

**IMPLEMENTATION AND EVALUATION OF THE EDMONTON SYMPTOM  
ASSESSMENT SCALE IN GYNE-ONCOLOGY PATIENTS ADMITTED TO  
ACUTE CARE: A PILOT PROJECT**

**BY**

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**Implementation and Evaluation of the Edmonton Symptom Assessment Scale in Gynecology Patients Admitted to Acute Care: A Pilot Project**

**BY**

**Michelle Kralt**

**A Thesis/Practicum submitted to the Faculty of Graduate Studies of The University of**

**Manitoba in partial fulfillment of the requirement of the degree**

**Of**

**Master of Nursing**

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## Abstract

An estimated 149,000 new cases of cancer and 69,500 cancer deaths will occur in Canada in 2005 (Canadian Cancer Society, 2005a). Patients with cancer will have multiple symptoms that impair function and quality of life. The optimal management of symptoms is dependant on frequent and accurate symptom assessment and communication between patients and health care professionals. Nurses identifying symptoms early and accurately may alter the symptom burden. Notwithstanding the recent proliferation of hospice programs, most cancer patients die in acute care settings. However, current literature indicates that inadequate symptom assessment in practice remains a major barrier to symptom management. Inadequate symptom control throughout the trajectory of life-limiting illness not only produces suffering, but may even affect the course of the illness. Therefore, an important challenge for nursing is to better understand and effectively manage the cancer-related symptoms in patients admitted to acute care.

It has been suggested that symptom measurement scales could improve symptom assessment by health care professionals. Standardized symptom assessment tools provide the basis for detecting symptoms, evaluating their severity, exploring distress and assessing the effectiveness of interventions.

In this pilot project, the Conceptual Model of Symptom Management was utilized as a framework in the implementation of the Edmonton Symptom Assessment System (ESAS) with gynecological cancer patients admitted to an acute care setting within a large tertiary hospital. Following the implementation of the tool, a descriptive

evaluation was undertaken of both patient (N=20), and nurse (N=21) participants. Given that this was a pilot project, the findings are limited by the small, convenience sample. However, the results revealed that the ESAS improved symptom awareness and the communication of the symptom experience between the patient and nurse. Qualitative data from this project also revealed barriers patients face in disclosing their symptoms to health care providers.

This project includes a description of the ESAS and a discussion of the outcomes of the evaluation, including barriers to symptom assessment in practice, and recommendations for practice, education, and research.

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## Chapter I

### Statement of the Problem

This first chapter focuses on the current state of symptom management in oncology patients, addresses the purpose and significance of this clinical project, and provides a description of the conceptual framework that guides the project study.

#### *Background*

Cancer is a significant health burden to Manitobans and Canadians. An estimated 149,000 new cases of cancer and 69,500 cancer deaths will occur in Canada in 2005 (Canadian Cancer Society, 2005a). In Manitoba alone, 2,600 cancer deaths are expected this year (Canadian Cancer Society, 2005b). Based on these current statistics, it is estimated that, in Canada, 38% of women and 44% of men will develop cancer during their lifetime (Canadian Cancer Society, 2005a). Cancer is not only the leading cause of premature death for both men and women in Canada (Canadian Cancer Society 2005a), but also among the most feared of all diseases.

Cancer is associated with disfigurement, loss of bodily function, emotional anguish, financial crisis, pain, and premature death (Canadian Strategy for Cancer Control, 2002). Because it can precipitate drastic changes in a person's life, cancer is often a catastrophic experience. These changes are associated with many different forms of cancers, but especially in types of cancer malignancies that convey a poor prognosis, such as gynecological cancers. The National Cancer Institute of Canada (2005), estimated that gynecological cancers would account for approximately 2,660 Canadian deaths, and

approximately 7,650 women would be diagnosed with cancer of the reproductive organs in 2005. Despite aggressive surgery and intensive chemotherapy and radiotherapy regimes, long term survival rates remain poor for many of the gynecological cancers. Therefore, an important challenge for nursing is to better understand and effectively manage the cancer-related symptoms in women with advanced gynecological cancer.

Traditionally, emphasis on the management of patients' symptoms only begins during palliative care, when the extent of curative therapies has been exhausted. Despite the well known modest effect of "life-prolonging therapies," such as chemotherapy or radiotherapy (Weeks et al., 1998), health care providers and patients continue to put more value on medical investigation and cure rather than symptom identification and management (Cella, 1994; Koffman, 2001). These life-prolonging therapies may have limited beneficial effects on the tumor and are often both toxic and unpleasant in relation to the variety of symptoms and side-effects associated with them. Inadequate symptom control throughout the trajectory of life-limiting illness not only produces suffering, but may even affect the course of illness; poorly controlled symptoms can directly alter the treatment of cancer by early treatment cessation or poor treatment response (Cleeland, 2000; MacDonald, 2002). Consequently, as a result of disease progression or aggressive treatment, patients with advanced cancer may have a multitude of disabling symptoms that impair their ability to function, as well as their enjoyment of life.

For individuals with cancer, symptoms do not only arise in the last weeks of life. Contrarily, they tend to suffer with symptoms long before end of life care becomes a

prominent issue. Symptoms have a major impact on the quality of life of cancer patients, as well as their families (Cella, 1994; Cleeland, 2000). Most advanced cancer patients suffer from a variety of devastating symptom complexes (Bruera, 1990). Moreover, it is not uncommon for these symptoms to become so severe that hospitalization is required for acute symptom management, adding substantially to health care costs and further disruption in the lives of patients and their families (Reyes-Gibby, McCrory, & Cleeland, 2003).

Notwithstanding the recent proliferation of hospice programs, most patients die in acute care settings (Institute of Medicine, 1997), and often with poor symptom management (SUPPORT Principal Investigators, 1995; Teno et al., 2004). Studies have indicated that cancer-related deaths in the acute care setting are often prolonged and painful (SUPPORT Principal Investigators, 1995). Therefore, it is important for health care providers working in these settings to have a better understanding of palliative care practices. Based on this premise, it follows that the care of patients with cancer who are treated in acute care settings must be transformed to include a philosophy of symptom assessment and management. The principles of palliative care need to be fully understood by the wide range of professionals who care for persons with cancer in acute care areas, namely nurses and physicians. These principles must be applied throughout the course of the illness, and not limited to end of life care.

Appropriate symptom assessment and management are integral to providing optimal care to the palliative patient in the acute care setting. However, in spite of the

high incidence of debilitating symptoms, most palliative patients will not undergo any form of systematic symptom assessment before they die (Nekolaichuk, 2000). Symptoms are neither well assessed, nor well managed (Nekolaichuk, 2000). Better symptom control could be achieved if symptoms were actively assessed (Schuit et al., 1998). Therefore, a formalized symptom assessment would provide a foundation for effective symptom management. Furthermore, when both the presenting symptoms and underlying cause are concurrently managed, patients are more likely to remain in treatment and benefit from the expertise of health care professionals (Buccheri & Underwood, 1993). The basic premise of this project was that the implementation and use of a clinical symptom assessment tool would aid in early symptom detection, more effective management, and ultimately, the amelioration of distressing symptoms. Ideally this would shorten patients' hospital stay and improve their quality of life.

#### *Purpose of the Practicum*

Symptoms and their associated distress are believed to alter the cancer experience and the individual's quality of life (Rhodes, Watson & Germino, 1987). Nursing care has been shown to positively influence morbidity and mortality rates (Aiken, Smith, & Lake, 1994), and symptom management is a key component of that care. Traditionally, nurses have concerned themselves with effective management of symptoms to maximize quality of life (Germino, 1987). However, cancer related symptoms in the terminally ill are not always well-managed, particularly when they are treated in acute care settings where staff are accustomed to addressing the needs of acutely ill medical and surgical patients.

The purpose of this clinical practicum project was to implement and evaluate the effectiveness of a symptom assessment tool for cancer patients, who had been admitted to an acute medical/surgical gynecology unit. This project emanated from the identification of gaps in symptom assessment in the acute care setting by clinical nursing experts. The project leader partnered with a clinical setting with the goal of initiating evidenced based change in practice. The overall goal of the project was that the systematic use of an assessment tool would facilitate the ability of clinicians to intervene as early as possible to treat distressing symptoms. While this was a pilot project, with implementation on a gynecology unit in a large, urban teaching hospital, the overall objective was that this master's project would lead to widespread use of the assessment tool throughout the hospital.

#### Project Significance

The importance of systematic, on-going nursing assessment of symptom experience is essential to improving symptom status, and ultimately patient outcomes. These outcomes include personal costs, functional and emotional status, quality of life, and health care utilization. It was believed that the evaluation of symptom experience would guide assessment techniques and interventions designed to lessen symptom occurrence and related distress. Symptom distress and the consequent influence on psychosocial well being have been shown to negatively affect survival (Degner & Sloan, 1995; Kaasa, Mastekassa & Lund, 1989). Furthermore, appropriate use of medications and non-pharmacologic techniques for symptom control may promote rather than impede

recovery (MacDonald 2002). Therefore, a concerted effort to assess and control patients' symptoms may improve quality of life, as well as quantity of life (Cleeland, 2000).

In addition to improving quality of life for patients, the use of a systematic assessment tool can facilitate quality assurance in an institution. On-going standardized assessment can also be linked to evidenced-based guidelines to promote optimal symptom management. Routine assessment and treatment documentation provide institutions with information upon which to establish care criteria, measure outcomes, monitor effectiveness, and valuable information for accountability, quality assurance, and accreditation standards (Bruera & MacDonald, 1993).

Other potential benefits of standardized assessment include: identification of patients at risk for high symptom distress, improved communication between health care providers and patients, and ongoing monitoring of patient responses to treatment. The implementation of a routine, standardized assessment can also provide the means to measure clinical effectiveness, demonstrate the impact of nursing and other services, and develop strategies to improve care (Bruera & MacDonald, 1993). Standardized assessment also has potential gain for nurses; when nurses fail to address symptom relief or patient comfort, they deprive themselves of the opportunity for positive feedback and increased job satisfaction. Furthermore, although cancer is rarely curable, nurses can almost always provide more effective care when the patients' symptoms have been accurately and specifically identified.

Lastly, delineating variables that affect the symptom experience can be targeted

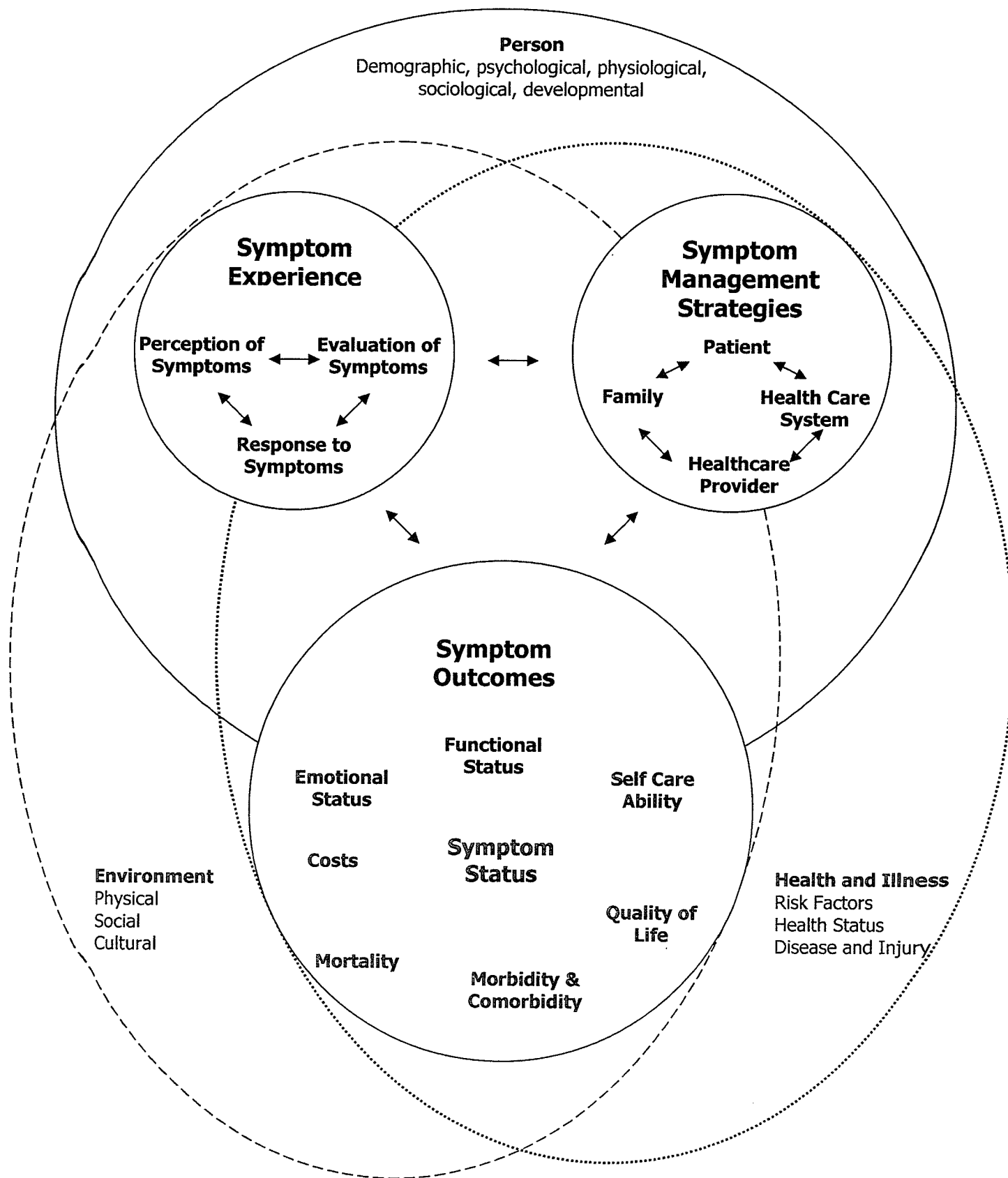
for further research in the clinical setting. An ongoing assessment system provides data to facilitate understanding of relationships between symptoms and patient contexts (Bruera & MacDonald, 1993). Thus, it was hypothesized that the appropriate use of a standardized assessment tool would serve as a first step toward improved recognition of symptom management for cancer patients in an acute care setting.

### Conceptual Framework

The use of a conceptual framework is essential to the development of knowledge because it presents an organized view of phenomena (Cooley, 2000). A conceptual framework provides the broader context within which investigational study is embedded. Larson et al., (1994) identified the need for a distinct framework to symptom management, and furthermore, that nurses should take the lead in articulating such a perspective because they are responsible for ensuring that patients' symptoms are effectively managed. Germino (1987) contended that the management of symptoms is within the nursing realm and an integral focus in oncology nursing. Likewise, it is well known that nurses spend more time with patients and families encountering advanced illness than any other health care professional, and they are intimately involved in all aspects of palliative care. Accordingly, Larson et al.'s Conceptual Model for Symptom Management (1994; see Figure 1: A Conceptual Model of Symptom Management) provided a framework for this clinical symptom assessment project. This framework was modified to conceptualize how the domains of nursing science affect all facets of the model (Dodd & Janson et al., 2001).

**Figure 1:**  
**Conceptual Model of Symptom Management**

(Dodd, et al., 2001; Larson et al., 1994)



*Overview of the Conceptual Model of Symptom Management*

The Conceptual Model of Symptom Management (herein referred to as the Model) proposes that symptoms are “subjective experiences reflecting changes in a person’s biopsychosocial function, sensation, or cognition” (Larson et al., 1994, p.273). Symptoms are an indication to an individual that some internal activity is different (Teel, Meek, McNamara, Watson, & Lareau, 1997). Within this model, the emphasis is on the patient’s subjective reporting, rather than objective signs, or what the health care provider sees. Therefore, the implementation of a systematic, patient-reporting symptom assessment tool is befitting within clinical practice, where symptom delineation is central to effective patient management.

Health care providers commonly view symptoms as objective, pathophysiologic phenomena that can be defined, treated, and controlled. However, in addition to the pathophysiologic component, symptoms can also have meanings and dimensions that extend beyond either a physical or psychological interpretation and can vary with the circumstance in which the symptom is experienced (Benner & Wrubel, 1989).

Understanding a person’s interpretation of a symptom is an important part of nursing care. For example, if a woman being treated for reproductive organ cancer has postoperative or radiation related pain and thinks that pain is an inevitable part of the cancer experience, she may be reluctant to report it to the nurse. Consequently, negative symptoms may be endured needlessly, or symptoms indicating progression of disease may be overlooked. Therefore, a formal inquiry about symptom patterns with a structured

assessment tool, which emphasizes the importance of this information and promotes patients' involvement in their care, could lead to more successful symptom management (Teel et al., 1997).

Inclusion of the patient's perspective of the symptom experience has been suggested as a necessary adjunct to the use of objective symptom assessment measures. This perspective is an essential component of the Model, with one's symptom experience viewed as an interaction of perception, evaluation, and response (Larson et al., 1994). Likewise, an assessment that focuses on the patient's perspective enables the patient to evaluate their own distressing symptoms and thereby has the potential to impart a heightened awareness and understanding of the meaning that symptoms may hold for them. It also provides a forum for the patient to express themselves, thereby giving the patient a "voice" and increasing their sense of control over the management of their symptoms. It has been well established in health care literature that the validation of feelings and the perception of control in a situation increase self esteem and decrease likelihood of depression and anxiety (Barder, Slimmer & LeSage, 1994).

#### *The Domains of Nursing Science*

Person, environment, and health/illness are the recognized domains of nursing science and are central to the Model as they are the contextual variables that influence the management and outcomes of the symptom experience. *Person* variables reflect demographic, psychological, physiological, psychological, and developmental factors (Dodd, Miaskowski, & Paul, 2001). Demographic variables are gender, ethnicity, marital

status, and financial status. Psychological variables include personality traits, cognitive capacity, and motivation. The sociological variables include the family unit, culture, and religion. Developmental variables include the level of maturation of an individual (Dodd, Janson et al., 2001).

*Environment* refers to the aggregate of physical, social, and cultural conditions or circumstances in which a symptom occurs (Dodd, Janson et al., 2001). The physical environment may encompass home, work, and hospital. The social environment includes one's social supports and interpersonal relationships. Cultural aspects of the environment are those beliefs, values, and practices that are unique to one's ethnic, racial, or religious community (Larson et al., 1994).

*Health and illness* refers to the unique health or illness state of the individual and includes risk factors, injuries, and disabilities (Dodd & Janson et al., 2001). Risk factors can encompass non-modifiable factors such as heredity, as well as modifiable or behavioural factors, such as a history of substance abuse.

The domains of person, environment, and health and illness are important to nursing because they are the metaparadigms that explain the profession of nursing. Accordingly, the three domains of nursing science affect and modify the three dimensions of the Symptom Management Model (Dodd, Janson et al., 2001), which will be discussed in the next section.

#### *Dimensions of the Conceptual Model of Symptom Management*

The Model of Symptom Management assists in the process of describing,

explaining, and predicting the phenomena of symptom experiences and rationalizes the implementation of a structured assessment tool within the clinical practice milieu. The Model has three interrelated tenets: the symptom experience, symptom management strategies, and symptom outcomes (see Figure 1 for Conceptual Model of Symptom Management). Each of these tenets will be discussed within the context of the current project.

### *Symptom experience*

Symptom experience is a dynamic interaction involving the patient's perception of a symptom, response to the symptom, and evaluation of the meaning of the symptom (Larson et al., 1994). Understanding the interaction of these components of the symptom experience is central to effective symptom management.

*Perception of symptoms.* Perception of symptoms refers to "whether an individual notices a change from the way he or she usually feels or behaves" (Larson et al., 1994, p.273). Perception and self report of symptoms are conscious and cognitive actions. The perceived components of the symptom experience include the symptoms' frequency, intensity, distress, and meaning (Armstrong, 2003). Symptom distress is the degree of physical or mental upset, anguish, or suffering experienced from a specific symptom (e.g., pain, nausea, or fatigue), and is relative to one's life situation (Rhodes & Watson, 1987). Therefore physical or mental anguish related to the symptom is dependent on the individual's subjective perceptions (McClement, Woodgate, & Degner, 1997). Each individual symptom, as well as the interaction of multiple symptoms, has the ability to

affect patients' perception of their situation (Armstrong, 2003).

As previously discussed, person, environment, and health and illness variables influence the perception and expression of symptoms and provide a unique context for each patient. These variables are intrinsic and critical to the subjective view of a symptom (Larson et al., 1994). For example, a person's ability to perceive the degree of physical and mental distress is thought to be influenced by demographic, sociological, and developmental variables in the person domain. These include age, socioeconomic levels, culture, family role, education, health knowledge, values, and past experiences (Rhodes & McDaniel, 1999; Rhodes & Watson, 1987). Bruera (1996) also identified variables from the person and environment domains as having a strong influence on the perception of symptoms; specifically, the patient's belief system, feelings (i.e., mood), cultural orientation, cognitive state, or life experience. The social environment such as the patient's relationships with family and professional care givers have notable effects on symptom perception and are especially relevant to the dynamics of being cared for in an acute care setting.

The impact of the developmental variable within the person domain on symptom perception was relative to this clinical project. For example, gynecological cancers tend to occur most often in middle aged or older women; therefore the symptom perception of women who are admitted to hospital and are experiencing symptoms from their cancer may be compounded by troublesome menopausal symptoms, either related to the aging process or a premature menopause that has occurred as a consequence of their cancer

treatment.

The variables included in the health and illness domain also have direct and indirect effects on symptom experience, management, and outcomes. For example, the type and extent of cancer will directly impact the perception of symptoms. Also, the intensity of morbidity that arise from cancer treatment or a combination of surgery, high dose chemotherapy and/or high dose radiation will affect the symptom experience. Thus, in conclusion, symptom perception is clearly a subjective process that is modified by a myriad of variables and therefore, perceptions of symptoms are unique to the individual.

*Evaluation of symptoms.* According to Larson et al. (1994), “evaluation of symptoms reflects a complex set of factors that characterize the symptom experience, including its intensity, location, temporal nature, frequency, and the associated pattern of disability” (p. 274). Evaluation of symptoms refers to the judgements people make about their symptoms such as severity, cause, appropriateness for treatment, and the effects of symptoms on their lives (Dodd, Janson et al., 2001; Larson et al., 1994). Evaluation also includes analysis of the threat posed by a symptom, such as whether or not it is dangerous or has a disabling effect (Larson et al., 1994). Past experience, knowledge, and coping mechanisms are likely to have an impact on these judgements. For example, an individual with long-term experience with a symptom may learn to catalogue various, discrete and subtle sensations associated with the symptom. Consequently, the individual’s description of the symptom’s quality may become fuller and richer than that of the same symptom experienced by a “naive” individual (Dodd, Janson et al., 2001; Lenz et al., 1997).

An issue related to symptom experience is the difficulty separating patient's perceptions of symptoms from evaluations of symptoms. Dodd, Janson et al., (2001) suggest that one way of viewing the difference between perception and evaluation is that evaluation is a "higher order" phenomenon: a person can perceive nausea by recognizing the sensations, whereas an evaluation involves a higher cognitive process of attaching meaning to the symptom.

*Response to symptoms.* Responses to symptoms include feelings, thoughts, or behaviors that are secondary to actual or potential health problems (Larson et al., 1994). Such responses to symptoms can be physiological, such as respiratory rate changes, or psychological, such as mood changes or decreased ability to concentrate. Behaviourial responses are objective expressions of symptom(s); an example may be crying or social withdrawal. Patients can also have sociocultural appropriate responses to their symptoms (Dodd & Janson et al., 2001), such as being stoic or aggrandizing of a symptom. While historically, symptom management interventions have been guided by patient responses to symptoms, such as wincing in response to pain or social withdrawal in response to depression, in this project, the focus was on the patients' perceptions and evaluations of symptoms.

In summary, this project was guided by the contention that the perception of the symptom experience by the individual should guide symptom management. Various factors within the person, environment, and health and illness domains impact on this perception. Symptom evaluation is also very individual as it, too, is influenced by factors

unique to each individual. The third component of the symptom experience, symptom response, is both an objective and subjective phenomenon. Because the symptom experience is so individual, it is essential for health care providers to address patients' unique perceptual experience. A structured assessment tool facilitates the articulation of the patients' subjective experiences of symptoms, and can be used to guide nursing to focus on variables that influence the symptom experience. A comprehensive understanding of the concept of the symptom experience will guide assessment techniques and promote effective symptom management.

#### *Symptom management*

The goal of nursing practice and the goal of symptom management in this model are one and the same: to avert or delay a negative outcome through medical, nursing, allied-health, and self-care strategies (Larson et al., 1994). According to Larson et al. (1994), "a basic assumption in the model is that all troublesome symptoms are in need of management, and symptom management should influence or control the symptom experience, not just symptom outcomes (p.274.). Symptom management begins with assessment of the symptom experience from the patient's perspective, and is followed by identification of interventions and evaluation of outcomes (Larson et al., 1994). Symptom management is a dynamic process that requires changes in strategies over time, in accordance with the patient's acceptance of a strategy (Larson et al., 1994). As conceptualized within the Model (see Figure 1: Conceptual Model), successful symptom management also includes a patient-family-clinician-health care partnership since any of

these elements could act as barriers to the management of symptoms. Larson et al. (1994) contends that the work of the health care provider should complement the efforts of the patient and family in preventing or managing a symptom.

Weisman and Worden (1976) underscored the importance of comprehensive symptom management of cancer patients. In their classic study, they examined psychosocial responses to the diagnosis of cancer; the number of physical symptoms was highly correlated with level of emotional distress (Weisman & Worden, 1976). Implicitly, the relief of a symptom is valued because of its associated benefit to patient function and well-being. Quality of life is understood to be both subjective and multidimensional (Cella, 1994). Because it is subjective, it is best measured from the patient's perspective; because it is multidimensional, its appraisal requires the nurse to contemplate various areas in the patient's life, including physical, functional ability, and emotional and social well-being. As alleviation of specific symptoms becomes the focus, health care providers must continue to evaluate the relationship between symptom intensity, symptom duration, and overall quality of life.

In current health care practice, many symptoms are treated by prescribing medications. While this is often effective in controlling or decreasing a symptom, such interventions may also give rise to additional symptoms. For example, patients who experience pain may be given opioids for pain control, but then may experience significant sedation, nausea, and constipation related to the opioid administration. Therefore, ongoing and simultaneous symptom assessment and management is essential

for nursing to effectively avert distressing symptoms. Congruent with the aim of the project and a key premise of the Model, reliable assessment is the first step toward effective symptom management.

### *Symptom outcomes*

Within the third dimension of the Model, Larson and colleagues (1994) conceptualized that symptom outcomes are associated with the symptom experience (see Figure 1: Conceptual Model of Symptom Management). Symptom status is central, with the other indicators relating to each other, as well as to symptom status. According to the Model, symptom status may affect one's functional or emotional state and self-care ability, and consequently, morbidity and/or mortality. Symptoms will also have an effect on one's personal costs, such as expensive medications to treat symptoms, missed work, missed professional opportunities for advancement, or comparable costs within the individual's personal life (Dodd & Janson et al., 2001). Ultimately, the symptom experience may have a significant effect on overall quality of life for the patient and their family. From a broader perspective within the Canadian socialized health care system, the symptom experience can also impact on society at large through increased health care utilization, disability, and missed time from work.

### Summary

The Conceptual Model of Symptom Management serves as an appropriate framework for understanding symptoms, designing management strategies, and evaluating outcomes. This clinical project was included in the first step of this process:

the assessment of symptoms. It is believed that initial assessment is necessary for symptom meaning and effective management to occur. Within the Model, symptom palliation is conceptualized as directly linked to the identification of symptoms through ongoing standardized assessment. Theoretically, as a result of this assessment, nurses will have an increased awareness, will make more informed and accurate problem identification, and will be able to target interventions to increase symptom relief and improve quality of life. In and of itself, accurate problem identification may have a therapeutic quality by validating the patient's symptom experience and providing hope for relief (Sarna, 1998). Thus, this model provided a sound framework for the implementation of a systematic symptom assessment tool, and established a broader context for this practicum project.

## CHAPTER II

### Literature Review

An understanding of the symptoms related to cancer in patients who are hospitalized in the acute care setting is an important foundation for nursing interventions. However, the process of implementing a symptom assessment tool and the subsequent impact of symptom identification on patient outcomes has not been well explored. Computer searches of the literature were performed using MEDLINE and CINAHL. Articles were searched using the keywords: symptom assessment, symptom identification, symptom distress, symptom experience, cancer, symptom measurement, Edmonton Symptom Assessment Scale, and ESAS. A manual search of the citations in the reference lists of all relevant articles was also completed.

This review of the current literature was driven by the Conceptual Model for Symptom Management (Larson et al., 1994) and therefore, was organized within the three headings of symptom experience, symptom management, and symptom outcomes. Because of its specific relevance to the current project, this review focused primarily on the symptom experience literature. However, an overview of other two dimensions of the model was central to the understanding of symptom management overall.

#### Symptom Experience

Symptoms are of vital importance in patient care and were the central focus of this project. In order to assess and target interventions to an individual's symptom experience, the term itself must be explored. Symptom experience is a multidimensional, dynamic

process of deriving meaning from a subjective, unusual sensation; in other words, it is a synthesis of symptom occurrence and perceptions of intensity and distress (McClement et al., 1997). As theorized in the Model, symptoms are perceived and evaluated. Symptoms are also affected by numerous variables. This section will present the literature related to symptom perception, including influencing variables, followed by a review of current literature on symptom evaluation.

### *Perception of symptoms*

Perception of symptoms and the consequent distress are influenced by person, environment, and health and illness variables; description of the literature will be discussed under these headings in turn.

*Person domain.* Specific to the person domain, the research literature is replete with studies that support a relationship between the age of the patient, and the type of symptom and degree of symptom (Cimprich, 1999; Collins, et al., 2000; DeMaria & Cohen, 1987; Degner, Hack, O'Neil, & Kristjanson, 2003; Degner & Sloan, 1995; Krech, Davis, Walsh, & Curtis, 1992; Morita, Tsunoda, Inoue, & Chihara, 1999; McMillan, 1989; Walsh, Donnelly, & Rybicki, 2000). For example, Krech, et al., (1992) noted that men with lung cancer who were older than 64 years had higher incidences of cough and greater than 10% weight loss, whereas men less than 64 years had higher incidences of fatigue, taste changes, and sleep problems. McMillan (1989) reported that older adults with cancer reported lower intensity of pain, nausea, and vomiting than their younger counterparts. Similarly, Morita et al., (1999), found that cancer patients who were young

in age, (defined as <75 years), were more likely to experience xerostomia, abdominal swelling, and pain. Donnelly and Walsh (1995), identified younger age as a risk factor for nausea.

Age has also been reported to influence symptom distress. Degner and Sloan (1995) conducted a study using a consecutive sample of 434 newly diagnosed ambulatory cancer patients with various types of malignancies. Participants completed the Symptom Distress Scale developed by McCorkle and Young (1978). Data from this study indicated that older patients had less symptom distress than younger patients. However, it should be noted that the statistically significant correlation in this large sample may have been due to the fact that most patients were older, and that most patients had overall low levels of distress.

In a cross-sectional survey that examined ascribed meaning of the breast cancer experience of 1012 Canadian women, Degner et al., (2003) found that women younger than 50 years were more likely to view their illness with a negative meaning than older women. Women who attached a negative meaning to their illness had significantly more depression and anxiety, and reported poorer levels of functioning and quality of life, than women who reported less negative meanings to their cancer.

In order to validate the Illness Distress Scale, Noyes et al., (1990) administered this scale to 405 outpatients with various types of solid tumors. Similar to the results in Degner et al., (2003), their findings indicated that patients who were younger than 59 years of age had statistically significant higher symptom distress scores than those who

were older than 60 years. These findings are consistent with other study findings, suggesting that increasing age is associated with less perceived symptom distress (Hwang et al., 2004; Sarna et al., 2005; Tilden, Tolle, Drach, & Perrin, 2004). Noyes et al., (1990) suggest that malignancy may have a more devastating impact on the younger age group. Greater distress was also reported by those who were unmarried and by patients with more advanced disease, further supporting the role that health and illness, as well as social environment variables can play in the evaluation of symptoms.

Cimprich (1999) conducted a study using a convenience sample of 74 women, newly diagnosed with breast cancer, from two comprehensive ambulatory cancer centers. Participants also completed the Symptom Distress Scale (McCorkle & Young, 1978). Although findings may be limited by the nature of the convenience sample, women younger than 55 years reported significantly greater overall symptom distress than older women. The younger age group also reported having significantly more symptoms than the older group. This is especially interesting as the majority (73%) of women in the older age group reported having one or more co-morbid conditions, whereas only 16% of the younger women reported any other medical problem.

There likely is not a single explanation to account for the relationship between younger adult age and increased symptom distress. In the Degner et al. study, the authors hypothesized that it may be that older women have encountered more serious illnesses before, either personally or through close family or friends, and therefore they have better coping mechanisms. Also, they identify the possibility that previous life experience is

important in helping women cope with symptoms and constructing a positive meaning to a life threatening illness; something that is not as easy for younger women with less life experiences (Degner et al., 2003). Other authors' provide possible rationale for the relationship between age and symptoms symptom experience; Mor, Allen, and Malin (1994), for example, contend that older patients have fewer competing demands on their time and resources than younger patients. This, along with different expectations, may mitigate the negative impact of psychosocial consequences of cancer and its treatment. As well, Weisman and Worden (1976) theorized that greater symptom distress may be related to existential concerns that arise from serious illness and may be greater in young persons because of the threat to life plans and responsibilities, such as those that accompany having a young family. Overall, this information suggests that malignancy and its related symptoms may have a more devastating impact on the younger age group.

In the research literature, income has been consistently found to be inversely related to symptom experience. In a study using the Symptom Distress Scale (McCorkle & Young, 1978) to explore the American experience of 69 women living with lung cancer, Sarna (1993a) found that low income was associated with a high level of symptom distress. In a more recent randomized study of 48 newly diagnosed lung cancer patients treated in outpatient oncology clinics, Sarna (1998) administered the Symptom Distress Scale every month for six months, and again identified that over time, symptom distress was related significantly to income. Additional research findings support the hypothesis that limited financial resources are a negative influence on symptom

experience in the cancer patient population (Kornblith et al., 1995; O'Hare, Malone, Lusk, McCorkle, 1993; O'Neill & Morrow, 2001).

It has been suggested that lower socioeconomic status is a proxy variable for less education and ignorance related to cancer symptoms, resulting in delayed symptom management (Sarna & McCorkle, 1996). It has also been suggested that uninsured adults are more likely to report that they could not see a physician when needed due to cost, especially among those in poor or fair health, further contributing to increased symptom distress and decreased survival in economically disadvantaged groups (Hwang et al., 2004; Leydon, Bynoe-Sutherland, & Coleman, 2003). The Rand Health Insurance Experiment (Manning et al., 1987) and the Beck and Horne study (1980) confirmed that it is the poor who use less medical care when forced to pay, which unfortunately results in sicker patients and more visits to the hospital emergency departments (Tamblyn, 2001). There is generally a consensus that poverty is the single largest determinant of health; overall morbidity and mortality are higher in the lower social hierarchy (World Health Organization [WHO], 2005). The social gradient in health reflects material disadvantage and the effects of insecurity, anxiety, and lack of social integration (WHO, 2005), thus supporting the premise of lower socioeconomic status and symptom experience. No studies could be located that specifically examined income and symptom experience in individuals who rely on different health care systems, such as the public health care system in Canada versus the privatized two-tiered system that is accessible in the United States.

Historically, minority ethnic groups have been over represented in lower socioeconomic groups. Interrelationships among poverty, race, and cancer have been discussed in the literature (Baquet et al., 1991; Ward, Jemal et al., 2004). As well, a number of published studies have explored the effects of ethnicity on the symptom experience. Koffman, Higginson, and Donaldson (2003) conducted a survey in the UK to compare the last year of life of first generation black Caribbeans (n=50) and white patients with advanced disease (n=50). The symptom profiles for these two groups were similar; however, symptom-related distress was higher for the black Caribbean patients than the white patients. Of the seventeen various symptoms examined, all but three were reported more frequently as having been “very distressing” in the black Caribbean patients. Although this study did not adjust for income, the authors concluded that ethnic origin had a bearing on the distress caused by cancer symptoms in the sample population.

In a descriptive study, O’Hare et al. (1993), administered the Symptom Distress Scale to 63, post-discharged, black patients with cancer. They too, found that there were high levels of symptom distress within their study population. In addition, the study also indicated that variables, such as being female, elderly, alone, and poor were more likely to result in patients’ having unmet needs. Bates and Edwards (1992), examined ethnicity and the symptom experience in 372 chronic pain patients from six ethnic groups. They reported that ethnic identity has an important influence on the pain experience and related this finding to the different locus of control and coping styles within different ethnic populations. Although no single explanation can account for these differences in

symptom experience, consideration of cultural variations in how symptoms are interpreted by patients and their families needs to be considered. In his seminal study, Zborowski (1952) for example, demonstrated differences among American, Irish, and other migrant communities' perceptions and illness behaviors surrounding pain. More recent research conducted among cancer patients from diverse populations yielded similar findings (Juarez, Ferrell, & Borneman, 2001). This data upholds the need for a patient-centered, structured, symptom assessment in acute care environments, to ensure that symptom perception among individuals across different ages, socioeconomic status, and ethnic backgrounds are accurately relayed to health care providers for the purpose of optimal symptom management.

Several studies have examined the influence of gender on symptom experience. Although not conclusive, it has been frequently reported in health care literature that women with cancer perceive more symptom distress than men (Degner & Sloan, 1995; Hopwood & Stevens, 1995; O'Hare et al., 1993; Tishelman, Taube, & Sachs, 1991). For example, Tishelman and associates (1991) conducted an explorative study within a community setting, to examine symptom distress in a heterogenous group of cancer patients (N=46). The authors found that symptom distress was significantly higher in women, unmarried, and younger persons. Although the small sample size is limiting, this study, along with others reporting similar findings, adds insight into the relationship between symptom distress and gender, age, and marital status.

*Environment domain.* The environment domain includes the variables of social

support and interpersonal relationships. As previously discussed, marital status has been found to have a positive influence on the symptom experience (Tishelman, et al., 1991). Noyes et al. (1990), also observed that symptoms were more disturbing to those who faced illness without a spouse. Similarly, Weisman and Worden (1976) found an increase in emotional distress among widowed and divorced cancer patients than married patients, soon after diagnosis. Lack of social support may have contributed to the distress experienced by these patients.

While social support from family and friends has been extensively studied as a protective buffer in the symptom experience (Bloom, Kang, & Romano, 1991; Ganz et al., 1993; O'Neill & Morrow, 2001), Kornblith et al., (1995) noted that the emotionally supportive role of the health care team to a patient's adjustment to illness is often overlooked by researchers. McCorkle and associates (1989), conducted a clinical trial assessing the effects of home nursing care versus office care for patients (N=166) with progressive lung cancer. Results revealed that the patients who received home nursing care experienced less physical and emotional symptoms than those who did not receive this service.

Similarly, Benor, Delbar, and Krulik (1997) conducted a quasi-experiential study of 94 ambulatory cancer patients. The intervention group (n=48) received 10 home nursing visits over three months, whereas the control group received usual clinic follow up. The findings of this study indicated that while the intensity of the complaints decreased in the experimental group during the three month period, they increased in the

matched control group, creating a considerable difference between the two groups on a multivariate analysis of covariance. Overall, the investigators reported a significant decrease in the amount of distress and suffering of cancer patients observed in the home nursing visit intervention group. As well, the investigators reported an increase in the ability of the experimental patients to assume responsibility for their own care, which may also suggest that an increased locus of control is inversely related to the perception of symptom distress. The findings of these studies suggest that the symptom experience may be influenced by the types of care providers or within types of settings.

Also within the environment domain, is the variable of health care setting. As cancer is primarily treated on an outpatient basis, the majority of studies drawn from the cancer population are from ambulatory or palliative care settings. Few studies could be found that examined the symptom experience in cancer patients within an acute care setting. Collins et al. (2002), conducted a validity study of a revised Memorial Symptom Assessment scale (Portenoy, Thaler et al., 1994) for children with cancer. Data were collected from two sample populations: an inpatient cohort in the United Kingdom (n=90) and an outpatient cohort in Australia (n=59). Although limitations of this study include the young age of the participants, unequal group sizes, and the comparison of two different cultures, the inpatient group experienced significantly more symptoms than the outpatient group. Similar findings were reported by Kornblith et al. (1995). In a study of women with (N=151) with ovarian cancer in an inpatient hospital versus ambulatory care clinic at the same cancer center, findings indicated that patients who were in high

symptom distress were significantly more likely to be from the inpatient group than the outpatient group.

Sahlberg-Blom, Terbestedt, and Johansson (2001) explored how a group (N=47) of terminally ill cancer patients rated their quality of life during the last month of their lives within an acute care versus a hospice setting. The researchers reported that there was a tendency for the patients cared for in the acute care setting to report more symptoms than those in the hospice setting. One exception was the symptom of "pain," which was reported more often by those in the hospice setting. Overall, the findings of these studies comparing patients in acute care versus hospice care have all reported that the symptom experience appears to be exacerbated in those who have been admitted to an acute care setting. Although the number of studies comparing the symptom experience in these two settings are few, it is of interest to discuss the rationale for these findings. One possible interpretation could be that the palliative units, where care is based on hospice philosophy, may have provided better symptom control. The fact that patients in the hospice setting reported "pain" to a greater extent than those in the cure-oriented setting speaks against this hypothesis (Sahlberg-Blom, Terbestedt, & Johansson, 2001). An alternative interpretation could be that those cared for in the acute care setting were actually sicker and had more symptoms, and/or that those with more severe symptoms were more likely to have been admitted to acute care. This explanation could also apply to the Collins et al. (2000) and Kornblith et al. (1995) studies between inpatients and outpatients, as it is common practice in health care today that only the high risk or

seriously ill individuals are admitted to acute care settings; others would be managed in community or if appropriate, hospice settings.

*Health and illness domain.* Health and illness factors also affect the symptom experience. Many studies have identified advanced cancer as a significant factor on symptom experience and the perception of symptom distress. For example, in a large (N=434) ambulatory, heterogenous, cancer population, Degner and Sloan (1995) reported patients with advanced disease recounted more symptom distress than those with early disease. Likewise, Kornblith et al. (1995) found that women (N=151) with ovarian cancer who had advanced disease were more likely to have high symptom distress. As previously noted, Noyes et al. (1990) also reported similar findings in heterogenous cancer patients (N=438), between increased symptom distress and advanced disease.

Conversely, Kurtz et al. (2000), found no significant differences in perception of symptom severity according to stage of disease in their study of 129 geriatric patients with lung cancer. The authors attributed this finding to the fact that older adults tend to have more co-morbid conditions and thus have more experience with illness. This is also consistent with Noyes and colleagues (1990), who also found that, in spite of older patients having more advanced disease, younger patients continued to experience greater symptom distress. This interpretation may correspond with the speculations previously discussed with regard to advanced age and improved coping patterns.

Type of illness has been consistently cited as an important influence on the symptom experience. In a study comparing symptom distress between 56 lung cancer

patients and 65 myocardial infarct patients, McCorkle and Quint-Benoliel, (1983) found that the lung cancer patients had significantly more symptom distress than the patients with myocardial infarction, which is considered to be a comparable disease with regard to survival. With respect to tumor site in cancer patients, Collins et al. (2000), found that patients with solid tumors had significantly more symptoms than patients with leukemia, lymphoma, or central nervous system malignancies. In the American study by O'Hare and associates (1993), patients with gynecological cancers and breast cancers reported the highest levels of symptom distress compared to patients with other solid malignancies, although this may be attributed to the fact that they were women and that overall, women may be more likely to have higher levels of symptom distress.

Degner and Sloan (1995), found that people with lung cancer had more symptom distress than individuals with other cancers. Similarly, Kukull, McCorkle, and Driever (1986) reported that individuals with lung cancer and associated symptoms may have more profound functional and emotional problems than those with other cancers. Noyes and colleagues (1990) found lung cancer patients to report the highest overall level of distress than patients with other primary tumor sites, reinforcing the notion that disease type does affect the symptom experience. Overall, it would appear that patients with cancer, especially solid tumors such as lung or gynecological cancers, are at high risk for symptom distress.

Published works have also supported the influence of co-morbid medical and clinical factors as negatively impacting the experience of symptoms (Collins et al., 2002;

Leidy, 1990; Pugh & Milligan, 1995; Sarna, 1998). Other studies have indicated that patients with high symptom distress also had significantly greater physical symptoms, and worse physical functioning and current well-being than those experiencing lesser symptom distress (Cimprich 1999; Collins et al., 2000; Kornblith et al., 1995; Kurtz et al., 2000; Noyes et al., 1990). Symptom distress also appears higher among people who are undergoing antineoplastic treatment (Collins et al., 2000). Surgery, chemotherapy, and radiation therapy can each have unique symptom sequelae that must be recognized and treated appropriately (Cooley, Short, & Moriarty, 2003).

Research has shown that cancer causes emotional distress, particularly in those who are physically compromised (Holland, 1989). As well, there appears to be a tendency for patients who experience psychosocial distress to consistently rate many of their physical symptoms at a high level, which lends support for psychosocial distress as an influencing factor in symptom experience (Bruera & Pereira, 1998; McDonald et al., 1999). Recognition of these factors through systematic assessment allows clinicians to be pro-active and to focus on psychosocial influences as well as addressing physical symptoms.

Occurrence of symptoms is a component of symptom perception, and therefore the incidence of the various kinds of symptoms associated with cancer requires exploration. Jenkins, Schulz, Hanson, and Bruera (2000) found that pain, anxiety, and poor appetite were most problematic in advanced cancer patients; Rees, Hardy, Ling, Broadley, and A'Hern (1998) reported that drowsiness, lack of activity, and appetite were

the untenable issues. Coyle, Adelhardt, Foley, and Portenoy (1990), found that fatigue, weakness, pain, sleepiness, and cognitive impairment were frequent symptoms of terminal patients, with fatigue and pain being most common. Strömngren, Groenvold, Pedersen, Olsen, and Sjogren (2002) reported pain, fatigue, and anorexia to be the most prevalent. Portenoy, Thaler, et al., (1994) found the most frequent reported symptoms were lack of energy, worry, feeling sad, and pain. Regardless of the study, symptoms of fatigue, pain, anxiety, and appetite loss appear to be the most common among the cancer population.

In a large (N = 1840), international study of heterogeneous, advanced cancer patients, Vainio and Auvinen (1996), found that over half of the participants reported weight loss, anorexia, constipation, nausea, and dyspnea as their most common symptoms. The prevalence of pain was 51%, ranging from 43% in stomach cancer to 80% in gynecological cancer. Nausea was prevalent in gynecological (42%) and stomach (36%) cancers, and dyspnea (46%) in lung cancer. There were statistically significant differences in the prevalence of most symptoms, based on the primary site of the cancer.

Female gynecological cancers have been called “silent diseases” because symptoms are often not present in early stages (Clement & Connor, 1998). Research substantiates that women diagnosed with reproductive cancer experience a wide range of physical symptoms, with over half experiencing anxiety and depression following diagnosis (Kornblith, et al., 1995). In advanced stages, tumor growth and ascites produce the typical clinical picture of abdominal distention and pain. The interference of pain with

patient's daily functioning has also been frequently reported within this cohort (Doyle, Crump, Pintile, & Oza, 2001; Ferrell, Smith, Culliane, & Melancon, 2003; Guidozi, 1993; Kornblith et al., 1995; Portenoy, Kornblith et al., 1994).

Given the high prevalence of physical suffering and psychological distress in women with a reproductive organ cancer, it is likely that they would benefit from close, systematically scheduled monitoring, to identify significant symptoms (Kornblith et al., 1995). The goal of palliative treatment in persons with cancer includes symptom relief and maintaining quality of life (Sarna, 1998). To this end, expedient and accurate assessment and management of physical and psychological distress is one of the main components of palliative care (Barg et al., 1994; Cleeland, 2000).

Overall, the research findings indicate that symptom perception is influenced by numerous variables from the person, environment, and health and illness domains, and thus it is unique to each individual. Awareness of potential influencing factors may assist health care providers to identify patients at risk for developing severe symptom distress, and perhaps to intervene to modify the distress. Given the prevalence of symptom distress among those with cancer, it is likely that patients would benefit from systematically scheduled assessment to identify those with significant problems. Moreover, because symptoms are dynamic, ongoing monitoring must be continued throughout the course of the cancer trajectory.

#### *Evaluation of symptoms*

Giardino and Wolf (1993) found that the patient's perception of symptoms and

desire for treatment may contrast with nurses' objective determinations of the presence and distress of symptoms. The authors further suggest that the use of an assessment tool is necessary in determining the nature of symptoms, but also warn that they do not measure the uniqueness of individual person. Continual assessment of patients' symptom experiences is essential and permits the nurse to adapt care to meet patient needs accordingly. This next section will discuss symptom measurement scales as a means to evaluate the symptom experience.

#### *Symptom Measurement Scales*

Symptom measurement scales are the core of adequate symptom assessment (Cleeland, Janjan, Scott, Seiferheld, & Curran, 2000). They provide the basis for detecting symptoms, evaluating their severity, exploring distress, and assessing the effectiveness of treatment. However, the practical use of assessment tools for symptom assessment in clinical settings, where frequent and reliable assessments are needed, have not been well published. Kravitz, Delafield, Hays, Drazin, and Conolly (1996) suggest that symptom assessment could be improved through the use of specific tools by health care professionals.

Abrahm (1998) states that the use of standard, validated assessment tools for pain and other symptoms needs to be adopted by health care professionals by being incorporated into routine monitoring and documentation. Communicating assessment information to all staff responsible for the care of patients is essential for effective symptom management (White, 1999). Donnelly and Walsh (1995) recommended that for

advanced cancer patients, symptom assessment and subsequent management should be the focus of attention to improve quality of life. McCorkle (1987) argued that the measurement of symptoms is essential to assess patients' needs, and to tailor effective nursing interventions in relation to symptom management. The use of simple measurement scales greatly improves the symptom assessment process, helps direct treatment choices, and provides information about the effectiveness of treatment (Cleeland, 2000).

There are a variety of assessment scales that measure the presence and intensity of specific symptoms, such as depression and anxiety (Passik & Breitbart, 1996; Zigmond & Snaith, 1983); nausea and vomiting (Morrow, 1992); fatigue (Mendoza et al., 1999) and pain (Bruera, MacMillan, Hanson, & MacDonald, 1989; Cleeland & Ryan, 1994; Melzack, 1987). However, symptoms seldom occur in isolation. Most patients with cancer who have advanced disease or are receiving treatment experience multiple symptoms. Published studies have indicated that patients with solid tumors reported an average of 11 to 13 symptoms that occurred concurrently (Chang, Hwang, Fuereman, & Kasimis, 2000; Morita, et al., 1999; Lobchuk & Degner, 2002; Portenoy, Thaler et al., 1994). Moreover, according to Lenz, et al. (1997), the occurrence of multiple symptoms is likely to result in an experience that is multiplicative rather than additive. Other researchers have reported similar findings (Graydon, Ross, & Webster, 1995; Tishelman et al., 1991). Therefore, an assessment tool that determines the presence and severity of multiple symptoms is central to effective symptom management in the cancer population.

A review of the current literature did not yield any articles that examined the regular use of a multiple symptom assessment tool with cancer patients in an acute care setting. A study by Trowbridge et al. (1997), found that the regular use of a standardized pain assessment tool led to improved pain management of cancer patients (N=510) in the outpatient setting. Likewise, Fortner, et al., (2003) wanted to improve the lives of outpatients with cancer pain by utilizing a pain assessment tool. Using various measures of satisfaction, quality of life, and costs to evaluate the project, findings showed that severity of pain was decreased, as was interference of pain on daily living. Patients also had improved satisfaction with pain treatment and with attitudes about opioid addictions. Direct medical costs consisting of pain related hospitalizations, emergency room visits, and physician office visits were greatly reduced. If these findings on pain assessment could be generalized to symptom assessment in an inpatient cancer population, the potential outcomes could be significant for the patient, as well as the health care system.

A number of instruments to specifically detect symptoms in cancer populations have been recently developed, but are primarily used as modules within quality of life instruments (Portenoy, Thaler et al., 1994; Sarna, 1998). Available quality of life instruments are often too extensive and abstract for seriously ill patients to complete on a regular basis. Jordhoy et al. (1999), found that compliance in completing multi-item questionnaires is effective up to one month before death, but in order to evaluate the final weeks of life they recommend the use of simpler methods. Hearn and Higginson (1997) reviewed measurement tools that examined outcomes in palliative care of people with

advanced cancer. The criteria for inclusion were measures that assessed more than one domain in a target population of patients with advanced disease. Forty-one measures were identified, twelve instruments met the criteria of the review; they contained between five and 56 items and encompassed physical, psychological, social, and spiritual domains. Each instrument met some, but not all of the objectives of measurement in palliative care and fulfilled some, but not all, of their criteria for validity, reliability, responsiveness, and appropriateness. Overall, measures vary by instrument, and most tools have been developed to detect symptoms within the context of clinical trials, such as epidemiological studies (Portenoy, Kornblith et al., 1994), in predicting survival (Chang, Thaler et al., 1998; Kukull et al., 1986), and aiding clinical care (Jenkins, Taube, Turner, Hanson, & Bruera, 1998).

### *Tool Selection*

Health care literature is replete with different symptom assessment scales for the purpose of cancer and quality of life research. Some instruments are comprehensive but very lengthy and/or require training prior to implementation, while others are simple and suitable for repeated use. A brief overview of four symptom scales that are used frequently in cancer research follows.

*Symptom Distress Scale (SDS)*. One of the most frequently used measures of multiple symptoms is McCorkle and Young's Symptom Distress Scale (1978). This scale asks patients to rate the symptom distress associated with the following ten symptoms: nausea, mood, appetite, insomnia, pain, mobility, fatigue, bowel pattern, concentration,

and appearance. A total distress score can be obtained by adding the numerical score of all ten items. This Likert scale is short enough for seriously ill patients to complete, but it may not include symptoms important for the care of some patients.

*The Memorial Symptom Assessment Scale (MSAS).* The MSAS (Portenoy, Thaler et al., 1994) evaluates 32 physical and psychological symptoms, asking patients to measure the presence, severity, frequency and distress of each symptom during the past week. A factor analysis yielded two factors that distinguished three major symptoms groups and several sub groups. The major groups were psychological symptoms, for example, worrying, feeling sad, and feeling nervous; high prevalence symptoms, such as lack of energy, pain, and feeling drowsy; and low prevalence symptoms such as numbness/tingling in hands and feet, cough, and "I do not look like myself." The MSAS is a multidimensional tool that has been used as a measure of symptom distress in clinical trials and in epidemiological studies. However, its length and multiple ratings for each symptom make it less practical as a clinical assessment measure in the acute care setting.

*The Rotterdam Symptom Checklist (RSC).* The RSC is a 31 item scale, developed by de Haes, Van Knippenberg, and Neijt (1990), designed to measure the symptoms of cancer patients who participate in clinical research. Patients are asked to rate the extent to which a particular symptom bothered them during either the past three days or the past week on a four-point Likert scale. Examples of symptoms on the checklists are: lack of appetite, irritability, tiredness, depressed mood, and nausea. An advantage of this scale is that it can be adapted for use with various patient groups by adding or deleting specific

items. The major disadvantages of this tool include its length and its use of rating system based on verbal descriptors that may be difficult for some patients to understand.

*The Edmonton Symptom Assessment Scale (ESAS; See Appendix A).* The ESAS was originally developed as a visual analogue scale (VAS) by Bruera, Kuehn, Miller, Selmsler, and MacMillan (1991), but has since evolved to a numerical rating scale from 0 to 10. It measures the current level of nine symptoms common to cancer patients: shortness of breath, pain, activity, nausea, depression, anxiety, drowsiness, appetite, and sensation of well-being (Bruera & Pereira, 1998). A general distress score can be obtained by totaling the scores of all nine scales. The score for each item is recorded on a graph (See Appendix B; ESAS Graph), allowing staff to visualize patterns of symptom experience over time. This tool can be completed by the patient, or by the patient's nurse or family member, if self report is not feasible.

Ideally, a symptom assessment tool for patients with cancer should include symptoms that occur frequently and are distressing for patients. Because patients tend to under-report symptoms (Cleeland, 2000), the presence of multiple, severe symptoms may not be identified unless patients are systematically assessed. An effective symptom measure also should include symptoms that patients may be reluctant to report, such as pain and psychological distress. As well, a good symptom measure must be short to avoid added burden on the already compromised patient (Strömngren, Groenvold, Pedersen, Olsen, & Sjogren, 2002); it should also be easy to comprehend so that patients from all educational backgrounds can complete it with minimal assistance. A tool which is simple

and fast ensures that even debilitated, seriously ill patients can comply.

The current delivery of health care requires various nurses, physicians, and other disciplines to treat a patient over a given time. Therefore, a tool that would allow for rapid assessment of different symptoms and for fast interpretation of the results by various health care providers would be beneficial to the continuity of patient care. The tool should be easily interpreted by all health care providers and capable of being implemented by any member of the team, at any given time.

A review of various assessment tools identified that the Edmonton Symptom Assessment Scale satisfies this criteria. Due to its simplicity, brevity, and ease of administration, the ESAS has received much interest as a bedside clinical assessment instrument. Unlike other assessment tools, it is useful to the clinical setting as it was developed for quick assessment of outcomes in routine practice, rather than an indication of quality of life. The subsequent discussion will further justify the suitability of the ESAS in the acute care setting.

The ESAS is a simple and effective tool for baseline and subsequent assessment of symptoms in patients with cancer. It standardizes patient symptom data, thereby facilitating communication among various health care providers by eliminating inconsistencies in symptom assessment. Regular review of the ESAS permits the recognition of symptom patterns and responses to interventions.

The involvement of multiple health professionals in a patient's care sometimes makes continuity of care difficult to maintain. The availability of ESAS scores on a visual

graph makes it very simple and fast for nurses or physicians to be updated on the patient's symptom profile. The use of a standard method of symptom assessment, such as the ESAS tool, allows community and adjunct institutions involved in the patient's care "to speak a common language" and monitor therapeutic interventions accordingly.

The ESAS has two parts; 1) the scale, which is completed independently by the patient, and 2) a graph of the patient's symptoms, which is recorded by a health care provider. This graph enables health care professionals to better understand and visualize the interaction between different symptoms and can facilitate more effective management of different problem symptoms. For example, if a patient was given increasing doses of opioids for severe and uncontrolled pain, the ESAS graph would help health care providers observe for significant increases in nausea, sedation, and constipation, which are common side effects of opioid medications. In 1997, the United Kingdom Audit Commission recommended that symptom assessment should be recorded alongside other routine vital signs (Schofield, 2003). The ESAS graph enables this to be done.

Consistent with the Conceptual Model of Symptom Management, the ESAS appears to capture the perception of key symptoms. The ESAS measures the most common symptoms experienced with cancer such as: pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, feeling of well being, and shortness of breath. It was believed that the use of the ESAS would allow for earlier and more effective identification of these symptoms. Most symptoms are easier to treat if they are identified before they become severe. A pilot project using the ESAS at Cancer Care Manitoba, a

provincial outpatient cancer treatment centre, found that 40% of patients would not have discussed their symptoms if not for the assessment tool (Johnston & Billey, 2003).

Moreover, use of the ESAS in the acute care setting would facilitate the identification of patients who should be referred to other members of the multi disciplinary team, including social work, spiritual care, nutrition services, pain clinic, and palliative care.

The ESAS tool was developed for use in a palliative care setting, as the result of an identified need for a simple tool to assist health care practitioners in the identification and management of cancer related symptoms (Bruera et al., 1991). In order to determine the effectiveness and usability of the ESAS, 101 consecutive patients with advanced cancer, admitted to a palliative care unit, were assessed using the ESAS (Bruera & McDonald, 1993). The ESAS was completed by the majority of the extremely debilitated and symptomatic patients. As reported by the authors of this prospective study, there was a significant improvement in symptom distress during the first five days of admission, and that this was likely a result of symptomatic interventions by health care providers on the unit. This symptom improvement was a result of monitoring the ESAS distress scores and patients symptom trends on the ESAS graph . The findings imply that the use of the ESAS in patients led to an improvement in symptom recognition and subsequent symptom management. Similar results were recently reported by Strömngren and colleagues (2005) who conducted a longitudinal study examining patient evaluated symptomatology and the impact of attrition in the use of various symptom scales. Significant improvement was seen in intensity for many symptoms after one week of

using the ESAS. Compliance rates for completion were also higher for patients using ESAS compared with other more lengthy assessment instruments.

Other authors have reported usefulness of the ESAS tool in clinical practice. For example, Dudgeon, Harlos, and Clinch (1999) have shown the ESAS to be a useful audit tool for assessing patterns of palliative symptom control within a palliative care unit; also it allowed for institutional comparisons, which is a useful feature in centralized healthcare. Sawicki and Nahigian (2001) conducted a descriptive study (N=26) in which they utilized the ESAS within their Palliative Consultation Service to inpatients, to determine the impact of the palliative care team's interventions on patient outcomes. The authors observed significant improvement in four indicators, (i.e., depression, appetite, tiredness and pain), as perceived by chronically ill patients in their study who used the assessment tool over five days. The authors contend that the use of the ESAS tool facilitated the palliative care consultation team by the placement of more emphasis on patient perceptions of symptoms, rather than illness or disease.

Although the ESAS tool was originally designed for use within in-patient palliative practice and continues to be primarily used as such (Fainsinger, Demoissac, Cole, Mead-Wood, & Lee, 2000; Jenkins, Schulz, Hanson, & Bruera, 2000), it has recently garnered interest for use in ambulatory oncology (Cancer Care Manitoba, 2003), geriatric (Pautex, Berger, Chatelain, Herrmann, & Zulian, 2003), home care (Heedman & Strang, 2001), and intensive care settings (Nelson et al., 2001). However, a search of the literature failed to locate a published article describing the application and evaluation of

the ESAS among acute care in-patients being treated for cancer. In most tertiary care settings, standardized symptom assessment is not incorporated into clinical practice (Society of Critical Care Medicine, 1995). Traditionally, palliative care has meant the treatment of symptoms for terminally ill patients. However, the term is expanding to cover all seriously ill people, including those with chronic or episodic ailments for whom symptom relief is viewed as part of good health care (Sawicki & Nahigian, 2001). Presumably, palliative patients who are seen in active treatment hospitals will differ from the traditional palliative population both in terms of their place in the disease trajectory and in their willingness to accept the historical model of palliative care. Thus, based on this expanding view of palliative care, the use of the ESAS for cancer patients in an acute care setting is warranted.

### Symptom Management Strategies

In the literature, patients who are considered “palliative” are the most intensively evaluated group as far as symptom control and quality of life are concerned. However, despite such intensive study, numerous cancer patients are still hospitalized for the purpose of achieving adequate symptom control. Recent studies have reported that over 70% of referrals to a palliative consult team within a acute care setting were for symptom control, rather than end of life issues (Manfredi et al., 2000; Virik & Glare, 2002). Despite concerns over symptom management at the end of life, there is substantial evidence that symptoms that could be well managed are undertreated, especially for patients who are still in active treatment (Cleeland, 2000). The prevalence of

treatment-related side effects, and the inevitable symptoms of disease progression in advanced cancer, underscore the importance for nurses to strive to minimize symptom distress and promote quality of life (Manegold & Schwarz, 1996).

Nurses who identify symptoms early and accurately may alter the symptom burden; however, few studies have focused on symptom assessment as the first step in effective management (Grant, 1994). No literature was found on the use of an assessment tool that captures symptoms and their progression in an acute inpatient setting. However, in a sample of outpatients with advanced lung cancer (N =48), Sarna (1998) tested the efficacy of the Symptom Distress Scale to assess symptom level and change of symptom distress over time. She concluded that the use of a structured assessment tool forestalled increased symptom distress over time, and that it was an effective way to enhance palliative care, by providing the necessary information for informed and personalized interventions for symptom relief (Sarna, 1998).

As outlined in the Conceptual Model for Symptom Management, successful symptom management strategies are founded on an accurate assessment of patients' symptom experiences (Larson et al., 1994). The reasons for assessing symptom distress include the identification of patients' needs and problems, and determining the effectiveness of various modes of treatment (McCorkle, 1987). Accurate and effective symptom assessment requires the involvement of two entwined elements; the patient, and the health care providers; "Such a relationship is one in which the work of the provider complements that of the patient and family, encouraging and assisting efforts to prevent

or manage the symptom” (Larson et al., 1994, p. 274). However, there are many barriers to effective symptom management in the patient with cancer, and contribute to inadequate symptom control. These barriers encompass the health care provider, the patient, and the health care system; each of which will be discussed in turn.

#### *Barriers - Health Care Providers*

Despite the growing development and research on symptom assessment, health care providers have not actualized these results within the hospital environment. Individuals with cancer continue to experience multiple, simultaneous, and/or episodic symptoms during the course of their illness. This next discussion will look at the barriers of inadequate education, assessment, patient and health care issues that impede successful symptom management.

*Education.* Health care providers who treat cancer patients need to develop a sophistication in symptom and side-effect management. Unfortunately, this is an area that is rarely addressed in medical school or post graduate medical education (Cleeland, 2000; Sloan et al., 2001). Furthermore, there is a lack of adequate undergraduate palliative-care education in many universities, and few funded post-graduate educational opportunities exist (Fainsinger, 2000). Only recently have universities in Canada and the United States started to offer accredited palliative medicine specialty residencies (P. Daeninck, personal communication, August 23, 2005).

On the other hand, nurses have traditionally focused on the effective management of symptoms, with the goal of maximizing quality of life (Germino, 1987). Nursing education also has a long history of including holistic palliative care principles (Bradley

et al., 2001). However, in a study examining nursing palliative care practices in an acute setting, 64% of respondents reported having palliative or hospice training, yet only 32% agreed that they were well trained in hospice practices (Bradley et al., 2001). The results of this study suggest there are gaps in knowledge about palliative practice among nurses in the acute care setting.

As a result of the recent advances in palliative care research, a complex theory base related to palliative care has been generated. While this is a very positive step, there is a consequent gap between palliative care nursing education and clinical practice. Ferrell and Coyle (2002) state that a major obstacle to providing high-quality end of life care is the fact that health care professionals are not adequately trained to work in this specialized area. Grantham (2004) suggests that there is limited nursing knowledge of palliative care, which has resulted in nurses expressing how difficult it can be to provide skilled and sensitive care to those with terminal illness and their families.

*Assessment issues.* Poor assessments have been considered one of the primary reasons for the under-treatment of cancer pain (World Health Organization, 1990). In several studies, a major factor accounting for the variance associated with inadequate cancer symptom management was a discrepancy between the patient and their health care provider's judgement of the intensity of the symptom, further highlighting the critical role of adequate assessment and monitoring of symptoms (Cleeland, 2000; Schafheutle, Cantrill & Noyce, 2001; Seers, 1987; Sprangers & Aaronson, 1992). In a review of related literature, Sprangers and Aaronson (1992) found low to moderate levels of concordance between symptoms assessed by the patient versus symptoms assessed by the

physician or nurse. The discrepancies between patients' and nurses' perceptions can potentially prevent patients' symptoms from being managed effectively, since the nurse's assessment generally provides the basis for the intervention (Larson et al., 1993).

Cleeland and Gonin et al., (1994) found a discrepancy between physician and patient in rating the severity of the patient's pain; this was also a major predictor of undermedicating pain. Other factors that predicted inadequate pain treatment for patients included being 70 years of age or older, being a woman, and having a better performance status. Therefore, careful and accurate assessment is especially important for patients with cancer from minority groups, elderly persons, women, and for patients who appear to be functioning well (Cleeland, Gonin, et al., 1997).

In a recent study, Nekolaichuk (2000) reported that health care providers consistently under-estimate pain, and that they are more likely to assess the absence, rather than the presence of symptoms. It was also found that both healthcare providers and family care givers tend to under-estimate performance status, while overestimating psychological concerns, such as depression or anxiety. In an earlier project, Nekolaichuk et al., (1999) compared patient and proxy symptom assessment in advanced cancer patients (N=49), and found that nurses and physicians who did not ask their patients to routinely rate their symptom intensity were likely to significantly under-assess and under-treat them. Rodriquez (2001) found that nurses continue to assess pain inappropriately; they under-medicate, and provide inadequate documentation of pain assessment and management. This is consistent with other studies that have shown that nurses consistently underestimate patients' pain in hospital settings (Brockopp, Ryan, &

Warden, 2003; Field, 1996; Seers, 1987; Zalon, 1993).

Poor symptom management in cancer patients, as a result of poor symptom assessments by physicians, has been the focus of several recent studies (Cleeland, Janjan, et al., 2000; MacDonald et al., 2002). In a survey of physicians published by von-Roenn, Cleeland, Gonin, Hatfield, and Pandya, (1993), 75% of physicians indicated that the most important barrier to cancer symptom management in their practice was inadequate assessment, and 50% of physicians felt they had inadequate knowledge about cancer symptom management. The survey also acknowledged that there was a substandard level of education about cancer symptom management and a reluctance to address it in practice, at all levels of professional health care. Compounded by inadequate training for physicians in the palliation of cancer symptoms, these barriers influence the management of patients with incurable cancer and profoundly affect end-of-life care.

An investigation by Strömngren, Groenvold, Sorensen, and Andersen (2001) revealed that patients experience many symptoms that do not appear in nursing records. These findings suggest that the nurse was unaware of the symptoms and therefore symptoms may have gone untreated. The study also showed that physical, as opposed to psychosocial symptoms are more likely to be detected by a nurse. Nurses may not routinely detect and monitor the concerns of individuals who have cancer, and both a poor level of facilitative communication and distancing are common (Dennison, 1995). In part this may be explained by research which suggests that communication in oncology nursing is characterized by avoidance of patients' expression of their concerns and poor appreciation of patients' needs (Wilkinson, 1991). Nurses may also reason that they

'assess' patients in the communication that occurs during treatment and during care. However, researchers have indicated that nurses do not accurately perceive the extent of symptoms suffered by the individual patient, especially less 'visible' problems such as depression (McDonald et al., 1999). Other researchers have reported similar findings (Shah & Davies, 2001), and thus lend further support for a tool that would facilitate the assessment of symptoms in the physical and psychological domains in an acute care setting. As well, the findings suggest that patient self-assessment questionnaires may be a valuable supplement to nursing records, thus enhancing the probability that the patients' symptom management needs are fully recognized by staff.

Overall, these results support the contention that inadequate assessment of cancer symptoms is a major barrier to effective symptom management. Study findings appear consistent in showing that nurses and physicians generally underestimate, downplay, or do not recognize the severity of patients symptoms. This is critical, given the importance of symptom assessment in the management of persons with cancer.

#### *Barriers - Patient Issues*

The assessment and subsequent management of symptoms is also reliant on the patient and their perception and expression of their symptoms. Patient attitudes and fears often compound the difficulty of symptom assessment. Patients may be afraid to spontaneously report symptoms to health care professionals for a variety of reasons. They may feel that reporting symptoms will be viewed as a criticism of the physician's or nurse's skills, and complaining of symptoms may defeat their efforts to be "good" patients (Cleeland, 2000; Ward et al., 1993), or they may have fears of being seen as "less

courageous,” or “emotionally weak” (Nekolaichuk, 2000). As well, differences in ethnic and cultural backgrounds may hinder effective communication about symptoms.

Patients also under report symptoms because they may perceive symptoms as a negative prognostic indicator and therefore an admission that their disease is progressing (Chang et al., 1998; Ward et al., 1993). Patients may feel that reporting symptoms could distract the physician’s attention from treating the cancer (Ward et al., 1993), or they may fear that reporting symptoms may result in a temporary or permanent stop to their cancer treatment. As well, patients may worry that divulging a symptom will lead to more medication and the associated side effects; if they are reporting pain, they may be concerned about the risk of opioid addiction. Strong beliefs held by cancer patients and their families about the best way to relieve pain, especially on the issue of opioid analgesic use, often hinders effective pain management (Dodd, Janson, et al., 2001).

Patients may also be reluctant to “bother” health care providers with symptoms that they consider to be an expected part of their disease or treatment (Reyes-Gibby, McCrory, & Cleeland, 2003). Furthermore, when no system of symptom assessment is in place, patients have to decide what symptoms to report and when to report them. The concerns listed above may constrain the patient’s willingness to do so. Therefore, an assessment tool that communicates the patients symptom experience and fosters communication between the patient, family members and health care providers would be a central to any symptom management strategy.

*Barriers - Health Care System Issues*

There are other barriers to comprehensive symptom assessments that are inherent to the current climate of health care. Adequate symptom assessment takes time, which is often a significant issue when organizations are faced with staffing shortages. Moreover, on acute care wards, the focus is on measures of acuity such as vital signs, so vital signs are traditionally recorded, even when these are of less importance to the care of the advanced cancer patient than the recognition of debilitating symptoms. Furthermore, on hospital units with post-op surgical patients, the primary focus of symptom management is often confined to the symptom of pain. Even when symptoms are assessed routinely, there is often no mechanism in place to evaluate the effectiveness of attempts at multiple symptom management (Cleeland, 2000).

Traditionally, cancer symptom management has been left to palliative care professionals during end-of-life care. However, it is not often possible, nor appropriate, for all cancer patients experiencing distressing symptoms to be treated in designated palliative care settings. Symptom assessment must be part of the standard care for the person with cancer in all settings to ensure efficient symptom management and optimal outcomes.

*Symptom Outcomes*

The major impetus for the implementation of an assessment tool is to facilitate symptom management in order to improve patient outcomes. The symptom experience for individuals with cancer has been found to have a tremendous effect on various

outcomes, including alterations in quality of life and its components, functional status, and emotional status. Cost outcomes will also be addressed.

Chan et al. (2001) conducted a longitudinal study to assess the impact of cancer symptoms on the quality of life in 144 women with gynecological cancer. The findings indicated that global health status, functional scales, and symptom scales demonstrated a dependent change over time. Relief of symptoms was associated with significant improvements in functional status. Similarly, Sarna (1993a) found that symptom distress was strongly related to quality of life in women (N=69) with lung cancer, predicting 53% of the variance in this outcome variable (1993b). The authors recommended that strategies for supportive care need to focus on symptom management.

Holmes and Dickerson (2003) conducted a study of 72 cancer patients admitted to hospital. They assessed the severity of symptoms and the impact of these symptoms on functional status. The researchers found that patients achieving low scores on the Symptom Distress Scale, were more likely to have scores on the Activities of Daily Living Scale (Katz et al., 1963), that reflected greater independence and functional status.

Similarly, other studies have reported that patients with multiple or more severe symptoms have lower functional status, less effective role performance, and lower physical performance (Cleeland, 2000; Graydon et al., 1995; Pugh & Milligan, 1995). In patients with cancer, symptom-related distress has been found to cause significant changes in patient functioning (Sarna, 1998). Disruption in the capacity to engage in a variety of physical activities has been noted in people with cancer, and this physical

compromise can contribute to a serious burden on family function (Kaasa, Mastekassa, & Thorud, 1988). Symptom distress hampers self-care and threatens independence (Rhodes & McDaniel, 1999). Implicitly, the relief of a symptom is valued because of the associated benefit to overall functional health status and quality of life.

Studies specifically focused on the emotional impact of gynecological cancer are not common, perhaps because of the variety of difficulties in studying this vulnerable population. A review of research in quality of life in women with gynecological cancer (Chan et al., 2001), suggests a profound impact of disease on the individual. If these findings are generalized to the patient's family, the burden of care and the need for support are profound.

Just as symptom distress has been correlated with quality of life, it has also been examined in relationship to survival rates. Kukull and colleagues (1986) found that post-diagnosis symptom distress was an important predictor of survival, after controlling for age, and functional status. Hwang and colleagues (2004) found that symptom distress scores could be combined with Karnofsky performance status scores to define prognostic survival in advanced cancer patients. Molassiotis, Van Den Akker, Milligan and Goldman (1997) described how reducing symptom distress increased survival in bone marrow transplant patients. This inverse relationship between symptom distress and survival has been supported by others (Degner & Sloan, 1995; Kaasa et al., 1989).

The symptom experience is also associated with tremendous costs. Financial costs can be attributed to the utilization of scarce health care resources when patients require

emergency or acute care management of their symptoms. Patient suffering is tied to emotional costs (Sarna & McCorkle, 1996); it complicates medical care and increases the use of costly health care services. Symptoms often impact a tremendous personal financial cost, precipitated by the inability to work (Bergman & Sorenson, 1987; Noyes et al., 1990), not only by the patient, but also by their care givers who take time off to look after their loved ones. As well, there are enormous costs affiliated with the expense of medications and nutritional supplements required to treat symptoms. There is also a body of literature supporting that fact that cancer is a disease affecting not only the person diagnosed, but the family as well (Sarna & McCorkle, 1996), thereby illustrating the emotional and physical costs for the family members of the individual.

The importance of a complete symptom assessment and management in the cancer population is supported by the extraordinarily high prevalence of physical and psychological symptoms. These symptoms impact on the overall quality of life in patients and their families, as well as costs to the health care system. Methods that improve symptom status, such as a standardized assessment like the ESAS, are essential in providing holistic quality care.

### Summary

A comprehensive review of the literature pertinent to the understanding of the cancer symptom experience has been presented. This literature review was organized into the context of the model and specific research was examined as it pertained to symptom experience, symptom management, and symptom outcomes.

Although self-report ratings of symptom distress have been shown to predict survival in persons with cancer, there remains a need to contemplate factors that mediate perceptions of the symptom experience, including the person, environment, and health and illness domains. Moreover, factors such as the symptom's frequency, duration, and intensity are believed to influence the saliency attributed to the symptom. Therefore, it cannot be assumed that mere occurrence of a symptom is stressful to the person with cancer.

Despite the distress that symptoms can cause, comprehensive symptom assessment is rarely part of routine cancer care. Health care providers often wait until patients spontaneously complain of symptoms before formally assessing them. Patients may be afraid to complain of symptoms for a variety of reasons.

Symptom assessment scales are the core of adequate symptom assessment. They provide the basis for detecting symptoms, grading severity and assessing the effectiveness of treatment. Understanding the concept of symptom experience will lend itself to guide assessment techniques and interventions designed to affect symptom occurrence and distress. Standardized assessment would encourage individualizing care to address the symptoms found to be most important to each patient, and therefore, provide a holistic approach, taking into account person, environment, and health and illness variables that may affect the symptoms experienced.

A variety of instruments now exist to measure the symptom experience. Based on its ease of administration, and simplicity, the Edmonton Symptom Assessment Scale was

chosen for use in this clinical project. It is believed that the use of a structured assessment tool such as the ESAS, will enable the nurse to identify symptoms early and accurately, with the aim to forestall symptom distress from increasing over time. Currently, there is a scarce amount of research that describes the use of the ESAS in cancer patients in an acute care setting.

### Conclusion

Based on this literature review, symptoms are not being adequately addressed in the acute care setting. The Edmonton Symptom Assessment Scale may be a useful and convenient way to improve assessment in patients with cancer. Further research is needed to provide evidence related to more effective symptom management and more comprehensive assessment. This literature review supports the rationale of evaluating the ESAS in an oncology focused acute care setting, with an ultimate goal of improving outcomes.

### Chapter III

#### Methodology

The implementation and evaluation of the Edmonton Symptom Assessment Scale (ESAS) in cancer patients admitted to a gynecological unit at the Health Sciences Hospital in Winnipeg, Manitoba, was undertaken as part of the clinical practicum experience in the Masters of Nursing Program at the University of Manitoba.

#### Design

This clinical project consisted of two parts: the implementation of the ESAS tool as a pilot project on a gynecological unit in a tertiary center, followed by a descriptive evaluation of the tool by patients and nurses on the unit. Øvretveit (1998) defines descriptive evaluation as “a description of the state of the targets of the intervention after the intervention” (p.55). The purpose of the evaluation was to appraise the tool’s utility for the accurate and comprehensive assessment of symptoms in the cancer patient on an acute care unit and the feasibility of its use by the nurses.

Discerning what patients and health care providers think of the ESAS intervention was an important source of information to assess the value of its continued use on this particular unit, and the extension of its use to other units within the facility. According to Øvretveit (1998), a “reason to do a descriptive evaluation of an existing service or policy is to give a precise description which allows other people to set up a similar service” (p.55). Therefore, this evaluation design will be useful in describing the outcomes of this ESAS project to decision-makers within the Health Sciences Centre, who are considering

implementation of the ESAS tool throughout the hospital.

This evaluation incorporated both quantitative and qualitative components. The quantitative component was completed in the form of surveys administered to both patients and health care providers (Appendix C and D, respectively); the qualitative component was done through brief, open-ended patient questions (Appendix C).

### Setting

This pilot project took place on a 42 bed, acute care, gynecology unit in Health Sciences Centre, a large, urban, tertiary teaching hospital, located in Winnipeg, Manitoba. The unit is a combination gynecology, oncology, high risk antepartum, perinatal loss, palliative care service provider and services 60% of all gynecological patients in Manitoba and Northwestern Ontario. Nurses on this unit provide care to both acute surgical/medical and palliative patients, and due to the nature of illness and type of admissions to this ward, these nurses also provide a considerable amount of grief support. This ward is staffed primarily by permanent nurses, with few in casual or float positions.

### Sample

The ESAS was administered to a convenience sample of diagnosed oncology patients on the pilot unit starting from May 17, 2004. After implementation of the ESAS on the unit, it was evaluated by two sample populations: the cancer patients who used the ESAS tool and the unit nurses. The patient population included any diagnosis of cancer, and any treatment modality such as chemotherapy, radiation, or surgery. All English speaking adult cancer patients who were mentally capable of completing paper and pencil

questionnaires, and who were admitted to the unit during designated recruitment days, were approached for participation. The minimum number required and procured for recruitment was a sample size of twenty patients.

The nurse population included all nurses employed in the unit. The unit is staffed with 35 nurses whose clinical experience backgrounds extend from novice to senior. At the time of the pilot, there were approximately four nurses with less than one year of nursing experience; six with one to two years experience, ten with three to five years experience, and six with five to ten years experience. The rest, approximately nine nurses, had more than ten years nursing experience. All nurses on the unit were invited to participate in the project; a sample size of 21 was recruited.

### Instrumentation

#### *Edmonton Symptom Assessment System (ESAS)*

The ESAS was developed for quick assessment of outcomes in routine practice (Hearn & Higginson, 1997); it assists the patient to identify his/her symptoms. Consequently, by utilizing the assessment scale repeatedly, values can be rated against the patient's own controls. As well, the scale can be completed by the patient's nurse or family member, if self report is not feasible for the patient. The ESAS measures the current level of nine common symptoms in advanced cancer patients: shortness of breath, pain, activity, nausea, depression, anxiety, drowsiness, appetite, and sense of well-being. In addition to the nine symptom indicators listed on the tool, the ESAS provides a space that allows the patient to add a symptom that may not be listed (see Appendix A: ESAS

scale). A general symptom distress score can be obtained by adding the scores of all the scales together. The ESAS is designed so that patients evaluate their symptoms on a graded scale from 0-10, which provides information on intensity associated with that symptom. The severity at the time of assessment of each symptom is rated; "0" means the symptom is absent and "10" indicates that it is of the worst possible severity. The ESAS is short enough for patients to complete in less than five minutes.

The original version of the ESAS used a visual analogue scale (VAS), which has since been replaced with a numerical rating scale. Chang, Hwang, and Feuerman (2000) recommend using numerical scales in severely ill and older patients with shaky hands and poor eyesight as they had experienced difficulty completing the VAS in their study. Previous studies have compared intra-subject variability and correlation of visual analogue scales to numeric rating scales and have shown them to be similar (DeLoach, Higgins, Caplan, & Stiff, 1998). The numerical scale was used for this project; this decision was based on the research that suggests that numeric rating scales are the best way to capture information about symptom severity. In clinical trials, numeric rating scales have been found to be more reliable than visual analogue scales, particularly when participants are less-educated and from varied cultures (Cleeland, 1990; Ferraz et al., 1990). Numerical scales have been endorsed for use in cancer clinical trial instruments because they are easier to understand and easier to score than visual analogue scales or verbal rating scales (Moinpour et al., 1989). Despite some shortcomings of numerical rating scales, primarily because of their unidimensional approach, they can be universally

implemented and regularly applied in all care settings.

Assessment tools for routine clinical use must combine clinical utility and psychometric robustness. If an assessment tool is to be clinically useful, it must be simple, appropriate for intended use in clinical practice, acceptable to patients, and should include a clear and interpretable scoring system (Corcoran & Fischer, 1987). An assessment tool must also demonstrate the psychometric properties of reliability and validity.

*Reliability of ESAS.* The reliability of an instrument that yields quantitative data is a major criterion for appraising its quality and adequacy. The reliability of an instrument is the degree of consistency with which it measures the attribute it is supposed to be measuring (Polit & Hungler, 1999). Measures of internal consistency explore whether the items in the tool are homogenous and capable of measuring concept(s). Chang, Hwang and Feuerman (2000) reported the overall Cronbach alpha for the ESAS instrument in their cancer population to be 0.79. Significant ( $p < 0.0001$ ) correlation coefficients were obtained when comparing the ESAS summary distress score with summary scores from the MSAS, with coefficients ranging from 0.56 to 0.74 (Chang, Hwang, & Feuerman, 2000).

Measures of stability explore the reproducibility of scores on different administrations of the measure (Brown et al., 2001). Interrater reliability of the ESAS, or the ability to measure similar results when used by different observers, has been estimated at 0.5 to 0.9 (Hearn & Higginson, 1997). Test-retest coefficients were determined against

the Karnofsky Performance Scale. All ESAS items were significantly correlated at 2 days, but at one week, this was only true for pain, activity, depression, shortness of breath, and ESAS distress (Cleeland, Mendoza et al., 2000). Where assessments are in a self-report form such as the ESAS, it is only possible to assess stability using a test-retest approach. However, in the self-assessment of fluctuating symptoms and the subjectivity of symptom experience, tools designed to assess these experiences may not demonstrate adequate levels of stability. Although, test-retests may not be appropriate for this type of measure, the tool should demonstrate internal consistency.

*Validity of ESAS.* Validity is the second important criterion by which a quantitative tool's adequacy is evaluated. Validity refers to the degree to which an instrument measures what it is supposed to be measuring (Polit & Hungler, 1999). The ESAS has been substantiated as a valid, self-administered scale when evaluated in palliative care settings (Cleeland, Mendoza, et al., 2000). Bruera and MacDonald (1993) compared hospice patient responses of the ESAS to results from the Support Team Assessment Scale (STAS), and found the two to be highly correlated. More recently, Hearn and Higginson (1997) also found the ESAS to have high criterion validity with the STAS. Philip, Smith, Craft, and Lickiss (1998) reported on the validity of the ESAS by authenticating the tool with two widely used self-administered instruments, the Rotterdam Symptom Checklist (RSCL) and the Brief Pain Inventory (BPI). Their study demonstrated that the ESAS has satisfactory concurrent validity, compared with the RSCL and the BPI, for hospice patients with cancer. The authors concluded that ESAS is

a valid, short, self-administered instrument for the assessment of pain and other symptoms in cancer patients.

More recently, Astradsson, Granath, Heedman, and Starkhammer (2001) found a high degree of correlation between the ESAS and their own quality of life instrument among cancer patients requiring palliative care. Strömngren et al., (2002) assessed the content validity of the ESAS by comparing the questionnaire against the symptoms and problems noted in the medical records of 171 cancer patients admitted to palliative care, and concluded that the ESAS covered many of the frequent issues faced by patients with cancer and was also highly practical due to its brevity.

In a validation study, Chang, Hwang, and Feuerman (2000) extended the ESAS to a general cancer population; the researchers examined ESAS validity in non-hospice ambulatory and inpatient cancer patients by comparing the ESAS with scores from the Functional Assessment Cancer Therapy Scale (FACT) and the Memorial Symptom Assessment Scale (MSAS). The results of this study suggest that the ESAS may be a valid instrument for use in a medical oncology population. Concurrent validity of the ESAS was demonstrated by comparison of the ESAS items and the distress score with the corresponding items from the MSAS and with FACT. The authors reported that the ESAS symptom distress score predominantly reflects physical well-being, as it correlated most closely with the physical well-being subscale of the FACT scale and the PHYS subscale of the MSAS. The ESAS had a smaller, but nevertheless significant correlation, both with the FACT emotional well-being subscale and the MSAS PHYS subscale. The authors

concluded that ESAS satisfied the criteria for internal consistency, criterion and concurrent validity in non-hospice cancer patients.

Based on this past research, the ESAS is simple to use, quick, and appropriate to use with individuals with cancer. It also can demonstrate psychometric properties of reliability and validity, and thus, is considered an ideal tool for this pilot project.

### Procedures

This next section will describe the procedures that were undertaken to implement and evaluate the ESAS tool within the previously described setting and population. These procedures included staff education, tool implementation, patient evaluation and nurse evaluation.

#### *Staff education*

The first step was to meet with the unit manager and clinical resource nurse to discuss the rationale and utility of the project. Once appropriate approval and support had been granted by the unit leadership staff, project leader's practicum committee, the University of Manitoba Education/Nursing Research Ethics Board (ENREB; see Appendix E: University of Manitoba Education/Nursing Research Board Ethics Review Approval Certificate), and site approval from the Health Sciences Centre Impact Committee (see Appendix F: Approval Letter from Health Sciences Research Impact Committee), the practicum project was initiated on the unit May 6, 2004. The second step was to distribute personalized letters to the thirty-five unit nurses via their e-mail and personal mailboxes on the unit (see Appendix G: Introductory Letter to Nursing

Staff). The first letter was distributed May 6, 2004, and a follow-up reminder e-mail was sent May 13, 2004. The purpose of the letter was to inform nursing staff of the proposed ESAS project as well as invite them to participate in an ESAS education session. A similar letter, outlining the clerical role in the project, was distributed to the clerical staff via e-mail and personal mailboxes on the same dates (see Appendix H: Letter to Clerical Staff). The unit manager had previously agreed to forward the letters to the staff via e-mail, as this is a primary route of communication on this ward.

Approximately one week after the letter distribution and throughout week two of the project, information sessions were provided for the nursing staff. The sessions were held during morning breaks (i.e., at 0900 and 0945, respectively) on the Monday, Tuesday, and Friday mornings of the second week of the project, for a total of six nurse education sessions. An additional session was given at 2200 hours on the Friday for evening staff that weren't able to attend morning sessions. Based on discussions with the unit manager, these sessions would capture most of the unit nurses on the various rotations.

The purpose of the education sessions was for the project leader to meet with staff and orient the nurses to the project and specifically to the ESAS and its utility. Topics discussed at the sessions included a) background/rationale for the project, including a description of the project leader's practicum; the conceptual framework for the project; and the ESAS tool; b) a demonstration of how to use the tool, and guidelines for its use; additional procedures and expected time lines of the project were also presented (See

Appendix I: ESAS Orientation ESAS Outline). Concerns and comments from the staff were encouraged. An ESAS information handout was developed and distributed to staff at the orientation meetings; additional copies were made accessible in the unit's charting area for the nurses to use as a resource (see Appendix J: ESAS Guidelines). The project leader also posted a memo on the unit, which explained the ESAS project to the additional multi-disciplinary staff that were associated with the pilot unit (see Appendix K: Memo to Multi-disciplinary Staff). Multi-disciplinary staff included physicians, social workers, Winnipeg Regional Health Authority long term care officers, Health Sciences Centre Palliative Care, aboriginal services, spiritual care, rehabilitation services, and home care services who were involved with the patients on WR5.

The project leader frequently visited the pilot unit during the 60 days after the introduction of the ESAS tool. The purpose of the project leader's presence was to ensure that the tool was being utilized appropriately, to invite discussion or clarify concerns or questions about the tool, and to invite suggestions from frontline staff about the ESAS tool. It also provided an opportunity to informally explore how the tool was being perceived by patients and staff. In case questions or concerns arose while the project leader was not on the unit, contact numbers were included on the information sheets, as well as being posted on the unit.

#### *Tool implementation*

Use of the ESAS tool commenced the week of May 17, 2004. The symptom assessment scale was completed by all oncology patients, with the guidance of their

nurse. The nurse then transferred the information from the tool to the ESAS graph on the chart to provide an ongoing symptom profile of the patient. The graph was kept in the patient's chart under the Graphic Flow Sheet Section, and the actual tool was kept with the patient's clipboard at the bedside, alongside the patients' vital sign flow sheets. Once the information had been transferred to the graph, the tool itself was discarded.

As recommended by Bruera et al. (1991), the ESAS tool was administered twice a day at 10 am and 6 pm. Additional assessments were encouraged if the nurse or physician deemed this to be necessary. On the other hand, if there were no notable differences in symptom scores after two days of the tool's use, the ESAS form could be completed once daily, during the nurse's routine morning shift assessment.

#### *Patient evaluation*

Following the continuous use of the ESAS tool for two or more days, the patient evaluation procedures were initiated. Between May 24 and August 7, 2004 data for the tool evaluation were collected from a convenience sample of 20 English-speaking oncology in-patients admitted to the unit, who had used the ESAS four times or more times since being admitted, and had consented to be part of the evaluation. The project leader asked the patient's nurse to approach the patient and request verbal consent for the project leader to discuss the patient's experience with the ESAS tool. The project leader asked the nurse to emphasize to the patient that she was under no obligation to participate and that her care would not be affected if she declined. The project leader met with willing patients, provided a brief explanation of the project, and asked the patient to

participate. Consenting patients were asked to sign a consent form (see Appendix L: Patient Consent Form) to participate in the ESAS evaluation. Once written consent was obtained, the Mental Status Questionnaire (MSQ; Kahn, 1960; see Appendix M) was administered to the patient by the project leader; this was completed immediately prior to the ESAS evaluation to verify cognition. The Mental Status Questionnaire is a well respected, reliable and valid test of cognitive function (McDowell & Newell, 1996). It is a simplified cognitive mental status examination of ten questions, and required less than two minutes to administer. Individuals who scored three or more errors on the MSQ were not included in the evaluation. Two patients were unable to complete the Mental Status Questionnaire, and accordingly, they did not participate in the evaluation. Following successful completion of the MSQ, the patient evaluation of the ESAS was administered. The patient ESAS evaluation consisted of eight nominal survey questions and approximately seven short and long answer interview questions (see Appendix C: Patient Evaluation), and required about 5-10 minutes to administer.

#### *Nurse evaluation*

After the ESAS tool had been utilized for approximately 7 weeks, the ESAS was evaluated from the nurses' perspective. The nursing staff were given surveys with a nominal style questionnaire developed by the project leader. The intent of the questionnaire was to evaluate the nurses' impressions related to the tool's contribution to improved symptom assessment (see Appendix D: Nurse Evaluation and Cover Letter). The questionnaire was accompanied by a consent form and was distributed to the pilot

unit nurses via their personal mailboxes on the unit on July 7, 2004. A cover letter requesting their participation and assuring confidentiality and anonymity accompanied the survey (see Appendix D: Nurse Evaluation and Cover Letter). Each nurse was asked to put the completed survey in a designated mailbox for the project leader on the unit. On July 12, 2004, a reminder was sent out in the form of an e-mail to each nurse, requesting that they complete the evaluation.

Informed consent was also completed by the participating nurses (see Appendix N: Nurse Consent Form). The nurses returned the questionnaire ESAS evaluation and consent form to a designated mail box on the ward; the forms were submitted separately to protect the nurses' anonymity. The nurses were also assured, both verbally at the information sessions and in written form (see Appendix D: Nurse Evaluation and Cover Letter, and Appendix N: Nurse Consent Form) that participation in the evaluation was voluntary and that withdrawal was possible at any time during the evaluation, without penalty.

### Ethical Considerations

This clinical project was reviewed and approved by three committees. The first approval process was completed by the project leader's practicum committee (see Appendix O: Practicum Committee Members). The second approval process was through the University of Manitoba, Education/Nursing Research Ethics Board (Appendix E: University of Manitoba Education/Nursing Research Ethics Approval Certificate). The third review was through the clinical site, Health Sciences Centre Research Impact

Committee (Appendix F: Approval Letter from the Health Sciences Research Impact Committee). The Health Sciences Centre Forms Committee had previously approved the ESAS tool and graph to be used with the Health Sciences Centre logo for the purpose of this project.

#### *Informed Consent and Confidentiality*

Informed consent was obtained from patients and nurses on the pilot unit. Both groups of participants were made aware that participation in the evaluation was voluntary and that withdrawal was possible at any time during the evaluation without penalty or negative consequences.

To ensure confidentiality and anonymity, questionnaires and interview answers contained no names. All raw data was stored in a locked cabinet and will be destroyed five years after project completion. The project leader is the only individual with a key to the locked data and participant information. Verbal and written reassurance was provided to all participants that confidentiality and anonymity would be maintained at all times.

#### *Potential Issues*

No ethical dilemmas were anticipated and none arose during this project. No known harmful effects were experienced by participants in this clinical project, nor were there any expected or potential risks associated with this project. Possible benefits to the patients included an opportunity to express their feelings about their symptom experience, and the potentiality for patients' symptoms to be more thoroughly assessed and managed by health care providers. Plausible benefits for nursing staff included a more accurate

symptom assessment of their patients and thus, improved ability to manage symptoms and improve outcomes. The benefits to nurses included a possible increased awareness of communication with their patients. Thus, it was anticipated that the results of this project could directly benefit participants and could also be used to provide valuable information in the use of assessment tools for symptom management.

### Data Analysis

Analysis of the evaluation survey responses was completed through computerized analysis using SPSS. Descriptive statistics were generated to characterize the population in terms of demographic variables and survey feedback for both patient and nurse ESAS evaluations. Thematic analysis of the patients' open-ended questions was guided by the principles of Burnard's (1991) thematic content analysis. The text was read several times to get a sense of the whole. Then each answer was read and an open coding was made, (i.e., category suggestions) were written down. These categories emerged from statements in the text. The categories were then reduced by grouping categories with similar content. The reduced categories were then reflected on and interpreted in themes.

### Summary

This practicum project involved implementing and evaluating the Edmonton Symptom Assessment Scale for regular use in individuals diagnosed with cancer admitted to an acute care gyne-oncology unit at the Health Sciences Centre. This chapter has described the project design and methodology, including education, data collection methods and data analysis employed for this symptom assessment project. The ethical

guidelines were considered and upheld.

## Chapter IV

### Findings

The focus of this chapter is the presentation of the findings obtained from the patient and nurse evaluation of the Edmonton Symptom Assessment Scale after it had been implemented on a gyne-oncology in-patient unit. A description of the patient and nurse participants will be presented followed by a summary of the results of the evaluation obtained from the questionnaires and open-ended questions.

#### Description of the Patient Sample

This descriptive evaluation included a sample of 20 women with a diagnosis of gynecologic cancer and who had undergone 70 treatment for various malignancies, but primarily ovarian and uterine cancer (see Table 4.1). The participants' ages at the time of the evaluation ranged from 36 to 78 years, with the a mean age of 56 years (see Table 4.1), and the majority being older than 54 years (n=12). The time elapsed since initial cancer diagnosis ranged from less than 1 month (45%) to 1 year. All of the women had had a recent surgical intervention except for one, who had been admitted for high dose radiation. All of the women interviewed were to be followed up at the cancer clinic upon discharge, with the possibility of further adjuvant treatment.

Among the respondents, the majority reportedly had high school education or less, although many of the women reported at least some college experience. Specific to cultural ancestry, most of the 20 patients were Caucasian. Fifty percent were married or living with a significant other, with the remainder either divorced, widowed, or single

(See Table 4.1).

Table 4.1: *Demographic Profile of Patient Participants*

Characteristics	Total Sample (N=20)
<b>Diagnosis:</b>  Ovarian  Uterine • Endometrial  Abdominal sarcoma  Cervical  Pathology pending	  7 (35%)  4 (20%)  1 (5%)  1 (5%)  1 (5%)  6 (30%)
<b>Age:</b>   36-44 years  45-54 years  55-64 years  65-80 years  Total	   6 (30%)  3 (15%)  4 (20%)  7 (35%)  20 (100%)
<b>Time since diagnosis:</b>  Less than one month  Within the past three months  More than 4 months	  9 (45%)  8 (40%)  3 (15%)

Education Level:	
Less than high school	4 (20%)
High school diploma	8 (40%)
Technical school/college diploma	5 (25%)
University degree	3 (15%)
Ancestry:	
Western European	5 (25%)
Anglo-Saxon	7 (35%)
First Nations	2 (10%)
Vietnamese	1 (5%)
African American	1 (5%)
Eastern European	4 (20%)
Marital Status:	
Married/Common-law	9 (45%)
Single	5 (25%)
Widowed	3 (15%)
Common law	1 (5%)
Divorced	2 (10%)

## Patient Evaluation of the Edmonton Symptom Assessment Scale

*Survey Questions*

The patient evaluation of the ESAS included eight nominal survey questions specifically inquiring about the patient's perspective of using this symptom assessment scale (See Figure 2: Patient Evaluation of ESAS Results). Most of the women reported that the instructions for using the ESAS form were clear and that the ESAS form was uncomplicated to use; of the two women who found it difficult to use, one of them attributed this difficulty to pain and disorientation and the other attributed her difficulty to being inconvenienced to fill the form out. Most of the patients reported that the ESAS included all the symptoms that were appropriate to their situation. One woman suggested that the symptom of diarrhea be added, another suggested constipation, and a third woman recommended that stress could be added to the ESAS form to help capture what they were experiencing.

Of the most troublesome symptoms experienced, pain was most frequently reported, followed by nausea, and emotional distress. It is important to note that a number of the participants experienced feelings of emotional distress as their most bothersome symptom, with 30% of the sample reporting depression or anxiety as their most bothersome symptom. Also notable is the fact that 45% of the patients had recently been diagnosed with cancer in the past month.

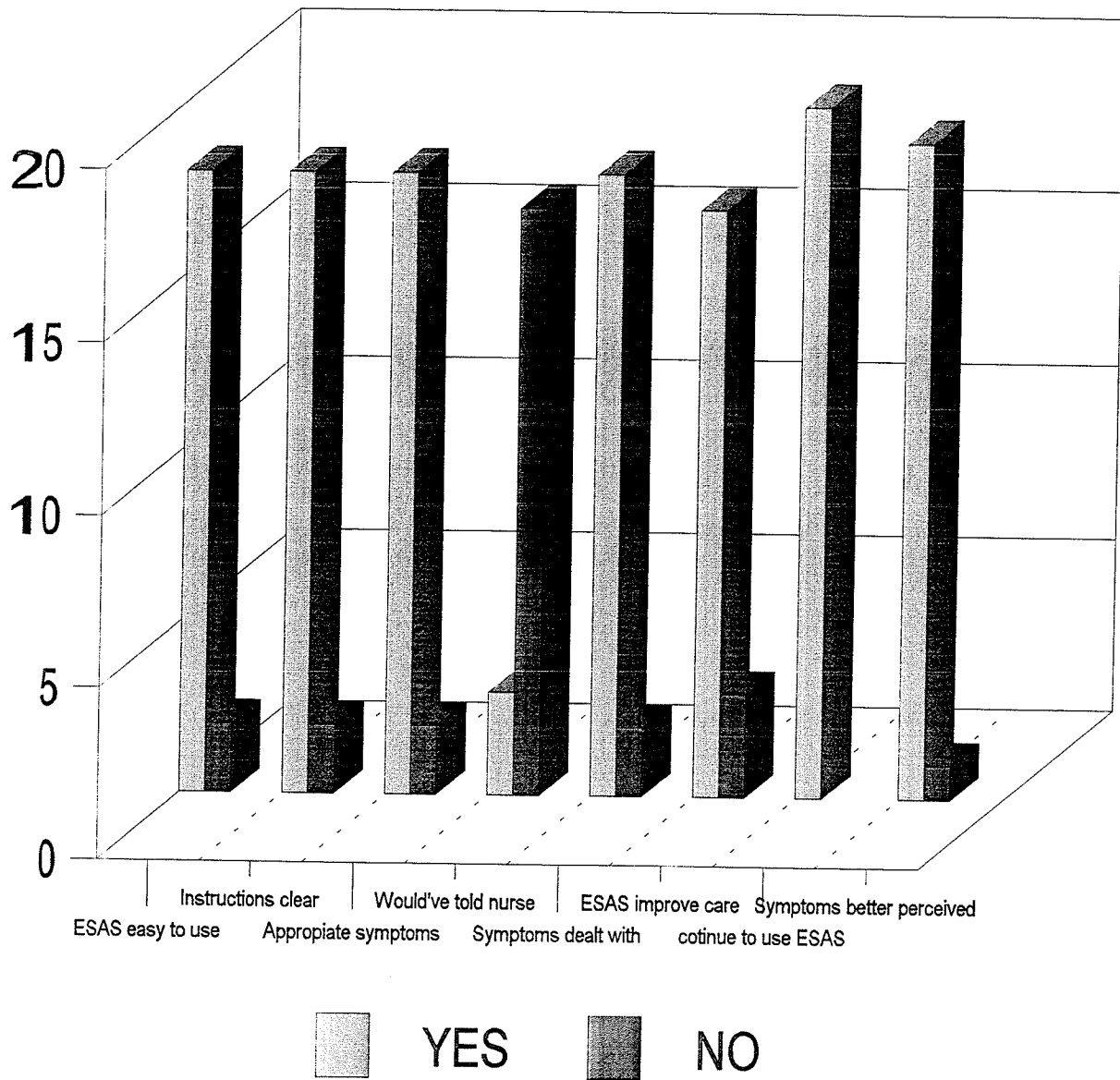
The ESAS appeared very effective in conveying patients' symptoms to health care providers. A large number of women respondents (85%) reported that they would not

have told their nurse about the symptoms they were experiencing if it had not been on the ESAS form. Most of the participants indicated that their symptoms were dealt with effectively, and the majority felt that using the ESAS form facilitated their symptoms being better addressed by their health care providers. Of particular relevance, 95% percent of the women reported that the ESAS form helped them better perceive and articulate the symptoms they were experiencing. All of the participants felt that the form should continue to be used even after the pilot study is completed.

Table 4.2: *Patient responses to questionnaire evaluating ESAS*

Question	Response (N=20)
1. Did you find the ESAS easy to complete?	Yes = 18 (90%) No = 2 (10%)
2. Were the instructions clear on how to complete the form?	Yes = 18 (90%) No = 2 (10%)
3. Did the ESAS contain all the symptoms that were of concern to you?	Yes = 18 (90%) No = 2 (10%)
4. Would you have told your nurse (or doctor) about your symptoms if it had not been identified on the ESAS form?	Yes = 3 (15%) No = 17 (85%)
5. Were your symptoms that were concerning to you dealt with effectively?	Yes = 18 (90%) No = 2 (10%)
6. Do you feel that by using the ESAS form, your symptoms were better addressed by health care providers?	Yes = 17 (85%) No = 3 (15%)
7. Do you think that this ward should continue to use this assessment form?	Yes = 20 (100%)
8. Did the ESAS tool help you better perceive the symptoms you were experiencing?	Yes = 19 (95%) No = 1 (5%)

Figure 2: Patient Evaluation of ESAS Results



*Open-ended questions*

Patients were asked to answer three open-ended questions about their perspective on using the ESAS. The answers to these questions were analyzed and categories emerged from the patient responses to each question. The categories were then reflected on and interpreted into themes that described patient' experience using the ESAS. These themes relevant to each open ended question will now be discussed.

*Open-ended Question Number One: Patient explanation as to why they did not disclose the symptoms they experienced to their health care provider.*

As previously mentioned, 17 (85%) of the 20 patient participants indicated that they would not have reported symptoms to their nurse or physician if they had not been identified on the ESAS form. Participants were asked to explain why they wouldn't have told their health care provider about their symptoms. The themes that emerged from this question included: (1) needing to be invited; (2) Lack of trust and vulnerability; (3) actualization; (4) guess work; (5) assumption of biophysical superiority; and (6) symptom irrelevance. A total of 21 responses were identified addressing these six main themes.

*Needing to be invited.* This category describes the instances in which patients are either uncomfortable with sharing their symptom experience or unaware of which symptoms to report to their health care providers and require encouragement to do so. Four of the twenty-one statements (19%) reflected the women's need to be invited to share their symptom concerns or experiences with nursing staff (e.g., "I was not asked about my symptoms," or "I would only tell them if they asked me").

*Lack of trust and vulnerability.* This category encompasses participant statements that describe the patient feeling vulnerable when sharing their symptom experience with health care providers. Symptoms can be perceived as intimate and thus, difficult to talk about. Six responses (28%) articulated feelings of vulnerability and lacking in trust when expressing the symptoms of depression or anxiety (e.g., “feeling depressed is hard to admit to” or, “...no one talked to me about depression, even though I circled it; nurses need to take the form seriously”).

*Actualization.* This category refers to the realization or validation of the symptoms patients were experiencing as being real, acceptable, and not unexpected. A focus on the actualization of symptoms was found in two (9%) of the responses, thereby communicating how the ESAS helped the women identify and articulate what they were experiencing. Without this actualization, they would not have been able to communicate these concerns to their care provider.

*Guesswork.* This category organizes the response themes that described feelings of uncertainty, particularly in regard to what was useful for health care providers to know and when they should be told of patients’ symptoms. Five (23%) responses reflected the guesswork involved for patients in knowing when and what they should be reporting to their nurse (e.g., “I didn’t know which symptoms to tell them, or I would forget to tell the nurse something when she was in the room”).

*Assumption of biophysical superiority.* This category describes the assumption patients made in deciding what the nurses ought to know and the assumption that nurses

are only concerned with symptoms related to the realm of the physical body. Two responses (9%) articulated the assumption that the body is given more priority than feelings or emotions, and therefore only the biophysical was worth acknowledging to their nurse (e.g., "...they treat nausea but not depression, which is more important").

*Symptom Irrelevance.* Two (9%) of the 21 statements revealed patients withheld their symptom experience from their nurse because they "didn't want to bother the nurse," thereby trivializing what they were experiencing as being irrelevant in the health care providers busy day. The complete list of patient responses are included in the appendices (See Appendix P: Thematic Categories).

*Open-ended Question Number Two: Patient feedback on using the Edmonton Assessment Scale*

Participants were asked to give their own general feedback or opinions regarding the use of the ESAS tool. Patients' comments were categorized as positive or negative feedback. The responses were transcribed verbatim and reviewed for common themes. The following is a summary of the patients' comments about using the ESAS tool, categorized into themes and organized into positive and negative feedback:

*Positive Feedback.* The respondents provided positive feedback that encompassed three thematic categories: (1) actualization and acceptance; (2) communication and; (3) affirmation. A total of 14 positive responses were identified in addressing these three main themes. Five statements (35%) reflected actualization and acceptance of symptoms experienced (e.g., "...[The ESAS] helped me deal better with what was happening by

organizing what my body was feeling”). Six responses (42%) articulated how the tool improved communication with the nurse. For example, one participant shared, “it helped me and the nurses talk about what I was going through,” and another said, “[the tool] helped me tell the nurse the right things.”

A focus on affirmation was identified in three (21%) of the responses. The affirmation category illuminates how the ESAS tool facilitated patients in validating that their symptoms were normal and to be expected (e.g., “the tool helped me see that what I was going through was normal,” or “[the tool] is a good idea for people who don’t want to speak up in case they are afraid of complaining”). Thematic data and specific positive feedback can be seen in Appendix Q: Positive Feedback from Participants.

*Negative Feedback.* The respondents provided negative feedback about using the ESAS which was categorized into two thematic categories: (1) skepticism and vulnerability; and (2) tool and administration inefficiency. A total of 8 negative feedback responses were identified and fit into these two main themes.

Four statements (50% of total negative responses) reflected the uncertainty and vulnerability faced by the women when communicating their symptoms on the form. Vulnerability was reflected in comments like “I was scared they wouldn’t let me go home if I had too many things wrong.” Other comments identified uncertainty in what the nurses were doing with the information collected on the form (i.e; “the nurses never addressed the symptoms I circled on the form”).

The remaining four responses (50%) articulated how use of the tool could be

improved. One woman mentioned that she didn't like having to choose between "drowsy" and "tired" as she felt these were too similar. Another woman found it difficult to rate her symptoms from 0-10 as it was a too wide of range for her; she would have preferred to choose 1 through 5. One woman found the ESAS form too difficult to contemplate when she was having pain. Another woman found the ESAS tool confusing to use initially. All of the negative responses regarding use of the Edmonton Symptom Assessment Scale are listed in Appendix R: Negative Feedback from Patient Participants.

#### *Summary*

The patient sample consisted of 20 women with gyne-oncology cancer, mostly Caucasian, with a mean age of 56 years. The most bothersome reported symptom was pain, followed by emotional distress and nausea. The survey revealed that the overall participant evaluation using the ESAS was very positive. Patients acknowledged that the ESAS tool was easy to complete, helpful in identifying concerning symptoms and facilitating communication of symptoms to their nurse. Consequently, patients reported that the ESAS improved the management of their symptoms. The open-ended questions provided additional insight. Patients reported that they believed their symptoms were better addressed as a result of the ESAS. Furthermore, as a result of using the ESAS, patients were also able to better perceive and actualize their symptoms and feel validated in their symptom experience. A large percentage of the patient cohort reported that without the ESAS, they likely would not have told their health care provider of their symptoms, particularly feelings of depression or anxiety. It was determined that many of

the patient participants needed to feel invited to share their symptom experience with their health care provider before they would mention bothersome symptoms. Other patients assumed that only the biophysical symptoms mattered and therefore did not mention the psychosocial distress they may have been feeling. The theme of trust emerged as a requirement for patients to admit feelings associated with vulnerability. Patients also needed to trust what the health care providers were planning to do with the information that patients indicated on the ESAS form. Patients expressed that using the ESAS eliminated some of the guess work involved in determining which symptoms to report and when to report them. The theme “symptom irrelevance” was used to describe the trivialization of symptoms by patients when they were concerned about bothering their nurse.

Patients also offered positive and negative feedback that they encountered when using the ESAS. This information was also categorized into themes; positive feedback included improved communication; affirmation of symptom experience, and actualization/acceptance of their symptom experience. Negative feedback included skepticism in regard to what how nurses were going to use the information patients provided on the form, and others didn't like small aspects of the tool's design (i.e., choosing from 0-10, instead of 1-5). Overall, all the participants unanimously responded felt that the hospital should continue to use the ESAS.

#### Description of Nurse Sample

This descriptive evaluation included 21 nurse participants, all of whom were

female. The nurse respondents' ages at the time of the survey completion ranged from 25 to 55 years, with the mean age being 33 years. Years of nursing practice ranged from 1 year to 30 years (mean=8.9 years); approximately two thirds of the sample had a baccalaureate degree and the remainder were diploma prepared. Demographic characteristics of the nurse participants are summarized in Table 4.3

Table 4.3: *Demographic Profile of Nurse Participants*

Characteristics	Total Sample (N=21)
Age at evaluation:	
25-29 years	7 (33%)
30-34 years	4 (19%)
35-39 years	4 (19%)
>39 years	3 (14%)
unanswered	3 (14.3%)
Mean Age	33.6 years
Education level:	
Diploma prepared	6 (28.6%)
Baccalaureate prepared	13 (61.9%)
unanswered	2 (9.5%)
Years worked as a registered nurse:	
< 2 years	4 (19%)
2-5 years	4 (19%)
6-10 years	7 (33%)
>10 years	6 (28%)
Mean	8.9 years

## Nurse Evaluation of the Edmonton Symptom Assessment Scale

The nurse evaluation of the ESAS included a survey with thirteen nominal questions specifically inquiring about the nurses' perspective of using this assessment scale in an acute care setting; survey responses are reported in Table 4.4. All of the nurse

participants reported that the ESAS was easy to use. Most of the respondents (95%) reported that the location of the ESAS in the patient's chart was appropriate; the remaining respondents suggested the ESAS be kept at the front of the patient's chart, for easier and quicker access. Ninety five percent of the nurse participants felt that the ESAS contained all the appropriate symptoms that they would assess in their patients; one participant suggested that "coping" be added. In this patient setting, the ESAS increased awareness of patient symptoms; just under half of the nurse respondents (42%) reported that use of the ESAS helped them become aware of symptoms that they would not have otherwise known to be present for their patients. The ESAS tool notably improved communication between the nurses and patients; 76% nurses reported that the ESAS improved communication regarding their patients' symptom experience. The ESAS also encouraged greater multi-disciplinary utilization; with almost 40% of the sample reporting an increase in the number of referrals to other multi-disciplinary providers, a result of better symptom recognition. All but one (95%) of the respondents thought the ESAS was easy for patients to complete without lengthy instructions; one nurse commented that it was difficult to explain how to use the ESAS to a patient that spoke poor English.

Overall, data from the nurse evaluation indicated that the ESAS tool was considered useful in practice. Eighty-five percent of respondents (n=18) reported the ESAS being a positive addition to their nursing practice, and that the ESAS graph enabled them to better assess the effects of medical and nursing interventions on the patient's symptoms. Many of the nurses (71%) reported that the ESAS enabled them to identify

their patient's symptoms earlier than if they had not used the ESAS tool. Sixty-one percent of the nurse respondents (n=13) reported that using the ESAS saved them time in their assessments of their patients. Ninety-five percent of the nurses indicated that the ESAS graph was a useful display of patient trends for their daily practice. Many of the nurses agreed that the information on the ESAS graph influenced the daily management of their patient care.

#### *Additional Nurse Evaluation Comments*

The nurse evaluation survey also gave the nurse participants an opportunity to give anonymous, open-ended feedback. Five of the 21 respondents provided comments. Two responses reflected concern that the ESAS was an increase in the nursing workload, i.e. "I did sometimes find it inconvenient to include this in my already heavy workload - it was not always a priority - it becomes redundant after awhile."

"ESAS does show symptom trends effectively at a glance, but I don't feel my assessments improved using this tool. I felt it was a pain to have to complete the ESAS and the transcription of results (especially if you had a number of patients who were using the ESAS). It's very time consuming and the extra paper work is not appreciated."

One comment indicated a concern about the increase in paper usage as a result of the tool, i.e., "Having to use a new sheet of paper with each assessment wastes a lot of paper you may otherwise not if scoring is done verbally between nurse and patient - also verbal scoring would allow patients to further discuss and or expand on their concerns."

Two participants offered why they thought the tool was of value, i.e., "[It was]

useful to bring summary sheets into multi disciplinary rounds. Team could best set goals; discuss symptom management and strategies in providing patient care.”

“I think the assessment tool is great for nurses who don’t do their own thorough assessment of patients each shift. It would also be very valuable tool for nursing student to use to learn the important questions to be asking when assessing their patients.”

### *Summary*

The nurse sample in this pilot project consisted of 21 female nurses, with a mean age of 33 years. Two thirds of this group were degree prepared, with an average of 9 years experience. Nurses reported that the ESAS did help them identify their patients’ symptoms earlier, and in some instances, it helped them identify symptoms that they would not have otherwise known was an issue for the patient. The symptom assessment graph allowed them to visualize patterns of symptom control and patient’s symptom status over time, a feature that was appreciated by 95% of the nurses. Many of the nurses felt that the ESAS improved communication between them and their patients, and that the ESAS was a useful way to monitor their interventions. Among the disadvantages of this symptom assessment tool, was the rare patient dislike (n=1) of the instrument and the occasional reluctance of the staff to use the tool in their already busy work day. However, 61% of respondents felt that it saved time by helping them focus on the problems that were an issue for their patient. Overall, the majority of nurses felt that the ESAS is a useful addition to their nursing practice.

Table 4.4: Nurse Evaluation Responses

Question	Response (N=21)
1. Did you find the ESAS tool easy to use?	Yes = 21 (100%)
2. Did you find the location of the ESAS graph in the patient chart appropriate?	Yes = 20 (95%) No = 1 (5%)
3. Did the ESAS contain all the symptoms you wished to assess?	Yes = 20 (95%) No = 1 (5%)
4. Did using the ESAS help you identify symptoms that you would not have otherwise known to be an issue for your patient?	Yes = 9 (42%) No = 12 (57%)
5. Did using the ESAS help improve communication between you and your patient related to the symptoms they experience?	Yes = 16 (76%) No = 5 (23%)
6. Has using the ESAS increased the number of referrals to multi-disciplinary providers (such as dietician, social worker, palliative care nurse, spiritual care, etc) as a result of better symptom recognition?	Yes = 8 (38%) No = 11(52%) Not sure = 2 (9%)
7. Were patients able to complete the ESAS without a lot of timely explanation?	Yes = 20 (95%) No = 1 (5%)
8. Has the ESAS been a useful addition to your practice?	Yes = 18 (85%) No = 3 (14%)
9. Did use of the ESAS graph enable you to better effects medical and or nursing interventions of your patients symptoms?	Yes = 18 (85%) No = 3 (14%)
10. Did use of the ESAS enable you to identify symptoms earlier?	Yes = 15 (71%) No = 6 (28%)
11. Did using the ESAS enable you to save time (i.e., allow you to focus on problems that were an issue and spend less time assessing problems that were not an issue?)	Yes = 13 (61%) No = 8 (38%)
12. Did you find the ESAS graph a useful display of patient symptom trends?	Yes = 20 (95%) No = 1 (5%)
13. Did the information on the graph influence or change day to day management of the patient's care?	Yes = 13 (61%) No = 8 (38%)

### Conclusion

Data from this descriptive evaluation supports the use of the Edmonton Symptom Assessment Scale in the care of patients with gynecological cancer in the acute care setting. Both patients and nurses rated the ESAS tool as simple to use and effective in increasing the communication of the patients' symptom experience to the health care provider. As indicated by both nurse and patient respondents, the tool includes the most relevant symptoms, and facilitated the identification of symptoms by both patients and nurses.

This chapter has presented a description of the patients and nurses who participated in the project. The results of the evaluation have been summarized. The following chapter will present a discussion of these findings.

## Chapter V

### Discussion

This chapter will discuss the results obtained from this descriptive evaluation project. The discussion will include the following: the prominent findings from the Edmonton Symptom Assessment Scale (ESAS) evaluation as they relate to the tenets of Symptom Experience and Symptom Management in the Conceptual Model of Symptom Management, challenges faced throughout the pilot project, limitations of the project findings, and recommendations for future research and practice.

#### Symptom Experience

Given that this pilot project was done on an acute care surgical unit, it was not surprising that pain was the most frequent symptom experienced by patients, followed by nausea. However, that the emotional component was so frequently reported was surprising, and possibly more important, because acute care surgical unit nurses would anticipate pain and nausea - but perhaps would not be as accustomed to the emotional aspect. This ESAS evaluation project also highlighted that physical symptoms were being addressed adequately, but there is work to be done on the emotional component of nursing practice when dealing with patients.

The premise of this project was to evaluate the ESAS among acute care patients, as the tool has only been used in palliative care settings. The results from this pilot project support the premise that a standardized, systematic symptom assessment tool improves symptom assessment and management in patients with gynecological cancer, admitted to acute care. Remarkably, 85% of the participants reported that they would not have told

their nurse about the symptoms they were experiencing if it had not been on the ESAS form; they reported that using the ESAS enabled their symptoms to be addressed more effectively by health care providers. The ESAS served as a pivotal first step in increasing communication of the patients' symptom experiences to their nurses. Recall that, according to the Model, symptom experience is a dynamic interaction of the patient's perception of a symptom, evaluation of the meaning of the symptom, and response to a symptom. Understanding the interaction of these components of the symptom experience is essential if symptoms are to be effectively managed. The results of this project provide beginning insights into the nurse's role in symptom management and improving symptom outcomes, because of the direct relationship of ongoing systematic assessments to the identification of symptoms.

#### *Perception of Symptoms*

Perception of symptoms refers to whether an individual notices a change from the way he or she usually feels or behaves (Dodd, Janson et al., 2001). A prominent finding resulting from this project was the striking response of 95% of participants who reported that using the ESAS tool helped them better perceive the symptoms that they were experiencing. Ninety percent of the women reported that the ESAS included symptoms that were appropriate to their situation; this is noteworthy as it implies that the tool is cogent in facilitating patients to identify relevant symptoms they were experiencing. Cancer and its treatment result in a variety of symptoms. Congruent with what has been reported in current health care literature, the most common symptoms perceived by

patients in this project were pain (65%), emotional distress (30%), and nausea (30%). Also noteworthy, was the qualitative theme of “actualization” that emerged from the evaluation; participants described how using the ESAS assisted them in focusing on what symptoms they were actually perceiving; for example: “...I wasn’t thinking of my symptoms, the [ESAS] form helped me focus on what I was feeling.”

Based on the participants’ comments, it is apparent that the ESAS tool helped them confirm their perceptions were real and gave them the language to communicate their symptom perception to their nurses. For some of the participants, this actualization of symptoms, initiated by the ESAS tool, is what enabled them to share what they were experiencing with their health care provider. Moreover, the ESAS facilitated communication in those of who spoke English as a second language; for example, one participant said: “I was better able to perceive my symptoms because English is not my first language.” Participants also commented that the ESAS helped them initiate speaking to the nurses specifically about what they were experiencing; others said it helped them to know what to disclose to their nurses. Communication of symptomatology to health care providers is key to achieving optimal symptom management. In the nurse-patient relationship, communication involves more than the transmission of information; it also involves transmitting feelings, recognizing these feelings, and letting the patient know their feelings have been recognized (Sheppard, 1993). Giardino and Wolf (1993) eloquently stated, “When nurses and other health care providers acknowledge that symptoms are real and that experience is as valid as measurement, they are in a position

to help manage the symptoms” (p.11).

It is known that symptoms elicit fear, anxiety, and concerns about loss of control (Giardino & Wolf, 1993). Using the ESAS tool may lessen emotional distress among patients by facilitating expression of symptoms and concerns, thereby increasing their sense of control and involvement of their symptom experience. One patient demonstrated this improved sense of control when she said: “the tool helped me see that I what I was going through was normal.” Studies of men and women with cancer have shown that greater perceived control is associated with better psychological adjustment (Lowery et al., 1993; Taylor et al., 1984; Taylor et al., 1991) and decreased anxiety and depression (Newsom et al., 1996; Thompson et al., 1993), while lower perceptions of control have been associated with psychiatric morbidity, cancer recurrence, and even death (Grassi & Rosti 1996; Watson et al. 1999). Several studies have shown that people have less emotional distress when they have high perceived control and use problem-focused coping, but have more distress when problem-focused coping is used in the setting of low perceived control (Osowiecki & Compas 1998; Vitaliano et al., 1990). According to Sines (1995), patients become empowered by a patient-centered approach to communication. Patient centered communication is defined by Langewitz et al. (1998) as “communication that invites and engages the patient to participate and negotiate in decision-making regarding their own care,” (p. 230). The ESAS tool in this pilot project proved to be an excellent way to increase patients’ awareness of their symptoms, communicate their concerns and have a role in addressing their own symptom needs. The ESAS educated

and encouraged patients to identify their symptoms and disclose them to their nurse, thus increasing their sense of control. Valuing the patients' self-report facilitates the realization of their symptom experience and enables them to be a partner in making decisions about their needs, rather than nurses making assumptions about their needs. Given the important role control seems to have in coping with cancer, use of the ESAS, which gives patients an active self-care role in the perception, assessment, and management of their symptoms, is also likely to impart a higher sense of control in their symptom experience.

#### *Response to Symptoms*

As indicated in the Model, patients' responses to symptoms include physiologic, psychological, sociocultural, and behavioural components. By definition, symptoms are subjective, present whenever patients say they are (McCaffrey, 1979). According to Giardino and Wolf (1993), symptoms are analyzed according to their occurrence (frequency, duration, and severity) and distress (physical and mental suffering that result from the occurrence of the symptom). Signs, on the other hand, are objective indicators of disease that are verified by physical findings or the results of technology (Giardino & Wolf, 1993).

Ideally, nurses plan care and gauge the effectiveness of their actions in response to changes in the patients' signs and symptoms. Nurses tend to monitor objective outcomes as indicators of the efficacy of their care, however, the patient's subjective experience is the true barometer of the resolution or abatement of symptoms following nursing actions.

It is not adequate for health care professionals to judge the presence of a symptom by a patient's response, as these responses vary from person to person, influenced by a variety of variables, including culture, age, gender, and socialization.

When assessing patients, nurses may recognize symptoms that patients fail to acknowledge, and patients may be concerned with symptoms which nurses do not detect (Giardino & Wolf, 1993). In this project, the use of a standardized tool that appraised symptoms from the patient's perspective was effective in addressing both of these issues. Overall, participants reported that the ESAS tool improved the identification and management of their symptoms by the nurses. However, when they differentiated symptoms that were more troublesome, some patients reported that emotional disturbances were not consistently acknowledged. Emotional concerns, such as anxiety or depression, may be symptoms in and of themselves or responses to other symptoms. Furthermore, emotional distress can be difficult to detect objectively because there is a tendency for people to disclose only socially acceptable answers to strangers. Participants also reported pain management to be a significant concern. This concurs with the most recent Patient Satisfaction Survey (2003) completed on this particular unit that also reported pain as a major concern for patients admitted to this ward. These findings suggest that not all symptoms, even common and expected ones, are being adequately addressed by health care providers. Therefore, it is crucial that nurses not only complete objective assessments of patients' signs, but also include the patients' subjective symptom experiences.

In this project, the ESAS provided an effective means for patients to realize the symptoms they were having and communicate this subjective experience to their health care providers. From the nursing perspective, almost 50% of the nurses who participated in the evaluation reported that using the ESAS helped them identify symptoms that they would not have otherwise known were issues for their patients. Regular and systematic use of the ESAS provides a fast and effective way for nurses to complete a symptoms assessment that moves beyond a reliance on physical and behavioural responses, to encompass a broader scope of symptoms that may be concerning to patients.

#### *Evaluation of Symptoms*

Patients evaluate their symptoms by making judgements about the severity, cause, appropriateness for treatment, and the effect of symptoms on their lives (Larson et al., 1994). In this project, one participant reported that using the ESAS tool enabled her to validate the symptoms she was experiencing as being acceptable and normal. Other participants described this sense of normalcy as a relief, demonstrating that it was not only relief of a symptom that eased the distress, but also the rationalization that she was not unusual and that it was appropriate to feel what she was feeling. For example, one participant said: "My mind was eased that I had normal symptoms."

An interesting finding was the theme of "assumed biophysical superiority". This theme illuminates the supposition that patients make about health care providers being largely concerned with symptoms that affect the body and less concerned about symptoms related to emotion or spirituality. One participant said, "...they treat nausea but not

depression, which is more important.” This theme may explain why some patients do not disclose their concerns to nurses, thus contributing to inadequate symptom management. In this project, the ESAS was successful in overcoming communication barriers between patients and their nurses; the ESAS tool also made patients aware that nurses needed to know more than just their biophysical concerns.

In addition to their assumptions about biophysical concerns being more important, patients also made judgements on what they sensed their nurse was interested in knowing and had presupposed what the nurse is capable or willing to do to relieve that symptom. For example, one participant said, “I only mentioned to the nurse about having pain and nausea because there is a pill for these.” Patient comments like this one imply that nurse-patient interactions exploring emotional experiences did not always occur, and that patients may have perceived that symptoms that could be managed with the quick fix of a medication were the priority for the nurses. This substantiates the need for ongoing patient education to dispel this misconception and ongoing nursing education to ensure that this is not the message being portrayed.

Although this project had a very small sample cohort, it would appear that participants did not feel that they had their non-physical symptoms well tended to by their nurses. Participants in this project perceived that nurses’ priorities were in the management of physical symptoms, and that there was a lesser priority in engaging in treatments for non-physical symptoms, such as therapeutic dialogue or discussion of patients’ distressing symptoms and their meaning. Ironically, an appreciable number of

the nurses (76%) in this assessment pilot project reported that using the ESAS improved communication between themselves and their patients in discussing the patients' symptom experience. While this is a positive finding, this incongruity leads to confusion as to how symptoms are treated by nurses, and confirms the need for a broader assessment tool, such as the ESAS, to be part of regular practice.

Nursing literature abounds with publications on communication. In ideal nursing practice, therapeutic communication is not considered an option in nursing care, but rather it should be a central feature of the role of the nurse (Fairlie, 1992). Others (Attree, 2001; Fosbinder, 1994; Peplau, 1988; Severston, 1990; Thorsteinson, 2002; Wilkinson, 1999) support this view and indicate that the development of a positive-nurse patient relationship is essential for the delivery of effective care. However, previous researchers (Crotty, 1985; Hodges et al., 1986; Reid, 1985) also highlight that nurses do not communicate well with patients and approach patients only to deal with administrative or functional activities. Jarman (1995), Hostutler et al., (1999), and Jarett and Payne (2000) suggest that this is because nurses are not aware of the meaning and significance of the nurse-patient relationship for patients. This state of ignorance results in nurses making assumptions about what nursing care a patient needs or wants because they do not ask patients (Bergen, 1992; Booth et al., 1996). In this project, nurses admitted that the ESAS tool improved communication with their patients and increased their awareness of patient symptoms that they would not have otherwise identified.

Lack of communication is one explanation as to why nurses may not attend to

patient symptoms. Although no single explanation can account for why nurses may not as thoroughly address symptoms beyond the physical domain, several hypothesis are worth exploring. First, participants may be correct in assuming that a physical symptom is often easier to resolve with a “quick-fix” medication than it is to resolve any form of emotional distress. This pilot project occurred on an acute care unit with a significant number of surgical patients. This type of care setting is well known for having a major focus generally, and appropriately, on physical symptoms, such as pain. Acute care units in today’s current health care climate are also known to be very busy; nurses may be prioritizing their care on the physical needs of their patients and, due to time constraints, may be unable to complete a thorough emotional assessment. Management of emotional distress often requires time for the patient to adjust to new stressors and to develop coping mechanisms, through strategies such as counselling, psychotherapeutic measures, pharmacologic interventions, or a combination of these measures. Nurses can use a range of counselling and communication skills to help patients talk through problems, express feelings, explore meaning, and make decisions (Burnard, 2002). Communication and counselling skills have widely been described in the nursing literature (Jennings, 1992; Jones, 1990; Wyatt, 1993). The benefits to patients’ well-being when they are able to make meaning from their symptoms or illness, have been well established (Degner et al., 2003; McClement, Woodgate & Degner, 1996; Rhodes & Watson, 1987; Wenger, 1993). Nurses are well-positioned to facilitate this meaning making in their management of patient symptoms through therapeutic dialogue, and yet this doesn’t appear to consistently

occur in practice. While the beneficial effects of allowing the patient to express their feelings, fears, and anger and listening in a nonjudgmental manner have been widely established (Burnard, 2002; McVey, 1998), such an intervention requires time, willingness, and competence to do so. Additionally, the existing problems in health care; namely, increased patient workload, marked increases in patient acuity, and significant reduction in patient length of stay, all significantly contribute to the nurse having less time for patient and family teaching, comforting, and discussion (Gordon & Fagin, 1996). This conclusion was verified in this project by comments such as: "I wish they [the nurses] had more time to talk to me about my depression, but since they don't the [ESAS] form is a good idea."

Second, some nurses may not feel comfortable, or competent, to address emotional distress issues in practice. On busy acute care units where time is short, nurses may have decreased opportunities to refine and master their counselling skills. Furthermore, there is a long-standing tension that exists between the ideals and reality of nursing practice in relation to the biopsychosocial model of nursing. Past research suggests that nurses experience communication difficulties and frequently block patients from divulging their worries or concerns (Wilkinson, 1991). Earlier literature identified that most interactions with patients occur when physical tasks are carried out (Seers, 1987) and physical aspects rather than psychological aspects of care appear to dominate most nurse-patient communications (Faulker, 1985). Some authors believed difficulties arose because nurses did not have the verbal skills to assess how patients feel about their

illness (Maguire, 1985). Other authors suggested that nurses did not necessarily lack the verbal skills, they may just not have been using them (Marshfield, 1985). Fulton (1996) argued that the failure to engage in biopsychosocial practice is due to nurses' understandable reluctance to connect themselves to care that entails difficult or painful relationships. Work by Menzies (1970) suggested that hospital nurses distance themselves from patients because of the high anxiety levels which are generated from working with sick and dying people.

More recent literature supports earlier contentions. Nursing is a profession that identifies caring as central to its practice, and relies heavily on emotional labour. Increased demands of emotional labour from nurses may contribute to a "protective" disengagement from patients (Herdman, 2004). Ritzer, (1993) suggests that this emotional link has been replaced by a quest for extreme efficiency, and refers to this phenomenon as 'McDonaldization.' This severed emotional link may contribute to why both nurses and patients seek a "quick fix" for symptoms. Moreover, in the context of a quick-paced, minimalist, and efficient 'McDonaldized' health care system, a broader scope of patient assessments is less of a priority. This may be a reason why some nurses in acute care settings are more concerned with predictable tasks and less focused on the emotional aspects of their work. The result is that the nurse-patient relationship is devalued because of a task orientated approach to patient care (McCabe, 2004). Nurses who are pressed by time constraints and or abstain from the emotional labour of nursing practice may unintentionally have a dehumanizing impact on patients who then just become part of the

'conveyor or assembly line' of hospital care (Ritzer, 1993, p.132).

'McDonaldization' also provides insight into the theme of "symptom irrelevance."

Symptom irrelevance refers to patients' evaluations of their symptoms as being too insignificant to share with the nurse. Nine percent ( $n = 2$ ) of the patients' responses revealed that they trivialized their own symptoms and withheld sharing them because "they didn't want to bother the nurse" or as another patient said, "Nurses are busy, and I would forget to tell them [about my symptoms] when they were in my room."

Unfortunately, these statements support the view of nursing as "assembly line hospital care," which places lower priority on emotional concerns and nurse-patient dialogue. It also highlights the sad reality that nurses are often too busy to adequately address patients needs.

Almost all of the participants in this ESAS evaluation project were admitted to hospital for the purpose of cancer-removing gynecological surgery. In this age of health care reform, patients having these surgeries have become the recipients of shortened hospital stays and are paradigms of 'McDonaldized' health care. Wigans (1997) argues that the aims of efficiency and productivity in the management of surgery predominate and are at odds with the ideology of individualized care. Nurses interviewed by Wigans claimed that they did not get emotionally involved with surgical patients and that short hospital stays reduces emotional demands. Hoschild (1983) highlights the personal costs of emotional work and it is interesting to note that some of Wigan's respondents were not displeased with the low emotional content of their work. Their main concern was

disguising the 'conveyor belt' nature of their work from patients. Nurses generally considered it acceptable to routinize care and reduce emotional interaction because the operations were considered standard. Early research by Menzies (1967) also revealed how nurses used routinization of care as a defense mechanism. Perhaps these findings explicate the inadequate communication of symptoms and concerns between patient and nurse in the acute care setting on the pilot unit. Length of stay for these women was, on average, approximately 3 days and because they were routine surgeries, post operative care may also be routinized. Participant comments such as "Nurses are busy...I didn't want to bother the nurse unless I really had to," illustrates that nurses were busy with tasks, and perhaps too busy to do thorough assessments and give the patients opportunities to discuss their distress. Nurses who participated in a recent Canadian study also admitted to the tasking versus caring nature of their work, and acknowledged that contemporary surgical nursing today is not nursing - it is tasking (Enns, 2002). These nurses reported feeling unfulfilled in their work, but also felt helpless with the situation. Participants in this study also admitted to shutting themselves off emotionally from their patients as a coping mechanism to endure the busy, non-supportive acute care surgical environment (Enns, 2002).

Empathy and caring have long been seen to be essential features of the nurse-patient relationship (Alligood, 1992; Burnard 2002). The importance of the nurse's ability to establish and communicate empathy is stressed as being a powerful facilitator toward a therapeutic nurse-patient relationship (Fairlie, 1992). In her Human-to-Human

Relationship Model, nursing theorist Joyce Travelbee asserted that the power of empathy stems from the rationale that a nurse who understands a patient's experience is better equipped to formulate strategies which meet the patient's overall needs (Rangel et al., 1998). However, Gould (1990) argues that the professional socialization, which occurs during nursing education and subsequent practice, contributes to a loss of empathy in nurses. This concurs with the literature (Burtin, 1985; Graham, 1994; McMahon, 1990; Mcoll et al., 1996; Menzies, 1960; Telford, 1992), which suggests that the professional socialization of nurses results in task-centered, rather than patient-centered communication. Nevertheless, nursing practice grounded in duty rather than compassion is empty. Meštrović (1991) expressed concern about the consequences of this kind of emotional detachment. He states: "Compassion stems from the heart, not the mind. It is irrational because it is not based on duty and fear, it is genuine, albeit momentary victory over mankind's innate egoism," (pp115-116).

Ironically, the hospital culture can be problematic for quality symptom assessment. It has been suggested that nurses' less than optimal focus on patients' emotions may be a consequence of nurses adopting the medical model, a model that is considered by some to be reductionist, mechanistic, and dehumanizing (Hagell, 1984; Herdman, 2004). Medicine's prescriptive theories, such as medical treatments and medical diagnostics, and the focus on the biophysical aspects of the person, continue to dominate the practice of health care (Fairlie, 1992). Examples of these biophysical theories are doctors' rounds, medical treatments, and scanning techniques, which continue

to be the focus in acute care settings. Consequently, activities relating to the nurses' unique holistic and caring approach, which includes assisting the patient to communicate emotions and needs, are seen as lower in priority. However, others argue that the desire to distance nursing from the medical model is problematic because it is a move that reinforces the notion of 'caring' as women's work, work that is considered a self-sacrificial service and economically valueless (Bradshaw, 1999; Chandler, 1991).

Others (Burton, 1985; Chant et al., 2002; McMahon, 1990; Menzies, 1960,1970; Telford, 1992) suggest that nurses do not communicate well because of the organizational culture in the acute care setting. Hospitals are generally bureaucratic organizations, and bureaucracies favour task division and afford little value to humanistic relationships (Fairlie, 1992). According to Flaskerud (1979) nursing practice is influenced by bureaucratic values which encourage nurses to have 'tangible end points.' This is communicated by framing nursing work within time-limited boundaries, such as shift work or tasks. Furthermore, McColl et al. (1996) found that nurses have the necessary communication skills to address emotional concerns, but choose not to use them because of the lack of organizational support and encouragement. According to Wilkinson (1991), the strategy to prevent stress among nurses related to emotional labour in the acute care setting has resulted in a socialization process that has perpetuated the notion that patient centered communication should be discouraged and is unsupported by hospital infrastructure. These hypotheses of 'McDonalization' attitudes held by both patients and nurses, in conjunction with decreased empathy, time, willingness, competence, and

nursing and hospital culture issues may explain the disengagement that nurses may demonstrate with their patients when addressing emotional distress, and give rise to the themes of assumed biophysical superiority, and symptom irrelevance. This evaluation of the ESAS in an acute care setting supports its use; even in a busy environment, the ESAS is a convenient, easy to use tool that initiated further discussion and identification of patients' symptoms experience to nurses, that may not have otherwise happened.

### Symptom Management

As outlined in the Conceptual Model of Symptom Management, successful symptom management strategies are grounded in an accurate assessment of the patient's symptom experience (Larson et al., 1994). In this project, a large percentage of patients (85%) reported that they thought using the ESAS tool facilitated their symptoms being better addressed by their health care providers. Congruously, almost half (42%) of the nurses in this project reported that use of the ESAS helped them become aware of symptoms that they would not have otherwise known to be present in their patient. Overall, nurses reported that the ESAS notably improved communication between themselves and their patients in discussion about their symptom experience, and use of the ESAS enabled nurses to identify their patient's symptoms earlier than if they had not used the ESAS.

Accurate and effective symptom assessment and the ensuing symptom management require the involvement of two entwined elements; the patient and the health care providers. However, as discussed in previous chapters, there are many barriers to

effective management of symptoms in the patient with cancer which contribute to inadequate symptom control. In this project, 85% of the patients responded that they would not have reported their symptoms to their nurses had it not been identified within the ESAS tool. Barriers to reporting, including the health care provider, the patient, and the health care system, will be discussed in turn.

### *Health Care Providers*

As discussed in the previous section, ‘McDonalization’ of health care, resulting in decreased empathy, time, willingness, and a changing nursing culture, may explain the disengagement that some nurses have when caring for their patients. This disengagement may be a barrier to effectual symptom management, especially if it causes nurses to ‘overlook’ patients’ symptoms. Some of the participants in this project reported that their nurses did not acknowledge that they had circled a particular symptom on the ESAS tool. The ESAS in this project was successful in eliciting symptom information from patients, but effective symptom management can only occur if nurses use this information offered by patients. The patient’s perception of symptoms is the most reliable source of assessment (Allcock, 1996; Carr, 1997); this assumption is the gold standard for the management of symptoms (Dodd, Janson, et al., 2001) . However, it has been frequently reported that nurses tend to see only objective responses to symptoms, when listening to individuals should be critical (Marks, 1999). Qualitative comments by some participants in this project described not feeling heard or believed by their nurses when reporting symptoms. As well, participants described feelings of uncertainty as to whether their

nurse valued their disclosure of their symptoms; these comments were categorized into the theme of “skepticism,” and included comments such as: “the nurses never addressed the symptoms I circled on the form.” Similar concerns have also been reported elsewhere (Schofield, 2003; McCabe, 2004).

When health care providers do not acknowledge patients’ symptom experiences, it is understandable why patients may become uncomfortable with disclosing symptoms and in turn, they may become increasingly dissatisfied with health care. When nurses engage in therapeutic conversations with patients about their symptoms and the meaning of patients’ symptoms, the emotional support in itself can significantly decrease the level of distress patients experience (Burnard, 2002; Holland, 1989), and ultimately impact favorably on patient outcomes. Patients’ interpretation of the nurse not acting on the information they shared may be explained by factors, such as disengagement or ‘McDonaldization’ attitudes as described above; it could also be related to time constraints in the nurse’s day; or it could have been a consequence of practitioners adjustment to using a new tool and therefore not using the ESAS to its fullest capacity during the pilot project. Other barriers could be attitudes within nursing, as it has been reported that symptoms such as anxiety and stress are commonly viewed as an individual problem, and its alleviation as a personal responsibility rather than a nursing one (Hingley & Harris 1986). Nurses need to be aware of how their own attitudes may be detrimental to a comprehensive symptom assessment and subsequent symptom outcome. It is critical for nurses to realize the impact of a thorough symptom assessment.

Despite the knowledge of effective pain control measures, pain was still the most prominent symptom that project participants were experiencing. This finding concurs with the Patient Satisfaction Survey, done just prior to the pilot project, indicating that overall patient satisfaction with pain control on this particular acute care unit was only rated as fair, with the desired Likert rating aimed at very good or higher (Unit Patient Satisfaction Survey, 2003). Poor pain control was also the most significant issue for patients who completed this satisfaction survey; this may be related to inadequate assessments or nurses not believing what patients say about their pain, or perhaps nurses or physicians having poor understanding of pain management techniques. Health care literature supports these views as there have been many publications outlining the ongoing challenge of the nursing profession to provide effective pain management (Barnason et al., 1998; Brockopp, Ryan, & Warden et al., 2003; Brockopp et al., 1998; de Rond et al., 2000). Based on the positive findings in this project, consistent use of the ESAS may likely improve pain management by encouraging patient-nurse communication regarding the presence and severity of the pain.

#### *Patient Issues*

The majority of participants admitted that they would not have disclosed symptom information to their care provider if it had not been identified on the ESAS. In explaining why they would not have done so, various themes emerged as barriers to symptom management. The theme of 'needing to be invited' described how patients felt they needed to be asked or encouraged by nurses to disclose details of their symptom

experience. This may be related to the patients' reluctance to 'bother' busy health care providers. Furthermore, as discussed in the theme of 'symptom irrelevance,' patients may have also trivialized their symptoms because they did not want to bother busy, task-oriented nurses, suggesting they felt that nurses' tasks were more important than their concerns. Participants commented that the nurses were more focused on their work and accepted this as being normal, although their comments indicated that they would have liked to be treated as individuals. However, even though participants felt there was inadequate communication about symptoms, they did not blame the nurses. Participants attributed the lack of time and therapeutic dialogue to the nurses being too busy. Pontin and Webb (1995) and Attree (2001) suggest that patients are reluctant to openly criticize nurses because of the fear of retribution, or the passive nature of the patient role, or acceptance of the constraints of health care. Consistent use of the ESAS may aid nurses in honing in on issues that are bothersome to patients. It would also improve and simulate communication between the nurse and patient, leaving the patient to feel that they had been the primary focus, rather than tasks.

Another theme that emerged related to barriers to symptom management was 'guesswork.' This theme describes the uncertainty that some patients had in knowing what symptoms they should report and when they should disclose this information. Because of this guesswork, patients may have trivialized their symptoms as not being important enough (i.e., symptom irrelevance) and waited to be asked about them (i.e., needing to be invited). A large part of the ESAS tool's success in this project is that it

eliminated the guesswork that patients had, as well as the need to be invited, as the tool is a form of invitation; thus, the patient was less likely to trivialize their symptoms, because the responses to their symptom experiences were central to the assessment. The theme of 'communication' emerged from the positive participant feedback on using the ESAS, and demonstrated that the tool did eliminate the guesswork involved in communicating their symptoms.

'Trust and vulnerability' was the theme cited most frequently from the discussions with the participants. Patients commented on how difficult it was to disclose their symptoms, particularly symptoms related to emotions, to their nurses. This may be explained by the 'McDonalization' of attitudes and lack of emotional link between nurse and patient, that resulted in patients not feeling reassured, safe, and cared for as individuals. According to McCabe (2004), patients need to know that they can trust nurses to be open, honest, understanding, and available to them. The 'skepticism' theme also reinforces this lack of trust. Patients indicated nurses didn't look at some of their responses on the ESAS, further contributing to the impression that they were not receiving individualized care. If nurses fail to hear and empathize with their patients, then they cannot help them to understand or cope effectively with their symptoms (Morse et al., 1992; Peplau, 1997; Reynold & Scott, 2000).

It is important to further prevent the trend toward a conveyor-belt culture of health care. A committed use of a symptom assessment tool such as the ESAS may help nurses hone in on patient symptoms and unmet needs, as made apparent in the responses of

nurses, who did report that the tool helped them in communicating with their patients. Based on the findings of this evaluation, use of a tool such as the ESAS is efficient and convenient to use in today's fast paced care settings, while still encouraging of a holistic approach to symptom management.

### Summary

Overall, the nurses who participated in this pilot project had positive feedback in using the ESAS. The majority agreed that it helped them improve communication with patients, saved time in their assessments, and identified more symptoms, earlier. The ESAS graph was reported to be helpful in monitoring and influencing the daily management of care they provided to their patients, and most respondents felt that it was a valuable addition to their practice. Patients overall agreed that the tool facilitated better communication and consequently, better care. Themes emerged from patient interviews describing why patients would not have disclosed details of their symptom experience if they hadn't used the ESAS. Essentially, the ESAS helped patients perceive, actualize, and affirm what they were experiencing. It also eliminated the need to be invited, and the guesswork involved in deciding what and when to disclose. Because this tool focuses on a patient's perspective, it put the patient's symptoms first, and gave patients a forum to discuss their symptoms; this may reduce patients' feelings of uncertainty and that symptoms are trivialized. The ESAS addresses emotional disturbance, hence, it facilitates discussion of symptoms such as depression or anxiety, which participants admitted were more difficult to talk about. Moreover, having these discussions may alleviate patients

thinking that nurses are only concerned with physical symptoms. If therapeutic dialogue ensues, patients will not feel that their emotions are of lesser value and they may be able to develop better coping skills to deal with their diagnosis and illness.

### Challenges

During the ESAS orientation meetings, nursing staff appeared supportive and keen to pilot the ESAS project on their unit. However, when the time came to administer the tool, nursing staff seemed less committed. For example, if the project leader did not prepare the ESAS graph and assessment forms and place them on the patients' charts, the assessments tended not to be done. If the project leader was not on the unit, the assessment would not have been started, despite repeated attempts to encourage staff to initiate the assessments on their own. Staff who were questioned felt that this was related to the fact that this was a new process. Other staff disliked the added paper work and some reported that their assessment skills were adequate without the use of this tool. In hindsight, further in-servicing and regular discussion about the ESAS with staff may have remedied some of these challenges. Using change theory, reflective practice and determining ways to give nurses more of a voice about their assessment patterns may have given them more control over the process, and thus, more ownership and appreciation of symptom assessment and management.

Although reminders were e-mailed, posted in the staff washroom, staff lounge, and charting areas, perhaps additional in-servicing may have enhanced nurses ownership in administering the tool. As well, during the pilot there was a change in leadership, both

the unit manger and the clinical resource nurse had left, so the culture on the unit was undergoing change.

Despite the inconsistent compliance using the tool throughout the project, nurses and patients generally gave positive feedback about its use. One nurse approached the project leader after a presentation of the ESAS patient evaluation findings and expressed that as a result of the participant feedback, she was going to continue to use it in her daily practice after the pilot.

#### Implications for Education and Practice

The findings of this project have illuminated communication issues related to symptom assessment and symptom management. Thus, there are important implications for nursing education and practice. Symptoms serve as an intervention focus for nurses as they care for acutely ill patients with cancer. As a professional practice, it is not enough for nurses to merely understand the process of symptom identification, evaluation, and response. Exploration of ways to influence this process and the subsequent outcomes is needed.

The participants' responses in this project indicated that nurses do not always communicate in a patient-centered way. However the literature (Fosbinder, 1994; Peplau, 1998; Thorsteinsson, 2002) suggests that nurse-patient relationships are essential for quality nursing care and that this can only be achieved through therapeutic, patient-centered communication. The implications of this evidence is that if health care management wants to ensure that patients receive quality nursing care, they must promote

therapeutic communication as essential, and not an option (Chant et al., 2002). Astedt-Kurki and Haggman-Laitila (1992) suggest that patient-centered communication does not require additional resources. Patient-centered communication is initiated by nurses in words and body language that they choose to use when approaching patients. This implies that staff shortages or being 'too busy' cannot be used as an excuse for poor nurse assessments and communication practices. It is the quality of the interaction, the emotional link that determines whether the nurse-patient communication is therapeutic or not. Commitment to providing patient-centered care and a change in individual, professional, and organizational values is sufficient to have a positive impact on the delivery of quality nursing care and symptom management strategies (Attree, 2001). Adopting a symptom assessment tool is a way of encouraging patient-centered communication, by putting patient needs and concerns at the forefront of the nurses' assessment. Management would do well to promote such a tool and provide continuing education for nurses to address the importance of a thorough holistic approach to patient assessment.

Regardless of what assessment tools are used in practice, symptom management can only improve if nurses remain interested in patient-centered care and communication. If this does not occur, tools like ESAS will likely become routine instruments in the assembly line of 'McDonaldized' health care. Reflective practice is necessary for nurses to critically examine their own practice and commitment to holistic nursing care. Such care of the nurse activities may help prevent nurses from the protective emotional

disengaging from patients that sometimes occur in practice and enable to perform holistic assessment of their patients.

At the undergraduate and graduate level, nursing education related to patient-centered communication should focus on illustrating that this type of interaction does not require a great deal of time, rather it requires putting the emotion back into the action. According to Ritzer (1996), 'McDonaldization' of health care may be too powerful to halt. While Meštrović (1997) offers no solution to this 'post-emotionalism,' he does suggest that "the first step towards eventual emancipation from post-emotionalism must include the realization that the problem exists" (p.162). Acknowledging that a problem exists may be the first hurdle; some of the nurses on the pilot unit did not feel that they needed the ESAS even though 85% of the nurse participants reported that the ESAS was a useful addition to their practice and 42% reported that it helped them identify symptoms earlier. An educational strategy to increase the 'buy in' for nurses to the use of the ESAS assessment tool is recommended. Nurses may also need ongoing continuing education to move beyond focused physical assessments to include the psychosocial perspective. In practice, the ESAS can facilitate this need for a more holistic assessment by providing an effective means to quickly establish if and what symptoms need to be addressed. Symptom experience is complex and multidimensional, and therefore the assessment and management of symptoms can be complex. Although the ESAS may not be the paragon of the ideal symptom assessment, it does provide our efficiency driven 'McDonaldized' health care system with "an organic french fry;" while it is not perfect, it is a simple,

quick, and efficient compromise.

Patient education should also be part of nursing practice. Patients need education and encouragement as to when and what to tell their care providers. The ESAS can contribute to this patient education by guiding patients to what the nurse needs to know, thereby increasing their control and ability to express unmet needs.

As a result of this project, the project leader is partnering with nurse leaders within the institution for the purpose of expanding the use of the ESAS through the center. The knowledge gleaned from the implementation of this project will provide insight into the strategies that will optimize the acceptance and integration of the ESAS in nursing practice. Accordingly, change theory techniques will be employed to facilitate the broader change and the specific findings of this project will be communicated to increase awareness of symptom assessment issues. Addressing the barriers to excellence in symptom assessment will be the focus, followed by further evaluation of the tool.

#### Recommendations for Research

While this project demonstrated that the ESAS improved symptom assessment and management for gynecology patients admitted to acute care, further research into symptom assessment, management and outcomes is required. Clinically, further validation of the ESAS for use in acute care would be a worthwhile endeavor. Retrospective chart reviews and or randomized trials examining symptom control before and after ESAS use would provide valuable data on the tool's long term use in symptom assessment and management.

If, as Fosbinder (1994) and Oermann et al., (2000) suggest, good communication is essential for quality nursing care and symptom management, then it is imperative that nursing research elicits and explores patients' experiences of nurse-patient communication and identifies what they value most in their interactions with nurses. Such information can inform nursing theory and education and therefore, enable nurses to develop patient-centered communication skills that are fundamental to the delivery of quality nursing care.

Woodward (1997) asks nursing to reflect on what it sacrifices as its professional identity shifts. Studies exploring the attitudes of nurses, the missing emotional link in the nurse-patient relationship, and what motivates nurses to provide excellent care are needed. Research that explores patients' experiences of how they communicate with health care providers is also needed. Patient focused studies may identify nursing behaviors that patients value highly in terms of patient-centered communication. This kind of information would enable nurses to demonstrate and develop specific interpersonal skills and assessment skills that are patient-centered.

Implementation of the ESAS on an acute care unit has been discussed in the context of Symptom Experience and Symptom Management within the Conceptual Model of Symptom Management. Further research that addresses the ESAS role within the third domain, Symptom Outcomes is also recommended. Study designs that evaluate the impact of the ESAS on the outcomes identified in the model, including: self-care ability, emotional status, functional status, health services utilization, morbidity,

mortality, and quality of life are recommended. Study that examines the relationship between locus on control and ESAS may also provide useful findings.

### Limitations

There were several important limitations in this project. This was a descriptive evaluation. The elementary design of a descriptive evaluation can be regarded as unscientific, biased, or trivial (Øvretveit, 1998), thereby limiting the impact of any findings. However, this design worked well in this project pilot in accomplishing the goal of providing baseline data on the use of the ESAS in an acute care setting. This project had a small convenience sample; although acceptable for the aims of a pilot project, convenience sampling is problematic as it is less likely than probability sampling to produce accurate and representative samples and thus impacts on the generalizability of the results (Polit & Hungler, 1999). Limitations are further compounded by smaller sample sizes because of the increased likelihood of sample bias, which tends to produce less accurate estimates than larger samples (Polit & Hungler, 1999). Moreover, the homogeneity of the sample, which consisted of women with gynecological cancers, limits the ability to generalize the findings to any other group. Bias may also have been introduced by the project leader through provision of specific items on the questionnaire for which participants selected their answers. Although these limitations have implications when interpreting data and drawing conclusions, the study has provided valuable insight into some of the complexities of symptom assessment and symptom management of the gynecology population in the acute care setting.

### Communication of Findings

Results of this project will be presented at the practicum defense. Results have previously been presented to the unit nursing staff involved in the project, and at the 14<sup>th</sup> Annual Provincial Hospice Palliative Care Conference in Winnipeg, Manitoba. A poster abstract was displayed for the 2005 Health Sciences Nurses Week Celebration. Results will be submitted for further presentations at other appropriate local, national, and international nursing conferences. The findings will also be submitted for publication in a peer-reviewed journal. Additionally, a written report will be made available to patient and nurse participants upon their request.

### Summary

This project was founded on the hypothesis that the use of the ESAS would improve symptom management in patients who were diagnosed with gynecological cancer and had been admitted to acute care, by providing a structured approach to symptom assessment. Used routinely, the scale provided an opportunity for patients to report their symptoms to their nurse, and focused communication upon a range of symptoms that patients felt were particularly relevant to them. The scaling of responses provided an opportunity for nurses to monitor the symptom experience over the course of treatment, and for evaluating the efficacy of treatments given for symptom relief.

The ESAS assesses commonly experienced symptoms and focuses on patients' experiences, including psychological symptoms. The use of a self report, and the measurement of severity provides a patient centered account of symptom experience.

Nurses have a key part to play in assessing patients' symptoms. A standardized symptom assessment tool is useful in practice but only if nurses remain open-minded, and above all listen to and believe what their patients tell them. Symptoms challenge nurses to examine the underlying causes, assess the manifestations, plan, implement effective measures of resolution, and understand the symptom experience. Ultimately, this should lead to more effective symptom management and overall patient outcomes.

Caring is the invisible essence of nursing. Although it is difficult to observe, recognize, and describe, caring is the dominant paradigm for nursing practice. Financial constraints in health care produces time constraints for nurses and thus, threatens the survival of the less quantifiable but most important dimension of nursing - caring. The utilization of an uncomplicated standardized symptom assessment tool such as the ESAS is not only timely to use in nursing practice, but will facilitate resolution of bothersome symptoms for patients and can be instrumental in engaging professional carers in therapeutic dialogue with patients about their experience of symptoms and the meaning it has for them.

The ESAS demonstrated to be a fast and effective means to open doors to patient and nurse discussion. In this project it educated nurses about symptoms that they would not have known are troublesome to their patients, as it guided patients to disclose information to their nurses that they would not have otherwise done. As symptom assessment is the first key step in improving symptom management and consequently, outcomes. The ESAS tool would be effective in increasing holistic, quality care in today's

busy, high paced acute care climate.

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DATE \_\_\_\_\_ HSC NO. \_\_\_\_\_  
 PATIENT \_\_\_\_\_  
 DOB \_\_\_\_\_  
 PROV HC# \_\_\_\_\_  
 DOCTOR \_\_\_\_\_  
 CLINIC/UNIT \_\_\_\_\_ LOC'N \_\_\_\_\_

**EDMONTON SYMPTOM ASSESSMENT SYSTEM:  
 NUMERICAL SCALE**

Please circle the number that best describes:

No pain	0 1 2 3 4 5 6 7 8 9 10	Worst possible pain
Not tired	0 1 2 3 4 5 6 7 8 9 10	Worst possible tiredness
Not nauseated	0 1 2 3 4 5 6 7 8 9 10	Worst possible nausea
Not depressed	0 1 2 3 4 5 6 7 8 9 10	Worst possible depression
Not anxious	0 1 2 3 4 5 6 7 8 9 10	Worst possible anxiety
Not drowsy	0 1 2 3 4 5 6 7 8 9 10	Worst possible drowsiness
Best appetite	0 1 2 3 4 5 6 7 8 9 10	Worst possible appetite
Best feeling of wellbeing	0 1 2 3 4 5 6 7 8 9 10	Worst possible feeling of wellbeing
No shortness of breath	0 1 2 3 4 5 6 7 8 9 10	Worst possible shortness of breath
Other problem	0 1 2 3 4 5 6 7 8 9 10	

Patient's Name \_\_\_\_\_  
 Date \_\_\_\_\_ Time \_\_\_\_\_

**Completed by** (check one)  
 Patient  
 Caregiver  
 Caregiver assisted



## Appendix C - Patient Evaluation

### Part One - Survey Questions

Script: Thank you for agreeing to take the time to complete this brief survey. The information that you provide will be very helpful in evaluating the symptom scale.

The following questions are about your experience using the Edmonton Assessment Tool (ESAS).

For the first 8 questions basically Yes or No answers are required, however, I will encourage you to elaborate on some of your answers if you wish.

1. Did you find the ESAS form easy to fill out?	YES	NO What made it difficult?
2. Did you find the instructions on how to fill out the tool clear?	YES	NO Why not? What was unclear?
3. Did the form contain all of the symptoms that are of a concern to you?	YES	NO What symptoms were missing?
4. Would you have told your nurse, or the doctors about your symptoms if it had not been identified in the assessment form?	YES	NO Why not?
5. Were the symptoms that were concerning to you effectively dealt with by your health care team?	YES	NO Can you give an example?

6. Do you feel that by using the ESAS form, your symptoms were taken care of in a better way?	YES	NO
7. Do you think this ward should continue to use this assessment form?	YES	NO
8. Did the ESAS tool help you better perceive the symptoms you were experiencing?	YES	NO

**Appendix C – Patient Evaluation**  
**Part Two - Open-ended Questions**

1. What are your most bothersome symptoms?
2. Is there anything you would like to add about your experience using the Edmonton Symptom Assessment Scale?
3. What kind of cancer do you have?
4. How old are you?
5. What is the highest level of education that you have?
  - Less than high school
  - High school diploma
  - Technical school/certificate/diploma
  - University degree
6. What is your marital Status?
7. What is your cultural ancestry?

### Appendix D - Nurse Evaluation and Cover Letter

Thank you for taking the time to complete this survey, it will be helpful in evaluating the Edmonton Symptom Assessment System (ESAS) and its continued use on this unit and possibly extending its use throughout Health Sciences Centre.

The following questions ask about your experience using the ESAS. Answer each question by circling YES or NO in the appropriate column. Extra space is provided for you to explain on your answers, or to provide examples, if you chose.

1. Did you find the ESAS scores easy to use?	YES	NO Why not?
2. Did you find the location of the ESAS graph in the patient chart appropriate?	YES	NO Where should it be kept?
3. Did the ESAS contain all the symptoms you wished to assess?	YES	NO What additional symptoms should be included?
4. Since using the ESAS, have there been symptoms that you would not have otherwise known to be present in your patients?	YES	NO
5. Did you find that ESAS helped to improve communication related to symptoms between you and your patients?	YES	NO
6. Since using the ESAS, has the number of referrals to other team members such as dietician, social worker, palliative care CNS, spiritual care, increased due to better symptom recognition?	YES	NO
7. Were patients able to complete the ESAS without a lot of timely explanation?	YES	NO
8. Have you found ESAS to be useful in your practice?	YES	NO

9. Did using the ESAS graph help you better assess the effects of medical/nursing interventions in your patient's symptoms?	YES	NO
10. Do you feel that using ESAS enabled you to identify symptom(s) earlier?	YES	NO
11. Did the ESAS help you to save time by allowing you to focus in problems that were an issue (less time needed to assess problems that were not an issue?)	YES	NO
12. Did you find the ESAS graph a useful display of patient symptom trends?	YES	NO
13. Did the information on the graph influence or change the day to day management of the patient's care?	YES	NO

The following information will be helpful in completing the evaluation if the ESAS.

Please answer:

1. How old are you?
  
2. What is the highest level of post-secondary education who have completed?
  
3. How many years have you worked as a nurse?

Additional comments (complete on back of page if needed):

## Appendix D – Continued

### Cover Letter to Nurses Accompanying the Nurse Evaluation

(DATE)

Dear Nurse:

It has been a pleasure working with you during the implementation of this ESAS scale on your unit. It is now time for the collection of the nurses' perspective of the ESAS tool's utility and feasibility. Enclosed, please find attached a 13 question "yes" or "no" survey, followed by three demographical questions. I ask that you complete it and add any additional comments you may have on the form. Please do not put your name on the form as all responses are to be kept anonymous and confidential. Participation is voluntary; you are not required to participate.

By returning the completed form, your consent to participate in this phase of the ESAS evaluation is assumed.

You can return the completed the evaluation, by putting it in the envelope provided and placing it in my designated mailbox on your unit. All the information you provide will be kept strictly confidential. Only myself and my project advisor will have access to the information you provide. Your name will not appear on any reports of this project, or any future publications. During and after the project, all data will be stored in a locked cabinet and kept for no more 5 years and then destroyed.

I would be pleased to share the results of this evaluation project with anyone who is interested. If you would like to receive a summary report of the findings, please contact me at the number listed below.

Again, I sincerely thank you for your assistance in this project. Please do not hesitate to contact me if you would like to discuss any aspect of this project further.

Sincerely,

**Michelle Kralt, RN**  
**University of Manitoba**



UNIVERSITY  
OF MANITOBA

RESEARCH SERVICES &  
PROGRAMS  
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## APPROVAL CERTIFICATE

28 April 2004

**TO:** **Michelle Kralt** (Advisor J. Sawatzky)  
Principal Investigator

**FROM:** **Stan Straw, Chair**  
Education/Nursing Research Ethics Board (ENREB)

**Re:** **Protocol #E2004:039**  
**"Implementation and Evaluation of the Edmonton Symptom**  
**Assessment Scale in gyne-oncology Patients Admitted to Acute**  
**Care: A Pilot Project"**

---

Please be advised that your above-referenced protocol has received human ethics approval by the **Education/Nursing Research Ethics Board**, which is organized and operates according to the Tri-Council Policy Statement. This approval is valid for one year only.

Any significant changes of the protocol and/or informed consent form should be reported to the Human Ethics Secretariat in advance of implementation of such changes.

**Please note that, if you have received multi-year funding for this research, responsibility lies with you to apply for and obtain Renewal Approval at the expiry of the initial one-year approval; otherwise the account will be locked.**

*Get to know Research ...at your University.*



MS7 - 620 SHERBROOK STREET  
WINNIPEG, MANITOBA R3A 1R9

DIAL DIRECT (204) 787-4514  
FAX (204) 787-4547

OFFICE OF THE DIRECTOR OF RESEARCH

April 30, 2004

Ms Michelle Kralt  
Principal Investigator

Dear Ms Kralt

**RE: IMPLEMENTATION OF EVALUATION OF THE EDMONTON SYMPTOM  
ASSESSMENT SCALE IN GYNE-ONCOLOGY PATIENTS ADMITTED TO ACUTE  
CARE: A PILOT PROJECT.**

**ETHICS #: E2004:039 RIC #: RI04:051**

The above-named protocol, has been evaluated and approved by the HSC Research Impact Committee.

The Department of Research wishes you much success with your study.

Sincerely

Ms Karen Shaw  
Research Protocol Officer  
Health Sciences Centre

cc: Director of Research  
Ancillary Services, Finance Division



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OF MANITOBA

**Appendix G**  
**Introductory Letter to WR5 Nurses**

Dear WR5 Nurse:

My name is Michelle Kralt and I am a registered nurse and currently employed at Cancer Care Manitoba. I am writing to inform you of an upcoming practicum project taking place on your unit. As a background, your clinical resource nurse expressed an interest in the use of symptom assessment tools in oncology patients, and so, as part of the requirements of my master's degree at the University of Manitoba, I will be implementing and evaluating the use of the Edmonton Symptom Assessment Scale (ESAS) as a pilot project on your hospital unit. The evaluation will be carried over 30 days.

The ESAS is an assessment tool to be used by nurses to help both patients and nurses recognize symptoms that oncology patients experience. There are two parts to the ESAS: 1) the scale, and 2) the graph. The scale will be given to the patient and they will be asked by their nurse to rate their symptoms twice a day. If the nurse deems it necessary, the scale may be used more or less frequently. Afterwards, the nurse will transfer the patient information onto the graph, which is similar to a vital signs record. This graph will be kept in the patient's chart.

Based on the nature of illnesses and types of admissions your unit has, your ward was chosen as the pilot unit for testing the ESAS before implementing it throughout Health Sciences Centre.

The project will start (date to be determined). I will start the project by providing three education sessions, to be held during your morning coffee breaks. At that time, I will explain more about the project and address any questions or concerns you may have.

Your input is invaluable to this project. Once the tool has been used for a few days, I will be evaluating patients' perspective on whether they feel the tool is useful in helping them express their symptoms. After a month of using the tool, I will be requesting your feedback as to whether you feel the tool is useful in your nursing practice. I will explain how I plan to do this at the education sessions. I have attached the ESAS forms for your review prior to the sessions.

Please feel free to contact me if you have any concerns or questions you would like to discuss prior to the session, or anytime during the project.

I am looking forward to meeting you and working with your unit on this project.

Sincerely,

Michelle Kralt, RN

Education session dates:  
Monday (DATE)  
Tuesday (DATE)  
Friday (DATE)

**Appendix H**  
**Introductory Letter to WR5 Clerical Staff**

Dear WR5 unit clerk:

I am writing to inform you of an upcoming symptom assessment project taking place on your unit. The Edmonton Symptom Assessment Scale is an assessment tool to be used by nurses to help both patients and nurses recognize symptoms that oncology patients experience. Starting (date to be determined), this tool will be used on WR5 in all oncology patients.

There are two parts to the ESAS: 1) the scale, and 2) the graph. The scale will be given to the patient and they will be asked by their nurse to rate their symptoms twice a day. If the nurse deems it necessary the scale may be used more or less frequently. Afterwards, the nurse will transfer the patient information onto the graph, which is similar to a vital signs record.

Your role in this project will be to addressograph both the forms. As the scale will be discarded after its information is transferred to the graph, you will not need to file this form in the chart. The graph is to be filed under the Graphic Flow Sheet section in the patients' chart.

I will be providing six education sessions for nursing staff during the week of (date to be determined). You are invited to attend one of these sessions.

Please feel free to contact me if you have any concerns or questions you would like to discuss prior to the session, or at any time during this project.

Sincerely,

Michelle Kralt, RN

Education session dates:  
Monday morning coffee break (DATE)  
Tuesday morning coffee (DATE)  
Friday morning coffee (DATE)

## **Appendix I**

### **ESAS Orientation Outline**

#### **Introduction**

- ▶ introduction of project leader
- ▶ brief introduction to the statement of the problem
- ▶ explanation of project, emphasis on its significance and rationale
- ▶ brief explanation of the conceptual framework that is guiding the project
- ▶ why WR5 is test pilot (i.e., many patients with life limiting illness, gyne-oncology patients have many symptoms)
- ▶ briefly discuss assumptions of the tool (i.e., earlier identification of symptoms, improved quality of life due to earlier symptom identification; enhanced symptom management; structured assessment tool is more sensitive than open-ended questions)

#### **Edmonton Symptom Assessment Scale (ESAS)**

- ▶ brief background of ESAS
- ▶ description of ESAS
- ▶ known benefits of using structured assessment tool
- ▶ discuss limitations of the tool (i.e., unidimensional)

#### **Procedure**

- ▶ how it to use ESAS
- ▶ project leader's role during project and availability on the unit
- ▶ expected time frame (start through finish)

#### **Project Evaluation**

- ▶ discussion of the nurses role in using ESAS
- ▶ explanation of the nurses role in approaching patient for consent for project leader to evaluate
- ▶ patients' perspective on the ESAS tool.
- ▶ request for nurses to participate in evaluation

#### **Discussion**

- ▶ questions, comments, suggestions from staff

## Appendix J

### Edmonton Symptom Assessment (ESAS) Guideline Information

(Capital Health Carinas Health Group. (N.D.). The Edmonton Symptom Assessment System. Retrieved Feb 1, 2004, from <http://palliative.info/pages/Tools.htm>)

#### What is the Purpose of the ESAS

- ◆ to assist in the assessment of nine symptoms common in cancer patients: pain, tiredness, nausea, depression, anxiety, drowsiness, appetite, well-being and shortness of breath

#### How does it work?

- ◆ The severity at the time of assessment of each symptom is rated from 0 to 10 on a numerical scale, 0 meaning that the symptom is absent and 10 that it is of the worst possible severity.
- ◆ The patient and family should be taught how to complete the scales.
- ◆ The ESAS provides a clinical profile of symptom severity over time. It provides a context within which symptoms can begin to be understood. However, it is not a complete symptom assessment in itself. For good symptom management to be attained the ESAS must be used as just one part of a holistic clinical assessment.

#### How use the ESAS

- ◆ The patient circles the most appropriate number to indicate where the symptom is between the two extremes.  

**No pain   0 1 2 3 4 5 6 7 8 9 10   Worst possible pain**
- ◆ The circled number is then transcribed onto the symptom assessment graph.
- ◆ Synonyms for words that may be difficult for some patients to comprehend include the following:
  - Depression - blue or sad
  - Anxiety - nervousness or restlessness
  - Tiredness - decreased energy level (but not necessarily sleepy)
  - Drowsiness - sleepiness
  - Well-being - overall comfort, both physical and otherwise; truthfully answering the question, "How are you?"

#### When to do the ESAS

- ◆ The ESAS should be completed twice daily for the first two days upon admission. Additional assessments can be made if the nurse deems necessary. Conversely, if there are no notable differences in symptom scores in the morning and evening after two days of use, the ESAS form can be completed once daily during the nurse's shift assessment.

#### Who should complete the ESAS form?

- ◆ Ideally, patients fill out their own ESAS. However, if the patient is cognitively impaired or for other reasons cannot independently do the ESAS, then it is completed with the assistance of a caregiver (a family member, friend, or health professional closely involved in the patient's care).

#### Where to document the ESAS

- ◆ The ESAS is always done on the ESAS Numerical Scale and the results *later transferred to the ESAS Graph*. Graphing symptom severity directly onto the ESAS Graph without the use of the numerical scale is not a valid use of the ESAS nor a reliable method of symptom assessment.

**Appendix K:  
Memo to WR5 Multidisciplinary Staff**

DATE

MEMORANDUM

TO: WR5 Nurses, Attending physicians/residents, Ella Manicure, RSC; Patti Findlay, RSC; Winnipeg Regional Health Authority Long Term Care Officers; Susan Finlay, Palliative Care CNS; Aboriginal Services; Health Sciences Centre Spiritual Care; Health Sciences Centre Rehabilitation Services; Health Sciences Centre Home Care Coordinators

FROM: Michelle Kralt, RN; Graduate student, Faculty of Nursing, University of Manitoba

SUBJECT: Edmonton Symptom Assessment Scale Pilot Project on WR5

---

The Edmonton Symptom Assessment Scale (ESAS) is a widely used symptom assessment tool, validated in studies and extensively used in research and day-to-day clinical care of individuals with life-limiting illness. The ESAS is to be implemented with all oncology patients on WR5 effective (date to be determined), which will be followed by a 30 day evaluation of the tool by patients and nurses. This project will be headed up by Michelle Kralt, RN.

The purpose of the tool is to improve symptom recognition among oncology patients. The purpose of the evaluation will be to appraise the ESAS tool's ability to remove barriers to adequate symptom assessment and facilitate symptom evaluation, thus leading to improved intervention of distressing symptoms. The ESAS graphical information can be found filed in the Graphic Flow Sheet section within the patients' chart. See enclosed ESAS forms for review.

If you would like to know more about this project, how you can use it in your practice, or have any concerns, please don't hesitate to contact Michelle Kralt

**Appendix L**  
**Patient Consent Form**

**Project Title: Implementation and Evaluation of the Edmonton Symptom Assessment Scale**

**Project Leader: Michelle Kralt, RN; BSN**

**Committee Chairperson: Dr. Jo Ann Sawatzky, RN; PhD**

*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 carefully and to understand any accompanying information.*

This evaluation is being conducted as part of my requirements for the Master of Nursing Program. If you choose to participate, your assistance is appreciated.

An accurate and thorough assessment of patients' symptoms is important so that the health care team, including doctors, nurses and others, can provide the best care possible and hopefully relieve bothersome symptoms and improve patient outcomes.

The purpose of this project is to pilot the Edmonton Symptom Assessment Scale (ESAS) form with a group of patients. The results of this project will be helpful in assessing whether this is an appropriate form to use for patients on this ward.

As part of the evaluation of the ESAS, all patients who have used the form are being asked to participate in this evaluation. You have had the opportunity to use the ESAS multiple times, and so, you are being asked to give your feedback on this form.

Participation is voluntary; you are not required to participate. If you chose not to participate, the care you receive on this ward will not be affected. Although your participation may not benefit you directly, it is hoped that the results of this project will benefit patients in the future.

There are no known risks to participating; the cost to you involves about 15 minutes of your time to complete the evaluation. The evaluation is comprised of 8 yes or no questions and 5 questions to be answered verbally. You do not have to answer all the questions. Your participation is voluntary.

All the information you provide will be kept strictly confidential. Only myself and my project advisor will have access to the information you provide. Your name will not appear on any reports of this project, or any future publications. Despite efforts to keep your personal information confidential, absolute confidentiality cannot be guaranteed. Your personal information may be disclosed if required by law. During and after the project, all data will be stored in a locked cabinet and kept for no more than 5 years and then destroyed.

If you are interested in receiving a summary report of the findings of this project, please contact the project leader, Michelle Kralt, at the number or e-mail address listed below.

Thank you for taking the time to read this explanation.

Michelle Kralt, RN, BSN  
University of Manitoba

*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. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions 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.*

Michelle Kralt - Master's Student  
Faculty of Nursing- University of Manitoba

Dr. Jo Ann Sawatzky - Supervisor  
Faculty of Nursing- University of Manitoba  
Tel: 474-6684  
E-mail: Joanne\_Sawatzky@umanitoba.ca

This research has been approved by the Faculty of Nursing Ethical Review Committee. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Secretariat at 474-7122 or e-mail Margaret\_Bowman@umanitoba.ca. A copy of this consent form has been given to you to keep for your records and reference.

---

Participant's Signature

Date

---

Researcher and/or Delegate's Signature

Date

**Appendix M – The Mental Status Questionnaire**

Adapted from Kahn, Goldfarb, Pollack, & Peck, (1960) as cited in McDowell, I. & Newell, C. (1996). *Measuring Health: A guide to rating scales and questionnaires* (2<sup>nd</sup> ed.). New York: Oxford University Press.

1. What is the name of this place?
2. Where is it located (address)?
3. What is today's date?
4. What is the month now?
5. What is the year?
6. How old are you?
7. When were you born (month)?
8. When were you born (year)?
9. Who is the prime minister of Canada?
10. Who was the prime minister before him?

### **Appendix N: Nurse Consent Form**

**Project Title: Implementation and Evaluation of the Edmonton Symptom Assessment Scale**

**Project Leader: Michelle Kralt, RN; BSN**

**Committee Chairperson: Dr. Jo Ann Sawatzky, RN; PhD**

*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 carefully and to understand any accompanying information.*

This evaluation is being conducted as part of my requirements for the Master of Nursing Program at the University of Manitoba. If you choose to participate, your assistance is appreciated.

An accurate and thorough assessment of patients' symptoms is important so that the health care team, including doctors, nurses and others, can provide the best care possible and hopefully relieve bothersome symptoms and improve patient outcomes.

The purpose of this project is to pilot the Edmonton Symptom Assessment Scale (ESAS) form with a group of patients. The results of this project will be helpful in assessing whether this is an appropriate form to use for patients on this ward.

As part of the evaluation of the ESAS, all nurses who have used the tool are being asked to participate in this evaluation. You have had the opportunity to use the ESAS multiple times, and so, you are being asked to give your feedback on this form

Participation is voluntary; you are not required to participate. Although your participation may not benefit you directly, it is hoped that the results of this project will benefit patient care in the future.

There are no known risks to participating; the cost to you involves about 10 minutes of your time to complete the evaluation. The evaluation is comprised of 13 yes or no questions and 3 demographical questions. Your participation is voluntary.

All the information you provide will be kept strictly confidential. Only myself and my project advisor will have access to the information you provide. Your name will not be recorded on the evaluation forms, however your signature is necessary on this consent form, which will be kept separately from the information you disclose during the evaluation, so that identifying information can not be related back to you. Upon completion of the evaluation, the questionnaire will be separated from the consent forms and assigned a numerical code for the purpose of analysis. The consent forms will be stored separately from the questionnaires. In the future, the

project findings may be published in print or presented at health-related conferences, but at no time will your name appear on any reports of this project, or any future publications. Despite efforts to keep your personal information confidential, absolute confidentiality cannot be guaranteed. Your personal information may be disclosed if required by law. During and after the project, all data will be stored in a locked cabinet and kept for no more 5 years and then destroyed using a paper shredder.

If you would like to receive a summary report of the findings, please complete and return to me the "Request Form for Summary of Project Findings," attached to this consent form.

Thank you for taking the time to read this explanation.

Michelle Kralt, RN, BSN  
University of Manitoba

*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. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions 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.*

Michelle Kralt - Master's Student  
Faculty of Nursing- University of Manitoba

Dr. Jo Ann Sawatzky - Supervisor  
Faculty of Nursing- University of Manitoba  
Tel: 474-6684  
E-mail: Joanne\_Sawatzky@umanitoba.ca

This research has been approved by the Faculty of Nursing Ethical Review Committee. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Secretariat at 474-7122 or e-mail Margaret\_Bowman@umanitoba.ca. A copy of this consent form has been given to you to keep for your records and reference.

---

Participant's Signature

Date

---

Researcher and/or Delegate's Signature

Date

**Request form for Summary of Project Findings**

I would like to receive a summary of the findings for the project titled: "Implementation and evaluation of the Edmonton Symptom Assessment Scale in gyne-oncology patients admitted to acute care: a pilot project".

Name:

Address:

e-mail address:

Please specify if you would like to receive the summary by e-mail or by Canada Post:

\_\_\_ e-mail

\_\_\_ Canada Post

## Appendix O

### Practicum Committee Members

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### **Appendix P - Thematic Categories**

#### **Why patients would not have told their doctor or nurse about the symptoms they had indicated on ESAS, categorized into themes**

##### **Thematic Category 1: NEEDING TO BE INVITED (19% of responses)**

- ◆ "I was not asked"
- ◆ "I wasn't asked about my symptoms"
- ◆ "The nurses didn't ask me about my anxiety/depression/appetite"
- ◆ "I would only tell them how I was feeling if they asked me"
- ◆

##### **Thematic Category 2: TRUST AND VULNERABILITY (28% of responses)**

- ◆ "Admitting to anxiety is hard to do out loud"
- ◆ "Depression is hard to report"
- ◆ "Feeling depressed is hard to talk about, especially with a stranger"
- ◆ "Feeling depressed is hard to admit to.....no one talked to me about depression, even though I circled it, nurses need to take the form seriously...(they treat nausea but not depression, which is more important)"
- ◆ "[The ESAS tool] is useful for people who are shy or private"
- ◆ "Depression is difficult to talk about"

##### **Thematic Category 3: ACTUALIZATION (9% of responses)**

- ◆ Having the form helped me realize that it was normal to feel depressed.....The form helped me give more details when talking with the nurse"
- ◆ "I wasn't thinking of my symptoms"

##### **Thematic Category 4: GUESSWORK (23% of responses)**

- ◆ "I didn't know which symptoms to tell them, or I would forget to tell the nurse something when she was in the room"
- ◆ "I wasn't sure what symptoms the nurses needed to know"
- ◆ "I didn't know that nurses would want to know these symptoms"
- ◆ "I did not know what to report"
- ◆ "I didn't know to report these symptoms"

##### **Thematic Category 5: ASSUMPTION OF BIOPHYSICAL SUPERIORITY (19% of responses)**

- ◆ "I only mentioned to the nurse about having pain and nausea because there is a pill for these"
- ◆ ".....they treat nausea but not depression, which is more important"

##### **Thematic Category 6: SYMPTOM IRRELEVANCE (9% of responses)**

- ◆ "Nurses are busy, and I would forget to tell them when they were in my room"
- ◆ "I didn't want to bother the nurse unless I really had to."

### Appendix Q: Positive Feedback from Participants

#### Thematic Category 1: ACTUALIZATION and ACCEPTANCE (35% of responses)

- ◆ “[The tool] helped me be aware of what I was experiencing”
- ◆ “...it also helped me to focus my mind on what I was feeling...it helped me deal better with what was happening by organizing what my body was feeling”
- ◆ “it made me realize what I was feeling and that I was anxious”
- ◆ “it helped me stay in touch with my feelings”

#### Thematic Category 2: COMMUNICATION (42% of patient responses)

- ◆ “[The tool] helped me tell the nurse the right things
- ◆ “I was better able to perceive my symptoms because English is not my first language”
- ◆ “I wish the they had more time to talk to me about my depression, but since they don’t the form is a good idea”
- ◆ “it helped me and the nurses talk about what I was experiencing”
- ◆ “I didn’t know enough to talk about it - the tool helped me know what to talk about”
- ◆ “I was unsure what to tell the nurse or if it was a problem, so the form helped”

#### Thematic Category 3: AFFIRMATION (21% of positive patient responses)

- ◆ “the tool helped me see that what I was going through was normal”
- ◆ “my mind was eased that I had normal symptoms”
- ◆ “it’s a good idea for people who don’t want to speak up in case they are afraid of complaining”

### **Appendix R: Negative Feedback from Patient Participants**

#### **Thematic Category 1: SKEPTICISM and VULNERABILITY (50% of negative responses)**

- ◆ “I was scared they wouldn’t let me go home if I had too many things wrong”
- ◆ “Nurses didn’t look at what I circled”
- ◆ “The nurses never addressed the symptoms I circled on the form”
- ◆ “Nurses didn’t act on the information collected”

#### **Thematic Category 2: TOOL and ADMINISTRATION INEFFICIENCY (50% of responses)**

- ◆ “Tired and drowsy are too similar”
- ◆ “Too many choices in numbers
- ◆ Pain made me too confused at first to do the [ESAS]
- ◆ “The first time filling out the form was hard because I didn’t understand what I was supposed to do”