	0	1	2	3	4
Lack of appetite		1	2	3	4	1	2	3	4	0	1	2	3	4
Dizziness		1	2	3	4	1	2	3	4	0	1	2	3	4
Difficulty swallowing		1	2	3	4	1	2	3	4	0	1	2	3	4
Feeling irritable		1	2	3	4	1	2	3	4	0	1	2	3	4

(Continued on the next page)

Memorial Symptom Assessment Scale (Portenoy et al., 1994)

DURING THE PAST WEEK, Did you have any of the following symptoms?	DID YOU HAVE	IF YES, How OFTEN did you have it?				IF YES, How SEVERE was it usually?				IF YES, How much did it DISTRESS or BOTHER you?				
		Rarely	Occasionally	Frequently	Almost Constantly	Slight	Moderate	Severe	Very Severe	Not At All	A Little Bit	Some-what	Quite A Bit	Very Much
Mouth sores		1	2	3	4	1	2	3	4	0	1	2	3	4
Change in the way food tastes		1	2	3	4	1	2	3	4	0	1	2	3	4
Weight loss		1	2	3	4	1	2	3	4	0	1	2	3	4
Hair loss		1	2	3	4	1	2	3	4	0	1	2	3	4
Constipation		1	2	3	4	1	2	3	4	0	1	2	3	4
Swelling of arms or legs		1	2	3	4	1	2	3	4	0	1	2	3	4
"I don't look like myself?"		1	2	3	4	1	2	3	4	0	1	2	3	4
Changes in skin		1	2	3	4	1	2	3	4	0	1	2	3	4

** IF YOU HAD ANY OTHER SYMPTOMS DURING THE PAST WEEK, PLEASE LIST BELOW AND INDICATE HOW MUCH THE SYMPTOM HAS DISTRESSED OR BOTHERED YOU.

OTHER:	0	1	2	3	4
OTHER:	0	1	2	3	4
OTHER:	0	1	2	3	4

Appendix M

COMMUNITY RESOURCES

There are many support groups and counseling services offered at *Cancer Care Manitoba*. Many people find that talking to someone or joining a support group helps ease some of the distress that may be associated with your illness. Please call

for information regarding these services available in your community. The phone number to the department of psychosocial oncology at St. Boniface General Hospital is (204) 237-2006.

If you are interested in speaking with someone who has been in a similar situation either in person or over the phone call the CCS Cancer Connection at (204) 774-7483 or 1-888-939-3333. If you have a colostomy, this number will also connect you with someone who can provide you with information regarding a Colostomy Support Group,

If you do not feel comfortable accessing these services or do not feel that they are applicable to you and continue to have concerns, please follow up with your family doctor or your surgeon.