# PREVALENCE OF DELIRIUM AND ITS RELATIONSHIP TO SYMPTOM DISTRESS IN TERMINALLY ILL CANCER PATIENTS

by

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A thesis submitted to the Faculty of Graduate Studies in partial fulfillment of the requirements for the degree of Master of Nursing

University of Manitoba

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THE UNIVERSITY OF MANITOBA

FACULTY OF GRADUATE STUDIES

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## ABSTRACT

Delirium is a frequent and serious clinical problem in the terminally ill cancer inpatient population with an incidence of 80% to 90% being reported just prior to death (Fainsinger, Tapper, and Bruera, 1993). Moreover, the palliative care literature suggests that delirious patients experiencing symptom distress are not assessed or managed well (Bruera et al., 1992; Fainsinger et al., 1993). The overall purpose of this study was to determine the prevalence of delirium and/or confusion in terminally ill cancer patients upon admission to a palliative care unit and to determine if there is a significant difference in symptom distress between delirious/ confused and non-delirious/non-confused terminally ill cancer patients using the Edmonton Symptom Assessment Scale upon admission to a palliative care unit. Symptom Perception Theory guided the conceptual framework for this study. A retrospective study examining 110 terminally ill cancer patients' medical charts from Riverview Health Centre was used. Thirty-two (29%) of patients were diagnosed as delirious/confused by the palliative care physician. The nursing staff diagnosed 23 (21%) of patients as being delirious/confused upon admission to the palliative care unit. Results of this study also found a significant difference in symptom distress between delirious and non-delirious patients, as diagnosed by the palliative care physician. Non-delirious patients had higher levels of symptom distress than delirious patients. It is important that care providers are able to recognize and identify delirious patients and their levels of symptom distress upon admission to a palliative care unit so that interventions to reverse the causes of delirium and management of symptom distress can immediately be implemented.

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# CHAPTER ONE

## STATEMENT OF THE PROBLEM

Delirium is a frequent and serious clinical problem in the terminally ill cancer inpatient population with an incidence of 80% to 90% being reported just prior to death (Fainsinger, Tapper, & Bruera, 1993). There is a lack of consensus in the literature regarding the prevalence rates of delirium. The prevalence of delirium in terminally ill cancer patients has ranged from 20% to 44% on admission to a palliative care unit (Gagnon, Allard, Masse, & DeSerres, 2000; Pereira, Hanson, & Bruera, 1997; & Lawlor et al., 2000; Sarhill, Walsh, Nelson, LeGrand, & Davis, 2001) and 28% to 45% of patients developed delirium while on a palliative care unit (Caraceni et al., 2000; Minagawa, Uchitomi, Yamawaki, Ishitami, 1996; Lawlor et al., 2000). Other research studies found that 68% to 90% of patients with advanced cancer experienced delirium just prior to death (Bruera et al., 1992; Massie, Holland, & Glass, 1983; Pereira et al., 1997; Lawlor et al., 2000; Fainsinger, DeMoissac, Mancini, Oneschuk; 2000; Morita, Tei, Tsunoda, Inoue, & Chihara, 2001). These wide variances in prevalence rates of delirium were due to differences in the populations, method of delirium assessment, intensity of follow-up, and the lack of a uniform diagnostic classification system.

Delirium is a complex phenomenon that is not easily defined. Lipowski (1987) defined delirium (acute confusional states) as "a transient disorder of cognition and attention, one accompanied by disturbances of the sleep-wake cycle and psychomotor behavior" (p.1789). The American Psychiatric Association (APA) has identified the primary criteria for the diagnosis of delirium (Table 1). These primary criteria illustrate

the multiple dimensions and transient symptoms of delirium that make definition, measurement, and assessment challenging.

Table 1: DSM IV Criteria for Diagnosis of Delirium

| |
|---|
| - Disturbance in consciousness (reduced clarity of environment awareness) with impaired ability to focus or shift attention. |
| - Change in cognition (memory impairment, disorientation, language disturbance) or the development of perceptual disturbance that is not better accounted for by a preexisting, established, or evolving dementia. |
| - Disturbance evolves over a short period of time (hours-days) and fluctuates during the course of the day. |
| - Evidence is derived from the history, physical exam, or lab findings that the disturbance is caused by physiologic consequences of a general medical condition. |

From the American Psychiatric Association (1994) *Diagnostic and Statistical Manual of Mental Disorders* (4th ed.) Washington, DC: APA.

Delirium is an altered state of consciousness (reduced clarity of environmental awareness) with impaired ability to focus or shift attention. Delirium disrupts cognitive functions such as memory, orientation, language, and perception. The major neuroanatomical area involved in delirium is the reticular formation that houses the reticular activating system. The somatosensory system deals with the reception of internal and external stimuli and transmits this information via the reticular activating system to the brain (Marieb, 1992).

There are three primary levels of neural integration in the somatosensory system. The first level, the receptor level, involves the sensory receptors that detect stimulus energies from the environment and convert them into neural impulses. The circuit level is the second level that includes the ascending reticular activating system, which consists of afferent fibers running through the reticular formation. Information is relayed for three

purposes: perception, arousal, and motor control. The third level, the perceptual level, consists of the neuronal circuits in the cerebral cortex. Sensory information is transmitted to the thalamus and then to the somatosensory cortex which translates the sensory information into something meaningful (Marieb, 1992).

Delirium causes cerebral insufficiency with widespread dysregulation of neurotransmitter systems. A number of hypotheses for the pathophysiology of delirium have been generated. The first hypothesis is that delirium is a reduction in the cerebral oxidative metabolism. Engel and Romano (1959) found that a reduction in cerebral oxidative metabolism accounted for both the cognitive impairment and the concurrent slowing of the electroencephalography (EEG) background activity. Thus, any disease or toxic agent that caused a reduction of the supply, uptake, or utilization of substrates for brain metabolic activity could lead to delirium.

Another hypothesis is that delirium is an imbalance of neurotransmitters, a increase of dopamine and a decrease in acetylcholine. A reduction in cerebral oxidative metabolism causes reduced synthesis or an impaired release of the neurotransmitter acetylcholine (the main neurotransmitter for cerebral functions such as memory retrieval, attention, and arousal). Blass and Plum (1983) demonstrated that delirium could be readily induced in experimental subjects by administration of various anticholinergic agents and be reversed by physostigmine salicylate, a cholinesterase inhibitor.

Stress-induced hypercortisolism is another hypothesis for the pathophysiology of delirium. A research study by Kral (1975) proposed that an increase in plasma cortisol levels caused a stress reaction (including psychological) that manifests as confusion, and altered attention and information processing. Brain lesions are also thought to cause

delirium, with even relatively small lesions in the thalamus producing delirium. Finally, cytokines (modulators of the inflammatory response that are capable of disrupting the blood-brain barrier by injuring capillary endothelium) have been implicated in delirium from inflammatory or infectious causes (Trzepacz, 1996).

Terminally ill cancer patients are at considerable risk of developing delirium, especially older patients. Uncontrolled cancer pain, tumors in the brain, and the consequences of cancer treatment are frequent causes of delirium (Weinrich & Sarna, 1994). Cancer patients are also typically on a large number of medications, on high doses of narcotics, and take corticosteriods, antipsychotics, antidepressants and other anticholinergic drugs that are potential risk factors for delirium (Stiefel & Holland, 1991; Breitbart & Strout, 2000; Rabinowitz, 2002). As well, fluid imbalances (due to dehydration and fluid overload), biochemical imbalances such as hypercalcemia due to bone metastases, hypoalbuminemia, increased urea and creatinine levels, hypo/hyperkalemia, and hypo/hypernatremia, metabolic imbalances (hyper/hypoglycemia), nutritional deficiencies/malnutrition, hypoxia and low hemoglobin levels, and infections (that commonly arise in the lung and urinary tract), can all make the terminal cancer patient vulnerable to delirium (Macleod, 1997; Breitbart & Strout, 2000; Morita et al. 200; Lawlor & Bruera, 2002). General discomfort to the client such as urinary retention, constipation, diarrhea, and fecal impaction can also cause delirium (Weinrich & Sarna, 1994). Terminal delirium or restlessness may have existential causes such as lack of personal meaning and purpose in life or unresolved concerns about death (Travis, Conway, Daly, & Larsen, 2001). Many of the causes of delirium are potentially reversible and therefore can be treated (de Stoutz, Tapper, & Fainsinger, 1995; Pereira et

al., 1997). Delirium can be reversible even in patients with advanced cancer. However, it may not be reversible in the last 24-48 hours of life due to multiple organ failure.

Delirious patients are especially sensitive to their environment. Extremes in the patient's environment, sensory deprivation or overload are commonly associated with delirium. The hospital setting can subject patients to multiple psychological stressors and unpleasant stimuli, often in an anxiety-provoking atmosphere of urgency and crisis. As well, an unfamiliar environment, sleep deprivation, and decreased contact with family and friends are environmental factors leading to negative adaptive responses to delirium (Martin, 1990; Meagher, 2001).

The clinical presentation of delirium typically occurs shortly after admission to hospital. This time frame can range from the first 24 hours to the sixth day of hospitalization (Foreman & Zane, 1996). The onset of delirium is acute, often at night, and has a fluctuating course with lucid intervals during the day. Early diagnosis of delirium may be difficult because the patient could appear to be only anxious, angry or depressed (Adams, 1988; Nicholas & Lindsey, 1995; Roth-Roemer, Fann, & Syrjala, 1997). As well, if the nursing or physician assessment occurs during a period of lucidity, delirium is often missed. Delirious patients may present clinically as hypoactive, inactive, lethargic, withdrawn, and slow to respond, or hyperactive and agitated with constant motion, excessive and semi-purposeful activity and rapid, loud speech (Johnson, 1999; Rapp, 2001). Frequently, cancer patients may also have a mixed delirium that fluctuates unpredictably between hyperactive and hypoactive states. In these situations, it is likely that a number of cerebral mechanisms occurring simultaneously are being affected due to more than one causal factor (Trzepacz, 1996). Some of the early signs and symptoms of

delirium in terminally ill cancer patients include: anxiety, restlessness, impaired recent memory, a shortened attention span, defective orientation (especially to time), the tendency to mistake the unfamiliar for familiar places and persons, easy distractibility, changes in sleeping patterns, fluctuating emotions (in particular fear), and activity that is disorganized and without purpose (Zimberg & Berenson, 1990). Late symptoms of delirium include some of the following: uncooperative, aggressive or abusive behavior, perceptual disturbances, and speech that is incoherent, slow or rapid, or fragmented (Bergevin & Bergevin, 1996).

An accurate diagnosis of delirium in the terminally ill cancer patient is urgently needed upon admission to a palliative care unit. The misdiagnosis or under-detection of delirium not only results in the dissolution of patient autonomy and dignity but also jeopardizes optimal quality of life for the patient (Macleod, 1997). The clinical features of delirium can also be associated with other psychiatric disorders. Hypoactive delirium is typically misdiagnosed as depression or goes unnoticed completely. However, the patient with depression does not have any impairment of arousal or consciousness and has less cognitive impairment. One study by Levine et al (1978) found that 26% of patients were misdiagnosed as depressed by the physician.

Delirium is frequently undetected or misdiagnosed due to a lack of knowledge and awareness in nurses (Schuurmans, Kuursma, Shortridge-Baggett, 2001). Nurses often rely only on observation of behavior when assessing delirium. Studies have shown that nurses did not assess other functions of cognitive capacity beyond orientation to person, place, and time, and thus rates of undetected delirium ranged from 55% to 72% (Palmateer & McCartney, 1985). It has been suggested that without the use of a screening tool, even

experienced palliative care nurses overlook the presence of delirium in 24% of cases (Fainsinger, Bruera, Miller, Hanson, & MacEachern, 1991). While nursing assessment techniques may provide some data regarding a patient's mental status, subtle deficits may not be identified without formal assessment testing.

Some consequences of delirium include: falls and fractures, incontinence, pulmonary emboli and deep vein thrombosis from physical restraints, prolonged hospitalization, increased hospital costs, poor prognosis, and increased nursing care and supervision requirements (Weinrich & Sarna, 1994; Trzepacz, 1996; Boyle, Abernathy, Baker, & Wall, 1998). As well, delirium can dramatically interfere with the recognition and control of other symptoms in the terminally ill cancer population. Furthermore, delirium is disturbing to family members because it disrupts communication between the family and patient during a time when closeness is particularly important and life-closure issues could be addressed (Breitbart & Strout, 2000). It has been suggested in the literature that family members of the delirious cancer patient may feel increased emotional stress and subsequently put pressure on nursing staff to relieve the patient's suffering. Nurses consequently put pressure on physicians to quickly solve this problem by sedating the patient. Physicians then sedate rather than assessing the patient and looking for reversible causes (Fainsinger et al., 1993). Fainsinger et al. (1993) coined this phenomenon as the "destructive triangle". Thus, it is imperative that palliative care providers both recognize and manage delirium in a timely and effective manner.

Nurses have difficulty assessing pain intensity in cancer patients with agitated delirium. One study by Bruera, Fainsinger, Miller, and Kuehn (1992) found that nurses tend to overestimate the patient's level of pain and consequently administer increased

(and perhaps unnecessary) amounts of narcotics. The fourteen patients in this study could not even recall having significant discomfort during their delirious episode. Additional narcotics may exacerbate delirium or cause an opioid toxicity, further impairing the patient's ability to distinguish pain from other perceptions (Coyle, Breitbart, Weaver, & Portenoy, 1994). Assessment of pain intensity is difficult and often inaccurate in delirious patients. Family members often interpret agitated delirium as an indirect expression of pain that requires increased narcotic doses and sedatives (Bruera, 1991). However, the literature suggests that delirious patients who have pain or discomfort that is disproportionate to previous pain levels may be better treated with tranquilizers instead of rapidly escalating opioid doses (Harlos, 2000, personal communication).

Once a diagnosis of delirium has been made, specific interventions can be implemented to treat the delirium. First and foremost, the underlying cause of the delirium should be treated. A review of the patient's medications and blood work such as a complete blood count (in particular, white and red blood cells, hemoglobin, platelets), electrolytes, urea, creatinine, calcium, albumin, glucose should be done. It is also appropriate to test urine for culture and sensitivity and/or chest x-ray if symptoms of infection are noted. For the palliative cancer patient with irreversible delirium who is close to death, the goal may be to enhance the frequency and duration of periods of cognitive acuity.

If narcotics are the suspected cause of the delirium, the narcotic should be switched. Typically, since many drugs may cause delirium, discontinuation of the drug or dose reduction may result in significant improvement. In many cases, rapid and safe sedation may help to prevent injury to the agitated delirious terminal cancer patient, their

family, and health care providers. Haldol is the drug of choice for the terminally ill delirious cancer patient (Stiefel & Holland, 1991; Macleod, 1997). For the patient in their final hours to days of life, the focus of care may be on patient comfort rather than clear cognition. In this situation, sedation may be necessary. Sedation is commonly used for symptoms of agitated delirium near death (Morita, Tsunoda, Inoue, Chihara, 2000). Midazolam, which has a rapid onset and short duration of action, is useful for quickly sedating an agitated delirious patient, while allowing easy titration and reversal of sedation by decreasing the dose (Macleod, 1997). Other neuroleptics frequently used in the management of delirium and/or terminal sedation include methotrimeprazine, chlorpromazine, olanzapine, and risperidone.

Implementation of interventions to correct delirium can improve the outcome of delirium in terminally ill cancer patients, despite impending death. In a study by Lawlor et al (2000), it was found that delirium was reversible in 49% of patients with advanced cancer. Morita et al. (2001) found a remission rate of 20% in delirious terminally ill cancer patients, 37%-38% in delirium related to medications and hypercalcemia. As well, neuroleptics alone may also reverse delirium. Breitbart, Tremblay, & Gibson (2002) found that 76% of hospitalized cancer patients had a complete resolution of their delirium on olanzapine therapy. Therefore, accurate assessment and diagnosis of delirium is required so that interventions can be quickly implemented to reverse the causes of delirium.

**Purpose of the Study**

Although delirium is extremely prevalent in the terminally ill cancer population, delirium frequently goes undetected by nurses and physicians, and/or gets misdiagnosed. Anecdotal evidence suggests that delirious patients may experience greater symptom distress compared to non-delirious cancer patients. Moreover, the palliative care literature suggests that delirious patients experiencing symptom distress are not assessed or managed well (Bruera et al., 1992; Fainsinger et al., 1993). Specifically, it has been reported that health care providers looking after such individuals generally make their own assessments of the delirious patient's level of symptom distress without attempting to elicit this information from the patient directly. However to date, no studies have been conducted examining the levels of symptom distress experienced by delirious patients, as compared to their non-delirious counterparts. Therefore, the overall study's purpose is:

- to determine the prevalence of delirium and/or confusion in terminally ill cancer patients upon admission to a Palliative Care Unit.
- to determine if there is a significant difference in symptom distress between delirious/ confused and non-delirious/non-confused terminally ill cancer patients using the Edmonton Symptom Assessment Scale upon admission to a Palliative Care Unit.

It is important to know the presence or absence of delirium upon admission to a palliative care unit so that interventions can be initiated to correct a delirious state amenable to reversal.

## Research Questions

1. What is the prevalence of delirium and/or confusion in terminally ill cancer patients upon admission to a Palliative Care Unit?

2. Is there a significant difference in symptom distress upon admission to a Palliative Care Unit between delirious/confused and non-delirious/non-confused terminally ill cancer patients using the Edmonton Symptom Assessment Scale (ESAS)? Total ESAS scores and sub-scale scores using multiple comparisons are examined.

This study also sought to describe differences between the two groups (delirious/confused versus non-delirious/non-confused) with respect to demographic data, medications (narcotics and other medications), lab values, and Mini Mental State Evaluation (MMSE) scores. As well, interventions for delirium/confusion were examined through extraction of chart data.

## Summary

Research studies that seek to understand the prevalence of delirium and the relationship between delirium and symptom distress are needed. Knowledge generated from the results of this research study will be useful to help identify the prevalence of delirium in the hospitalized, terminally ill cancer population and determine if there is any difference between delirious and non-delirious patients in their determination of their symptom distress. The results of this study may aid care providers' assessment and management of symptom distress in delirious patients.

# CHAPTER TWO

# CONCEPTUAL FRAMEWORK

Accurate reporting of symptoms depends on the patient's ability to perceive symptoms normally and communicate the experience appropriately. As delirium is a global brain dysfunction, disturbed arousal, attention, cognition, and communication could impair the patient's ability to perceive and report symptoms accurately. The Symptom Perception Theory guided the framework for this research study.

**Symptom Perception Theory** (see appendix one)

Symptom perception theory is a biopsychosocial perspective on symptom perception that seeks to explain the processes that affect symptom reporting (Gijsbers Van Wijk & Kolk, 1997). In the context of this theory, 'symptom' is defined as an aversively perceived internal state. The central assumption for this theory is that a symptom is the outcome of a perceptual process. Another assumption inherent in the theory is that information that is perceived is partly dependent on the cognition and personality traits of the individual.

There are six steps in the symptom perception model: 1) information input, 2) attention, 3) detection, 4) attribution, 5) experience, and 6) behavior. The first step in symptom perception is the input of somatic information. Somatic information refers to any potential (patho)- physiological change that triggers receptors throughout the body. Somatic information input can be triggered by physiological fluctuations in normal bodily process (a decrease in blood glucose when hungry), by emotions (an increase in heart rate when angry), by environmental conditions (a drop in skin temperature due to cold), and

by pathology (an increase in body temperature due to infection). Only a small part of this internal somatic information leads to conscious sensation.

The selection of information through attentional processes is the second step. There are two processes influencing selection: external (environmental) information and selective attention to body. External information refers to any stimuli emanating from outside the body, such as sights, sounds, smells, and tactile information. The more stimulating and distracting the environment, the more external information will enter the information processing system. Selective attention to body is defined as the propensity of individuals to direct attention to normal, physiological bodily processes like energy level, hunger, and body temperature for example. A heightened selective attention to the body will enhance the processing of somatic information and thus promote the detection of somatic sensations.

The third step in symptom perception is the detection of somatic sensations. Sensation is defined as the detection of a change in somatic information. A symptom implies an evaluation of that sensation as indicative of illness or psychological turmoil. An increase in the processing of somatic information will result in the detection of somatic sensations. Somatic sensations are perceived as symptoms of somatic or psychological distress.

Attribution of sensations to somatic or psychological causes is the fourth step in the symptom perception model. Attribution of sensations refers to the meaning of somatic information for the experiencing person. There are two ways that individuals perceive sensations. These are through somatic attribution (illness resulting from psychological distress) or psychological attribution (psychological distress resulting from illness).

The fifth step of the model identifies the importance of personality characteristics on the individual's experience or expression of the perceived symptom. Two personality traits, somatisation and negative affectivity, are presumed to enhance the individual's current experience of distress. Somatisation is defined as the tendency to experience or express psychological states as somatic symptoms (Lipowski, 1988). Negative affectivity represents a diffuse, non-specific measure of subjective distress and dissatisfaction (Vassend, 1989).

The sixth step in the symptom perception model is behavior, which is formed by somatic and psychological symptoms and illness behavior. Psychological and physical symptoms are reflected in the individual's verbal and written self-report. These experienced symptoms are then reflected in the individual's illness behavior, which is divided into subjective health, sick role behavior, and medical care utilization. Subjective health is the individual's personal evaluation of his/her general health status. Sick role behavior is defined as actions taken by the individual in adopting the sick role, excluding actions that involve medical care providers. For example, self-medication or cutting down on usual activities due to illness. Medical care utilization refers to behavior that does involve the health care system, like visiting the doctor, being hospitalized or using prescription medication.

Since delirium is an altered state of consciousness with impaired ability to focus or shift attention, the selection of information through attentional processes (step two) would be altered. Delirious patients may have a decreased selective attention to the body and thus have less processing of somatic information and a lower detection of somatic

sensations. This model may explain why delirious patients have a difficult time perceiving (and thus reporting) symptoms.

**Definition of Concepts**

This study is guided by the concepts of delirium and/or acute confusion, symptom distress, perception, and palliative care. The terms 'delirium' and 'confusion' are used interchangeably in this thesis.

Delirium- a transient disorder of cognition and attention, one accompanied by disturbances of the sleep-wake cycle and psychomotor behavior (Lipowski, 1987, p.1789).

Acute Confusion- an organic brain syndrome characterized by transient, global cognitive impairment of abrupt onset and relatively brief duration, accompanied by diurnal fluctuation of simultaneous disturbances of the sleep-wake cycle, psychomotor behavior, attention, and affect (Foreman, 1986, p.34).

Symptom Distress- the degree of discomfort reported by the patient in relation to his/her perception of the symptoms being experienced (McCorkle & Young, 1978, p.373).

Perception- the process by which we organize and make meaningful the mass sensations we receive. Perception is influenced both by the stimuli that impinge our senses and by our internal mental processes (Martin, 1991, p.155).

Palliative Care- management of patients with active, progressive, far advanced disease for whom the prognosis is limited and the focus of care is quality of life (Doyle, 1993, p.253).

# CHAPTER THREE

# LITERATURE REVIEW

The review of the literature, which was limited to studies published in English, will be separated into five categories: prevalence of delirium, assessment of delirium, prevalence of symptom distress, assessment of symptom distress, and delirium and symptom distress.

## Prevalence of Delirium

The review of the literature consisted of the available published studies that focused predominantly on the prevalence of delirium in terminally ill cancer patients. Some of the research studies determined prevalence of delirium upon admission to a palliative care unit or hospice as well as delirium prevalence rates during hospitalization and prior to death. A prospective study by Lawlor et al. (2000) found that in a sample of 104 patients with advanced cancer that were admitted onto an acute palliative care unit, 42% had delirium upon admission, 45% developed delirium while hospitalized, and terminal delirium occurred in 88% of these patients. Patients in this study underwent twice weekly cognitive screening using the Mini-Mental State Exam (MMSE) and patients meeting DSM-IV criteria for delirium on admission were assessed for delirium severity using the Memorial Delirium Assessment Scale (MDAS). Gagnon et al. (2000) reported a positive incidence for a diagnosis of delirium in a prospective cohort study using the Confusion Rating Scale (CRS) in 20% of the terminally ill cancer patients who were admitted onto a 15-bed hospice. Of the patients who were negative for a diagnosis of delirium on admission, 32.5% developed delirium while admitted. Another study by

Pereira et al. (1997) used a sample of 348 advanced cancer patients admitted onto a palliative care unit to determine the frequency and clinical course of cognitive impairment. Administering the MMSE on admission and then every one to two weeks, they determined that 44% of patients had an abnormal MMSE on admission and 68% prior to death. However, this study assessed cognitive impairment and the MMSE does not specifically assess for delirium. Sarhill et al. (2001) conducted a prospective study of 50 advanced cancer patients admitted onto a palliative medicine unit. They used the Bedside Confusion Scale (BSCS) to assess for delirium and found 32% of patients were delirious on admission.

Other research studies examined the incidence of delirium in terminally ill cancer patients during hospitalization or prior to death. Caraceni et al. (2000) used a prospective multi-center consecutive case series study on 393 advanced cancer patients referred to the palliative care program. Using the Confusion Assessment Method (CAM) to screen patients for delirium, they detected a 28% incidence of delirium during hospitalization. A chart review study done by Massie et al. (1983) explored the prevalence of delirium, using a 58-item delirium scale three times per week, in 19 terminally ill cancer patients on an oncology ward. Results of this study indicated that 85% of these patients developed delirium as the patient became more ill and frequently near death. Bruera et al. (1992) reported an 83% prevalence of cognitive failure averaging 16 days before death in 61 terminal cancer patients admitted onto a palliative care unit. In this prospective study, the MMSE was used three times per week between admission and discharge or death to determine a diagnosis of cognitive failure in this study population. Morita et al. (2001) utilized a prospective study with 237 terminally ill cancer patients admitted onto a

palliative care unit to determine a 90% prevalence of delirium during patients' inpatient stay. Patients were assessed for delirium by the physician using the DSM-IV criteria for delirium, and if delirious, the severity of delirium was assessed by the MDAS and the Delirium Rating Scale (DRS). Lastly, Fainsinger et al. (2000) found a delirium prevalence rate of 80% in terminally ill cancer patients just prior to death on four palliative care units.

One research study looked at the prevalence of all psychiatric disorders in terminal cancer patients admitted onto a palliative care unit. A prospective study done by Minagawa et al. (1996), examined the prevalence of psychiatric disorders in 93 terminal cancer patients on a palliative care unit using the MMSE and the Structured Clinical Interview for DSM-III-R (SCID) within one week of admission. These researchers found that there was a high prevalence of psychiatric disorders (53.7%) in this patient population. Delirium was the most prevalent psychiatric disorder with a prevalence of 28% within one week of admission.

Two studies examined the prevalence of psychiatric disorders in cancer patients admitted onto oncology units. A retrospective chart review by Levine et al. (1978) found that 40% of 100 cancer patients (referred for psychiatric consult) on an oncology unit developed 'organic brain disease'. The 'organic brain disease' was referred to as a 'confusional state' which may indicate delirium. In another study examining the prevalence of psychiatric disorders in 215 cancer patients on three inpatient and outpatient cancer centers, 8% had an 'organic mental disorder', diagnosed using the DSM-III criteria for delirium (Derogatis et al., 1983). However, the prevalence rates in

these studies were not exclusive to delirium, nor were they exclusive to the terminally ill cancer population.

**Assessment of Delirium**

It is important that care providers are able to recognize and identify delirium in terminally ill cancer patients upon admission to a palliative care unit. Delirium is frequently undetected and misdiagnosed because of its fluctuating course (including periods of lucidity), subtle presentation of symptoms (especially in the hypoactive form of delirium), and the absence of the use of a delirium assessment scale in clinical practice. However, several scales currently exist to measure delirium. They include: the Confusion Assessment Method, the Delirium Rating Scale, the Delirium Symptom Interview, and the Confusion Rating Scale. Delirium assessment instruments should be brief, easy to read, understand, and score. As well, instruments should have some estimate of reliability and a test of validity done. Currently available delirium assessment scales that are useful for this patient population are reviewed.

Confusion Assessment Method (CAM)

This instrument, developed by Inouye et al. (1990), is a set of nine operationalized criteria for delirium from the DSM-III-R criteria, seven with open-ended questions and two with scales. The CAM has been shown to be a good diagnostic tool for terminal delirium as the CAM can quickly (five minutes) and accurately identify delirium, even if only the algorithm is used. The algorithm focuses on four domains: 1) acute onset and fluctuating course, 2) inattention, 3) disorganized thinking, and 4) altered level of consciousness. A diagnosis of delirium requires the presence of the first two domains and either of the last two domains. Studies have shown that this instrument has excellent

diagnostic and screening validity, as well as high face validity (Smith, Breitbart, & Platt, 1995). Inter-rater reliability ranged from 81-100%, sensitivity from 90-100%, specificity from 90-95%, and has excellent reliability (Inouye et al., 1990). The CAM requires information about patient abilities, which the rater may be able to answer after spending time with the patient or speaking with family members. Some limitations of the CAM include: it is not useful for assessing severity of delirium, there is a false positive rate at 10%, and some training is required for optimal use (Rapp et al., 2000).

Delirium Rating Scale (DRS)

The DRS, developed by Trzepacz, Baker, and Greenhouse (1988), is the most widely used scale to assess delirium. It may be useful for populations with terminal delirium because it has fewer ratings of cognitive items. This instrument is a ten-item rating scale that specifically integrates the DSM-III diagnostic criteria from the American Psychiatric Association and is fairly simple to administer. This scale focuses on the following domains: temporal onset of symptoms, perceptual disturbances, hallucinations, delusions, psychomotor behavior, cognitive status during formal testing, physical disorder, sleep-wake disturbance, lability of mood, and variability of symptoms. Items are scored from 0 to 3 or 0 to 4 with a maximum score of 32. The higher the score on the DRS, the more likely the patient will have a diagnosis of delirium. Lower scores may be indicative of dementia or other psychiatric disorders. The recommended cutoff score for a diagnosis of delirium is 12 points (Trzepacz, 1999). All available information from the patient interview, medical history and tests, nursing observation, and family report is used. The DRS has been studied in multiple settings with various populations. The DRS is validated specifically for use in detecting delirium, can distinguish delirium from dementia, and

assesses multiple clinical features (Rockwood, Goodman, Flynn, & Stolee, 1996). The DRS has been shown to have very good construct validity when rated over a twenty-four hour period (Trzepacz, 1999). It is reported to be a valid measure of the characteristic symptoms of delirium and measure the severity of symptoms which may allow for monitoring of patient improvement or deterioration over time (Trzepacz et al., 1988). Use of the DRS has typically been rated by psychiatrists and has not been tested using nurses as raters. Some subjective judgment is required by raters (Rapp et al., 2000).

Delirium Symptom Interview (DSI)

The DSI was developed by an interdisciplinary group of investigators as a diagnostic interview schedule to be administered daily by non-clinicians (Albert et al., 1992). Administration should take approximately 15 minutes. The DSI is appropriate for terminally ill patients who are non-communicative, since the DSI focuses on behavioral observations of delirium. DSM-III criteria are used for this instrument. Seven symptom domains are focused on: 1) disorientation, 2) disturbance of consciousness, 3) disrupted sleep-wake cycle, 4) perceptual disturbance, 5) incoherent speech, 6) change in psychomotor activity, and 7) fluctuating behavior. Each domain is assessed by a series of questions to determine the presence or absence of symptoms. The three symptoms that are critical to the diagnosis of delirium are disorientation, disturbance of consciousness, and perceptual disturbance. If one of these domains is rated positive, then a diagnosis of delirium is made. The documentation manual is needed to provide detailed instructions on scoring. The limitations for the DSI include the following: it is difficult and fairly slow to administer, the severity validity is unknown, and the scale does not assess rapidity of onset and etiology (Trzepacz, 1994).

Confusion Rating Scale (CRS)

The CRS is intended for use by nurses to be quickly and easily administered after every eight-hour shift. The CRS is appropriate in the terminally ill population due to its quick administration and lack of patient participation. Developed by Williams, Ward, and Campbell (1988), the CRS uses the DSM-III-R criteria and rates four behavioral dimensions of confusion: 1) disorientation, 2) inappropriate behavior, 3) inappropriate communication, and 4) illusions/hallucinations. The presence or absence of these four dimensions is recorded. Confusion is considered with a score of one or more. There are many limitations to this immature scale which still needs comparative testing for validation (Williams, 1991). The behaviors for confusion need to be operationalized more specifically, and this instrument is limited in its usefulness to detect delirium because it does not address all the symptom domains required for delirium (Levkoff, Liptzin, Cleary, Reilly, & Evans, 1991). As well, the CRS uses only behavioral observations, lacks the ability for screening for hypoactive as well as hyperactive delirium, and because of its low cutoff score, there is an increased risk for false positives.

Folstein Mini Mental State Evaluation (MMSE) (see appendix two)

The MMSE is a well-established screening instrument to assess global cognitive function. This instrument requires five to ten minutes to administer. There are eleven questions asked that assess orientation, memory, attention, calculations, recall, and language (Folstein, Folstein, & McHugh, 1975). Total scores range from 0 to 30. A score of less than 24 is considered evidence of cognitive impairment. Several methods of validation have been reported. In a review of confusion assessment instruments, the MMSE had good inspection and severity validity, very good construct validity, excellent

screening validity, and fair diagnostic validity (Smith, Breibart, & Platt, 1994). Inter-rater reliability was excellent at .86, test-retest reliability averaged .95 in previous research studies (Foreman, 1989). Some limitations to this instrument include: its inability to distinguish delirium from dementia, it can only depict the presence or absence of general cognitive changes, not the degree of abnormality, and factors such as low education level, language barrier, fatigue, vision or hearing impairment, aphasia, and depression can affect the score (Anthony, LeResche, Niaz, von Korff, & Folstein, 1982; Tombaugh & McIntyre, 1992; Yue, Fainsinger, & Bruera, 1994; Boyle, Abernathy, Baker, & Wall, 1998). However, the MMSE is a relatively low burden cognitive screening tool on terminally ill cancer patients and can be easily administered by the nursing staff or non-physicians.

Currently available delirium assessment scales require patients to be able to talk, must be administered by experienced clinicians, or are lengthy to administer. In a review of delirium evaluation instruments, Smith et al. (1995) determined that scales useful in assessing patients with terminal delirium should be quick to administer, place minimal burden on the patient, include less cognitive items and attend more to the assessment of behavioral symptoms. It may be presumed that the patient with terminal delirium is unable to tolerate a prolonged interview or is not able to carry out lengthy cognitive testing. The only drawback for the use of the currently available delirium assessment scales is that they are based on the old DSM criteria rather than the current DSM IV criteria.

**Prevalence of Symptom Distress**

There are few research studies that have explored the prevalence of symptoms in terminally ill patients. Fainsinger et al. (1991) conducted a retrospective analysis to determine the prevalence and severity of different symptoms using the Edmonton Symptom Assessment Scale (ESAS) in 100 terminal cancer patients admitted onto a palliative care unit. Results indicated that 99% of patients complained of pain, 46% exhibited dyspnea, 71% had nausea, and 39% experienced delirium. Another retrospective analysis done on an inpatient hospice unit found that pain (87%), dyspnea (56%), and constipation (40%) were the most prevalent physical symptoms in terminal cancer patients, while family coping (43%), stress (22%), and anxiety (15%) were the most prevalent psychosocial problems (Weitzner, Moody, & McMillan, 1997). Heedman & Strang (2001) assessed 431 cancer patients' symptoms using the ESAS in an advanced palliative home care program. Results of this study indicated that pain and nausea were well controlled and patients were less satisfied with appetite, activity, and sense of well being.

In a descriptive study by Sarna & Brecht (1997), advanced lung cancer patients on an inpatient oncology clinic who were receiving palliative treatment rated fatigue, disruptions in outlook, pain, and insomnia as the most distressing symptoms using the Symptom Distress Scale (SDS). Pain and fatigue were again the most prevalent and severe symptoms in 1000 inpatient and outpatients with advanced cancer referred to a palliative care program (Donnelly, Walsh, & Rybicki, 1995).

In the community setting, 120 terminal cancer patients at home described the most common "unendurable" symptoms prior to death were dyspnea (33 patients), pain (31),

delirium (11), and vomiting (5) in a prospective study by Ventafridda, Ripamonti, DeConno, Tamburini, and Cassileth (1990). Another research study by Cobb et al. (2000) found that pain and delirium were the most common reasons terminally ill cancer patients were admitted onto an inpatient hospice from home.

**Assessment of Symptom Distress**

Terminally ill cancer patients are continually burdened by distressing symptoms such as pain, dyspnea, nausea, anxiety, and fatigue. Unrelieved symptoms result in decreased quality of life and ability to function independently. Optimal management of these symptoms requires frequent and accurate monitoring using a symptom assessment scale. Use of a symptom assessment scale provides the basis for detecting symptoms, grading their severity, and evaluating treatment effectiveness. Existing symptom assessment scales that have been tested and used in the cancer population are reviewed.

Edmonton Symptom Assessment Scale (ESAS) (see appendix three)

The ESAS is a simple, short scale that consists of nine visual analogue scales (VAS) for assessing symptoms of pain, shortness of breath, nausea, depression, activity, anxiety, wellbeing, drowsiness, and appetite (Bruera, Kuehn, Miller, Selmser, & MacMillan, 1991). Each visual analogue scale is a pre-measured 100-millimeter line with the left side indicating the lowest symptom intensity (e.g. 'no pain') and the right side indicating the worst possible degree of symptom intensity (e.g. 'worst possible pain'). Patients are asked to make a mark on the line indicating his or her perceived symptom intensity. The distance of this mark from the appropriate anchor is measured and translated into a score, ranging from 0 (none or best possible) to 100 (worst possible). A general symptom distress score is obtained by adding the scores of all nine VAS scales

together. The scores from each VAS is transferred to a bar graph which allows staff to visualize patterns of symptom control and expression over time. Completion of the ESAS once daily in the morning (10:00 am), can be done either by the patient alone or with the nurse's assistance, or by the patient's family if a self-report is not feasible. The ESAS has been validated compared with the Rotterdam Symptom Checklist (RSCL) and the Brief Pain Inventory (Phillip, Smith, Craft, & Lickiss, 1998). Another study found the ESAS to be a valid symptom assessment instrument compared with the Memorial Symptom Assessment Scale (MSAS), Functional Assessment of Cancer Therapy (FACT) and Karnofsky Performance Status (KPS) with good internal consistency and test-retest evaluation (Chang, Hwang, & Feuerman, 2000). Limitations for the use of the ESAS may include inconsistencies and/or missing values in symptom assessments when completed by proxy raters (Nekolaichuk, Maguire, Suarez-Almazor, Rogers, & Bruera, 1999; Nekolaichuk et al., 1999; Dudgeon, Harlos, & Clinch, 1999). However, the ESAS allows for rapid assessment and fast interpretation of multiple symptoms, with low respondent burden. The ESAS has been tested and validated specifically for use in the palliative cancer population. It is currently in use in both palliative care settings in Winnipeg on admission and throughout the patient's hospital stay.

Symptom Distress Scale (SDS)

The SDS is a 10-item Likert-type self-report scale that measures the severity of the following symptoms: nausea, mood, appetite, insomnia, pain, mobility, fatigue, bowel pattern, concentration, and appearance, caused by either the cancer or its treatment. A total symptom distress score can be obtained by adding the scores of all symptoms. Higher scores denote greater levels of symptom distress. This scale takes approximately

five to ten minutes to administer. A reliability coefficient of 0.82 has been reported for this scale in the cancer population (McCorkle & Young, 1978). This scale, however, may not adequately capture the intensity of symptoms felt by patients or symptoms that are important to the patient.

Memorial Symptom Assessment Scale (MSAS)

The MSAS is a patient rated multidimensional symptom assessment scale that measures 32 physical and psychological symptoms on three dimensions relevant to symptom evaluation: 1) symptom frequency, 2) severity, and 3) distress, each with their own 4 or 5 point Likert-type scales. The total MSAS score is the average of the symptom scores for all 32 symptoms. The three major symptom groups comprised in this scale include psychological symptoms (e.g. feeling sad, worrying, feeling irritable, difficulty sleeping), high prevalence physical symptoms (e.g. lack of appetite, lack of energy, pain, feeling drowsy), and low prevalence physical symptoms. Patients are asked to respond to symptom items that they experienced in the past week. The MSAS has undergone rigorous psychometric testing with inpatient/outpatient prostate, colon, breast, and ovarian cancer patient populations (Portenoy et al., 1994). However, this time consuming and lengthy scale has multiple ratings for each symptom, which may be burdensome to terminally ill cancer patients.

Rotterdam Symptom Checklist (RSCL)

The RSC is a 31-item scale that measures both psychological and physical symptoms such as lack of appetite, irritability, tiredness, depressed mood, and nausea. Patients are asked to rate the extent to which a particular symptom bothered them during either the past three days or the past week. Answers include not at all, a little, quite a bit,

and very much on this Likert-type rating scale. Completion of the RSCL takes approximately eight minutes. Reliability coefficients have ranged from 0.88- 0.94 on the psychological dimension and 0.71- 0.88 on the physical dimension (de Haes, Knippenberg, & Neijt, 1990). This scale was developed primarily to measure symptoms for cancer patients in clinical research. Limitations of this scale include its length and use of a rating system based on verbal descriptors that may be difficult for patients to understand.

M.D. Anderson Symptom Inventory (MDASI)

In this scale, 13 core symptom items are rated based on their presence and severity, and six symptom interference items are rated based on the level of symptom interference with patient function. The scale is easy and quick for patients to complete, approximately five minutes to rate the core symptom severity and interference items. This scale is used mostly for cancer clinical trials (Cleeland et al., 2000).

Symptom distress would be more accurately assessed in clinical practice with the use of a symptom assessment tool, as an accurate assessment of symptoms is necessary prior to the management of these distressing symptoms. Presently with computer technology, more computer-based questionnaires are becoming available as symptom assessment instruments (Naughton & Homsi, 2002).

**Symptom Distress and Delirium**

There have been no research studies that compare the severity of symptom distress in delirious versus non-delirious terminally ill cancer patients. Studies conducted on symptom distress have been primarily focused on symptom profiles and cognitive status for advanced cancer patients admitted onto a palliative care unit but no comparison is

made between delirious/confused versus non-delirious/non-confused patients. In a study done by Jenkins, Taube, Turner, Hanson, and Bruera (1998), a retrospective chart review of 96 cancer patients admitted onto a palliative care unit revealed that 64% had cognitive impairment, using the MMSE by the palliative care consultant. The highest symptom distress scores for all patients (not just cognitively impaired), as measured by the ESAS, were for fatigue, appetite, drowsiness, and well being. Another study done by Jenkins, Schultz, Hanson, and Bruera (2000), found that in 91 cancer patients in a tertiary acute care hospital referred by the palliative care consult team, 44% had cognitive impairment (using the MMSE) and the most intense symptoms were fatigue, appetite, and well-being as measured by the ESAS.

Although there have been no research studies conducted on levels of symptom distress between delirious/confused and non-delirious/non-confused terminally ill cancer patients, a few research studies have looked at the relationship between levels of pain intensity and delirious patients. Bruera et al. (1992) explored levels of pain in 14 terminally ill cancer patients admitted onto a palliative care unit. In this study, the MMSE was administered three times per week by the investigator and the Visual Analog Scale (VAS) was used to assess pain intensity. Eleven patients had an agitated cognitive failure episode (CFE) and were assessed by the nurse as having significantly higher levels of pain than the patient's assessment. These patients received an average of five extra doses of narcotic per day versus an average 2 extra doses for cognitively intact patients. Three patients developed a non-agitated CFE and the nurses assessment of pain was the same as the patients, before, during, and after the episode. Patients who recovered from their CFE had no memory of their pain. This study had an extremely small sample size and may not

be an accurate indication of cognitive impairment and pain intensity. However, the study concludes that nursing staff tend to overestimate levels of pain in patients with an agitated delirium and therefore delirious patient's levels of symptom distress may not be assessed adequately and hence managed appropriately. In a case study by Bruera (1991), family members concluded that their confused and agitated loved one was indirectly expressing more pain (although pain was never a problem previously) and required more narcotics and sedatives.

**Summary**

In summary, a review of the literature pertinent to delirium and symptom distress has been presented. Literature in the terminally ill cancer population has primarily focused on the prevalence and measurement of delirium. Discrepancies exist in the literature on the delirium prevalence rates of patients admitted onto a palliative care unit. These wide variances in delirium prevalence rates are typically related to the use of various delirium assessment scales and various criteria for the diagnosis of delirium in the terminally ill cancer population.

Results of research studies on the prevalence of symptom distress in the terminal cancer population conclude that these patients are continually burdened by various distressing symptoms. Scales have been developed to measure symptom distress, but many are useful only to clinical trial research and are not feasible in the clinical setting due to their lengthy administration time. As well, these scales have been used in a variety of cancer populations, and may not be specific to the terminally ill population. Few research studies included delirium with the symptom assessments upon admission to a palliative care unit. The research studies that assessed patients for delirium and symptom

profiles upon admission did not compare delirious versus non-delirious patients in their self-reported ratings of symptom distress.

Currently there are no research studies that examine if any difference exists between delirious and non-delirious terminally ill cancer patients and their levels of symptom distress. Research findings have revealed that many delirious patients have distressing symptoms upon admission onto a palliative care unit, but these studies do not compare if the presence or absence of delirium directly affects a patient's self-reported symptom distress level. Research studies have also shown that there are incongruent assessments between care providers and patients on their perceived levels of symptom distress, in particular, pain (Bruera et al., 1992). The review of the literature indicates that future research is needed to determine if delirious patients have more severe symptom distress, including symptoms such as nausea, anxiety, appetite, depression, dyspnea, and pain versus non-delirious patients.

# CHAPTER FOUR

# METHODOLOGY

## Research Design

As there is very little research to date on prevalence rates of delirium and comparing symptom distress between delirious and non-delirious patients, a retrospective chart review was used for this study. Initially a cross-sectional survey design was proposed. However, after initiating the data collection process, no research participants were recruited as there were too many research studies being conducted on both the Riverview and St. Boniface hospital settings.

## Setting

This study accessed select chart data from terminally ill cancer patients who had died on the palliative care unit at Riverview Health Centre between September 1999 to January 2000. While individuals with other terminal illnesses may be admitted onto this unit, individuals admitted for the purposes of palliative cancer care constitute the majority of patients found on this unit. Riverview Health Centre's palliative care unit has 30 inpatient beds. This palliative care unit admits approximately 440 patients per year, 30% of admissions are discharged and 70% of patients die on the unit.

## Sample

A convenience sample of 110 patients' medical records between September 1999 to January 2000 was selected for the study. A statistician was consulted to determine an appropriate sample size. One hundred ten patients gave an 80% power of detecting a medium sized delirium effect assuming a one-tailed 5% test of significance, and that 35%

of patients consisted of the delirium/confusion group. During this time period, the same palliative care physician did the initial patient admission assessment. As well, only charts of deceased patients were examined. Inclusion criteria for patients was that they had a diagnosis of terminal cancer.

**Instrument**

Data Collection Form (see appendix four)

Patient's charts were assigned an ID number from one to 110. The patient's admission date, date of death, demographic data (gender, age), location of primary tumor, presence of metastases, length of cancer diagnosis, reason for admission (as per palliative care physician death summary), and selected laboratory values (including urine culture and sensitivity if available) information was retrieved from their chart. As well, narcotics on admission, the total daily dose of the narcotic and PRN ('as needed') narcotic (both in oral morphine equivalents/24 hours) were examined. Other medications such as benzodiazepines, anti-psychotics, corticosteroids, anticholinergics, and antidepressants were tallied and the total number of other medications (not including narcotics and the aforementioned medications), including number of PRN medications used on admission was retrieved from the patient's medical record. Also investigated was whether the physician and/or the nursing staff diagnosed delirium/confusion on admission (stated in the nursing progress notes as "confusion" or "delirium"), and what interventions were used if a patient was diagnosed with confusion/delirium on admission. The MMSE score on admission, ESAS total score on admission and individual symptom sub-scale scores were located from the patient's chart if available. If confusion/delirium was not diagnosed on admission and the patient later became confused, the date of confusion was noted.

**Procedure**

Once Ethical Approval was received, access to the Riverview Health Centre was secured. An employee of Riverview's health records department pulled the charts selected for the chart review. Random samples of consecutive terminal admission charts were selected from the September 1999 to January 2000 time frame. Only two charts were pulled in which the patients had a diagnosis other than terminal cancer. Those two charts were not included in the sample and the employee pulled two different charts. Charts were reviewed by the principal investigator in the health records department at Riverview Health Centre.

**Protection of the Rights of Human Subjects**

Prior to commencement of the study, approval from the University of Manitoba Education/Nursing Research Ethics Board and the Riverview Health Centre access committee was sought. Informed consent was not required as all patients' medical records selected for this study were deceased, as verbally discussed with the Privacy Officer at Riverview Health Centre. The information collected was still treated in accordance with Personal Health Information Act (PHIA) regulations.

All information collected about participants was kept strictly confidential. The names of the participants or their family members were not used on any reports about the study or will be used in any future publications. Participants remain anonymous, identified only by a code number. This code number was used on all data collection forms. Findings were presented as aggregate data; thus individual data was not recognizable or identifiable. The researcher, the thesis advisor, and the statistician had access to the raw data. Data will be stored in a locked filing cabinet in the St. Boniface

Research Centre office for Cancer Nursing Research for a period of seven years, after which it will be destroyed and treated as confidential waste.

**Summary**

A retrospective chart review was used as the design for this study. A total of 110 medical charts were reviewed on terminally ill cancer patients who had died on the palliative care unit at Riverview Health Centre between September 1999 to January 2000. Utilizing the data collection form, various demographic characteristics of patients and answers to the two research questions were identified. A quantitative method of data analysis using the SPSS for windows statistical package was implemented.

# CHAPTER FIVE

# DATA ANALYSIS

The results of the analysis of the data collection form are presented in this chapter. Results from this study are divided into various categories. First, the characteristics of patients with terminal cancer admitted onto the palliative care unit are examined. Next, the prevalence of delirium as diagnosed by the palliative care physician and the nursing staff is then explored. Comparisons between the delirious and non-delirious groups are analyzed to determine if there is a significant difference with demographic data, narcotics, other medications, lab values, and MMSE scores between the two groups. Lastly, symptom distress in delirious versus non-delirious patients using scores from the ESAS is examined.

## Characteristics of Patient Sample

To determine patient sample characteristics, descriptive statistics were used to calculate frequency distributions, means (x), and standard deviations (SD). 110 charts (n=110 patients) were reviewed for this study. Patients were admitted between January 19, 1999 to January 5, 2000 and died between September 01, 1999 to January 10, 2000. Days from admission to death ranged from 0 to 301 days with a median interval of 22 days ($x = 30$ days, $SD = 37.59$).

There were 51 females (46%) and 59 males (54%) admitted onto the palliative care unit. Eight patients were between the ages of 18-50 (7%), 42 patients between 51-70 years of age (38%), and 60 patients between 71 years and older (55%).

The length of cancer diagnosis was calculated from the initial time of diagnosis until death. Thirty four percent of patients had a cancer diagnosis of greater than two years (n=37), 22% between six months and one year (n=24), 18% between one to two years (n=20), 15% between three to six months (n=16), and 10% had a cancer diagnosis of less than three months (n=11). Two percent were unknown (n=2).

Lung cancer was the most common malignancy (n=37, 34%), followed by cancers of the genitourinary and gastrointestinal systems (n=18, 16% for both). Genitourinary cancers included prostate, bladder, uterine/endometrium, and ovarian; gastrointestinal cancers colon and stomach. Breast cancer was the third most common malignancy (n=12, 11%), preceding cancer of the head and neck (n=8, 7%), brain (n=7, 6%), hematological (n=4, 4%), and lymph (n=2, 2%). Three percent were unknown (n=3). The most frequent sites of metastatic disease were to the bone (n=35, 32%) and liver (n=31, 28%), followed by the brain (n=18, 16%) and lung (n=14, 13%).

In general, cancer of the brain was more often found in the 51-70 year old age category (n=6) versus the 71 and over age group (n=1). Cancers of the head and neck (n=6), gastrointestinal (n=12), genitourinary (n=13), and hematological (n=4) systems were more common in the 71 and over age group versus the 50-71 year olds (n=2, 5, 5, and 0 respectively).

The two most common reasons for admission to the palliative care unit, as described by the palliative care physician on his death summary, were fatigue (n=61, 56%) and pain (n=40, 36%). Twenty six percent were admitted for terminal care (n=29), and 20% for both dyspnea (n=22) and 'other' (n=22). The fifth most common reason for admission was for delirium/confusion (n=14, 13%), followed by 9% for nausea (n=10),

8% for anorexia (n=9), and 5% for constipation (n=5). Other reasons for admission (n=22, 20%) included: inability to cope (n=6), dysphagia (n=6), depression (n=2), anxiety (n=1), falls, dizziness, cough, etc. (Table 2).

Table 2: Characteristics of Patients: n = 110 (100%)

| Gender: male/female | 59 (54%)/ 51 (46%) |
|---|---|
| Age: 18-50 years | 8 (7%) |
| 51-70 years | 42 (38%) |
| 71+ years | 60 (55%) |
| Location of primary tumor: | |
| Lung | 37 (34%) |
| Gastrointestinal | 18 (16%) |
| Genitourinary | 18 (16%) |
| Breast | 12 (11%) |
| Head & neck | 8 (7%) |
| Brain | 7 (6%) |
| Hematological | 4 (4%) |
| Unknown | 3 (3%) |
| Lymph | 2 (2%) |
| Other | 1 (.9%) |
| Length of cancer diagnosis: | |
| <3 months | 11 (10%) |
| 3-6 months | 16 (15%) |
| 6 months-1 year | 24 (22%) |
| 1-2 years | 20 (18%) |
| >2 years | 37 (34%) |
| Unknown | 2 (2%) |
| Site of metastases: | |
| Bone | 35 (32%) |
| Liver | 31 (28%) |
| Brain | 18 (16%) |
| Lung | 14 (13%) |
| Reason for admission: | |
| Fatigue | 61 (56%) |
| Pain | 40 (36%) |
| Terminal care | 29 (26%) |
| Dyspnea and Other | 22 (20%) |
| Delirium/confusion | 14 (13%) |
| Nausea | 10 (9%) |
| Anorexia | 9 (8%) |
| Constipation | 5 (5%) |

Patients admitted onto the palliative care unit were most frequently taking morphine (n=44, 40%). Dilaudid was the second most common narcotic at 23% (n=25), followed by the Fentanyl Patch (n=13, 12%) and codeine (n=10, 9%). Sixteen percent of patients admitted onto the palliative care unit were not on any narcotics (n=18). The total daily dose of narcotic in oral morphine equivalents in milligrams (mg) on admission to the palliative care unit ranged from 0 to 2700mg (x = 197mg, SD = 402.67, median=60mg) with 67% between 0 to 120mg (n=74). The total number of PRN narcotics (narcotics given on a 'as needed' basis) in oral morphine equivalents in the first 24 hours after admission ranged from 0 to 180mg (x = 14mg, SD = 33.78, median=0mg) with 66% of patients not receiving any PRN narcotic (n=73, mode=0mg).

Five medications commonly used by patients with terminal cancer include benzodiazepines (including Ativan and Valium), antipsychotics (such as Nozinan), corticosteroids (Decadron, Prednisone, but not including inhaled steroids), anticholinergics (for example Gravol, Ditropan), and antidepressants (many SSRIs and tricyclics). Patients admitted onto the palliative care unit were frequently taking corticosteroids (n=57, 52%). Patients were often taking benzodiazepines (n=41, 37%), and anticholinergics (n=38, 35%). Twenty three percent of patients were on antidepressants (n=25) and few patients were taking antipsychotics (n=10, 9%).

The total number of other medications and PRN medications on admission, not including narcotics, benzodiazepines, anticholinergics, antidepressants, corticosteroids, and antipsychotics, was retrieved from the admission medication list. The total number of other medications on admission ranged from 0 to 9 medications (x = 3, SD = 2.08) with 66% of patients prescribed from 0 to 3 medications (n=72, mode=1). The total number of

PRN medications on admission ranged from 0 to 3 medications (x = 1, SD = .81) with 77% of patients prescribed either no PRN medications or one PRN medication (n=85, mode=0). (Table 3).

Table 3: Characteristics of Patients: Medications (n=110)

| | |
|---|---|
| Narcotics on admission:<br>Morphine<br>Dilaudid<br>None<br>Fentanyl Patch<br>Codeine | <br>44 (40%)<br>25 (23%)<br>18 (16%)<br>13 (12%)<br>10 (9%) |
| Total daily dose of narcotic | x = 197mg (402.67) [in morphine equiv] |
| Total PRN dose of narcotic | x = 14mg (33.78) [in morphine equiv] |
| Common medications used:<br>Corticosteroids<br>Benzodiazepines<br>Anticholinergics<br>Antidepressants<br>Antipsychotics | <br>57 (52%)<br>41 (37%)<br>38 (35%)<br>25 (23%)<br>10 (9%) |
| Total number of other medications | x = 3 (2.08) |
| Total number of PRN medications | x = 1 (.81) |

**Prevalence of Delirium/Confusion**

Descriptive statistics were utilized to answer research question one, which relates to delirium and/or confusion prevalence rates. Delirium/confusion diagnosed by the palliative care physician or the nursing staff was retrieved from the admission progress notes. Twenty-nine percent of patients admitted onto the palliative care unit were diagnosed with delirium/confusion by the palliative care physician (n=32). Twenty-one percent of patients admitted onto the palliative care unit were diagnosed with delirium and/or confusion by the nursing staff (n=23). (Table 4).

Table 4: Delirium and/or Confusion Diagnosed by Doctor (MD) versus Nurse (RN).

| Delirium/confusion diagnosed by MD | Delirium/confusion diagnosed by RN |
|---|---|
| 29.1% (n=32) YES | 20.9% (n=23) YES |
| 70.9% (n=78) NO | 79.1% (n=87) NO |

A chi square test was used to test the difference between delirium and/or confusion diagnosed by the palliative care physician versus the palliative care unit nurse and both the nurses and physicians diagnosis versus the reason for admission. There was a significant difference between the nurse's versus the physician's diagnosis of delirium ($p = .000$). Nurses were significantly less likely to diagnose delirium on admission than the palliative care physician. Of the group of delirious terminally ill cancer patients admitted onto the palliative care unit (n=32), delirium and/or confusion was diagnosed by the palliative care physician but not by the nurse 10% of the time (n=11), compared to 2% diagnosed by the nurse and not diagnosed by the palliative care physician (n=2). When the reason for admission was for delirium/confusion (n=14), the palliative care physician had diagnosed delirium in the terminally ill cancer patient on admission 93% of the time (n=13), but had missed one patient who was admitted for delirium/confusion but not diagnosed by the physician ($p=.000$). In view of this fact, the nurse had diagnosed delirium 57% of the time (n=8) when the reason for admission was delirium/confusion. In six percent of cases, the nurse had not diagnosed delirium, yet delirium/confusion was the reason for admission.

Delirium/confusion often occurs after admission to a palliative care unit. For those terminally ill cancer patients that were not delirious/confused on admission, many became

delirious at some point during their hospital stay. The date that patients became delirious/confused as written in the progress notes either by the nursing staff or the palliative care physician was also retrieved from the charts. Thirty-five percent of patients became delirious/confused after admission to the palliative care unit (n=38). From the date of admission to date confusion diagnosed ranged from one to 299 days with an average of 29 days (SD=37.59, median=12 days) for those patients who were not diagnosed with delirium/confusion on admission. Confusion date until death ranged from zero to 82 days with an average of 13 days (SD=15.58, median=8 days). For patients diagnosed with delirium upon admission to the palliative care unit, the average number of days from admission to death was 19 days. A total of 64% of patients became delirious/confused either on admission (as diagnosed by the palliative care physician) or during their hospital stay (n=70).

**Comparisons Between Groups (Delirious versus Non-delirious Patients)**

Comparisons between the delirious and non-delirious groups are analyzed to determine if there is a significant difference with demographic data, narcotics, other medications, lab values, and MMSE scores between the two groups.

Chi square tests were used to determine the difference between groups diagnosed by the palliative care physician as delirious/confused (n=32) versus gender, age, location of primary tumor, length of cancer diagnosis, and narcotics on admission. There were no significant differences in patient gender, age, location of primary tumor, length of cancer diagnosis, site of metastases, and narcotics on admission between the two groups.

Fifty-six percent of patients with delirium/confusion were male (n=18) and 44% were female (n=14). The Pearson chi-square two-tailed test showed no significance

difference in gender between the two groups (p= .725) and Fisher's exact test (2-sided) was .834. In the delirious group of terminally ill cancer patients, 41% (n=13) were between the ages of 51-70 years and 53% (n=17) were over 71 years old, few patients with delirium were between the ages of 18-50 years old (n=2, 6%). The Pearson chi-square two-tailed test again showed no significant difference in age between delirious and non-delirious patients (p= .927).

Lung cancer was the most common malignancy (n=12, 38%) in the group of 32 patients diagnosed with delirium and/or confusion by the palliative care physician. However, those patients with a primary tumor in the brain had a higher frequency of delirium at 12.5% versus no delirium at 3.8%, but the sample size of this sub-group (brain tumor, n=7) was too small to determine any significant difference. The Pearson chi-square two-tailed test revealed no significant difference in the location of primary tumor between delirious and non- delirious patients (p= .557). Again, there was no significant difference in the site of metastases between the two groups. Patients with metastases to the brain were slightly more likely to become delirious than non-delirious patients but there was no significant difference in the two-tailed Pearson chi-square test (p= .665).

There was also no significant difference between length of cancer diagnosis and delirious versus non-delirious patients from the chi-square (p= .113). However, from the data it would appear that a cancer diagnosis length of one to two years slightly increased the frequency of delirium, but again this sub-group is too small a sample to detect a significant difference.

Many patients were on morphine when diagnosed with delirium and/or confusion by the physician on admission (n=13, 41%), but there was no significant difference on the type of narcotic and delirious versus non-delirious patients using the Pearson chi-square two-tailed test (p= .645) (Table 5).

Table 5: Patient Characteristics: Delirious versus Non-delirious

| | Non-delirious (n=78) | Delirious (n=32) | Sig. |
|---|---|---|---|
| Gender: | | | p=.725 |
| Male | 41 (53%) | 18 (56%) | |
| Female | 37 (47%) | 14 (44%) | |
| Age: | | | p=.927 |
| 18-50 years old | 6 (8%) | 2 (6%) | |
| 51-70 years old | 29 (37%) | 13 (41%) | |
| 71 + years old | 43 (55%) | 17 (53%) | |
| Location of primary tumor: | | | p=.557 |
| Lung | 25 (32%) | 12 (38%) | |
| Gastrointestinal | 13 (17%) | 5 (16%) | |
| Genitourinary | 14 (18%) | 4 (13%) | |
| Breast | 8 (10%) | 4 (13%) | |
| Head & neck | 7 (9%) | 1 (3%) | |
| Brain | 3 (4%) | 4 (13%) | |
| Hematological | 2 (3%) | 2 (6%) | |
| Lymph | 2 (3%) | 0 | |
| Site of metastases: | | | |
| Brain | 12 (15%) | 6 (19%) | p=.665 |
| Lung | 11 (14%) | 3 (9%) | p=.499 |
| Liver | 23 (30%) | 8 (25%) | p=.635 |
| Bone | 24 (31%) | 11 (34%) | p=.712 |
| Cancer diagnosis length: | | | p=.113 |
| < 3 months | 9 (12%) | 2 (6%) | |
| 3-6 months | 12 (15%) | 4 (13%) | |
| 6 months- 1 year | 19 (24%) | 5 (16%) | |
| 1-2 years | 9 (12%) | 11 (34%) | |
| > 2 years | 28 (36%) | 9 (28%) | |
| Narcotics on admission: | | | p=.645 |
| Morphine | 31 (40%) | 13 (41%) | |
| Dilaudid | 18 (23%) | 7 (22%) | |
| None | 12 (15%) | 6 (19%) | |
| Fentanyl patch | 8 (10%) | 5 (16%) | |
| Codeine | 9 (12%) | 1 (3%) | |

Many patients admitted with a diagnosis of delirium were not taking narcotics on admission (n=9, 28%). In fact, 63% of patients diagnosed with delirium were on low doses of daily narcotic between 0 to 90mg. The same can be said for the total PRN dose of narcotic taken in the first 24 hours after admission to the palliative care unit with 81% of patients diagnosed with delirium using only 0 to 15mg of PRN narcotic.

Using an independent t-test to calculate the difference between the total daily dose of narcotic and PRN dose of narcotic versus delirium diagnosed by MD, it was determined that there was no significant difference between these groups. The average daily dose of narcotic for patients diagnosed with delirium was 193mg (n=32, SD = 344.16) compared to 199mg for non-delirious patients (n=78, SD = 426.41). The average PRN dose of narcotic was the same for both delirious and non-delirious patients at 14mg. As well, there was no significant difference between the total number of other medications and PRN medications (excluding narcotics) with the delirious versus non-delirious groups (Table 6).

Table 6: Comparison between delirious versus non-delirious groups: medications.

| | Delirious (n=32) | Non-delirious (n=78) | F | Sig. (p) |
|---|---|---|---|---|
| Total daily dose of narcotic | x =192.19 SD=344.16 | x =199.48 SD=426.41 | .061 | .805 |
| Total PRN dose of narcotic | x = 14.22 SD=38.44 | x =13.74 SD=31.94 | .343 | .559 |
| Total # of other medications | x =2.31 SD=1.66 | x =3.23 SD=2.18 | 2.418 | .123 |
| Total # of PRN medications | x =.88 SD=.91 | x =.85 SD=.77 | 2.072 | .153 |

Patients admitted onto the palliative care unit had routine lab work (biochemistry and CBC) completed. Independent t-tests were calculated on all lab values retrieved from

the patients' charts to determine if there was a significant difference between the delirious/confused versus non-delirious/non-confused groups of patients. The analysis revealed that only sodium levels revealed a significant difference between the delirious and non-delirious patients. (Table 7).

Table 7: Comparison between delirious versus non-delirious groups: lab values.

| | Delirious | Non-delirious | F | Sig. (p) | Minimum-to maximum |
|---|---|---|---|---|---|
| | n x (SD) | n x (SD) | | | |
| Calcium | 28 2.35(.28) | 66 2.28(.26) | .863 | .355 | 1.90-3.59 N=2.1-2.6 |
| Corrected Calcium | 27 2.60(.28) | 64 2.56(.24) | 2.156 | .146 | 2.17-3.70 |
| Albumin | 27 27.44 (5.60) | 64 26.45 (4.40) | 3.729 | .057 | 17.0-40.0 N=35-50 |
| Potassium | 28 4.23 (.69) | 67 4.26 (.80) | .127 | .722 | 2.7-8.0 N=3.5-5.3 |
| Sodium | 28 135.75 (5.47) | 67 135.21 (3.74) | 5.760 | .018 | 122-144 N=135-147 |
| Urea | 28 10.35 (8.06) | 67 8.56 (5.53) | 2.663 | .106 | 2.1-35.2 N=2.8-7.1 |
| Creatinine | 28 92.43 (42.14) | 66 93.97 (60.83) | .739 | .392 | 32-359 N=35-97 |
| Glucose | 29 6.83 (2.64) | 67 6.42 (2.61) | .017 | .896 | 3.4-16.7 N=3.6-6.1 |
| WBC | 28 11.66 (6.88) | 68 11.06 (13.94) | .223 | .638 | 1.7-111.2 N=4.8-10.8 |
| RBC | 28 3.67 (.64) | 68 3.75 (.76) | .140 | .710 | 1.56-5.65 N=4.2-6.1 |
| Hemoglobin | 28 111.14 (20.94) | 68 109.04 (20.07) | .824 | .366 | 49-161 N=120-180 |
| Platelets | 28 286.43 (164.78) | 66 283.97 (135.85) | 1.648 | .202 | 26-676 N=130-400 |

N = normal lab values

Occasionally a urine for culture and sensitivity (C&S) was obtained from terminally ill cancer patients on admission to the palliative care unit (n=26, 24%), which may indicate a urinary tract infection if the results are positive. Twenty-three percent of

patients diagnosed with delirium/confusion by the palliative care physician had a positive urine for C&S (n=6) and 19% (n=5) had a negative urine for C&S.

To assess for cognitive impairment in terminally ill cancer patients on admission to the palliative care unit, staff nurses administer the MMSE to patients. Fifty-one MMSE scores were tabulated from the analysis of 110 charts. The scores ranged from 4 to 30 (minimum 0, maximum 30) with an average score of 24 (SD=5.91). An independent t-test was used to calculate the difference between MMSE scores in delirious versus non-delirious patients and it was determined that there is a significant difference between these groups. Delirious patients tended to have lower MMSE scores than their non-delirious counterparts. The average score for delirious patients was 20 out of 30, and for non-delirious patients their average score was 26 out of 30 (Table 8).

Table 8: Comparison between delirious versus non-delirious groups: MMSE scores

| Delirious n=11 | Non-delirious n=40 | F | Sig. (p) |
|---|---|---|---|
| x =20.00 SD=7.89 | x =25.68 SD=4.67 | 6.790 | .012 |

For patients diagnosed with delirium on admission by the MD (n=32), the most commonly utilized intervention was the use of neuroleptics (n=20). Other interventions used to reverse the delirium or to improve overall patient comfort were opioid rotation (n=15), decreasing or discontinuing a non-opioid drug (n=8), hydration (n=4), treating hypercalcemia (n=4), treating infection (n=4), and others (n=3) which included increasing the corticosteroid or starting an opioid. Nozinan was the most commonly used neuroleptic (n=12), followed by Versed (n=9), Haldol (n=8), and others (n=6), which included Olanzapine, Chlorpromazine, and Ativan.

**Symptom Distress in Delirious versus Non-delirious Patients**

Symptom distress in terminally ill cancer patients was measured using the ESAS on admission to the palliative care unit. The ESAS was most frequently administered to the patient with the help of the nurse or 'nurse assisted' (n=46, 49%) from a total of 94 cases. Twenty-eight percent of the time the ESAS was administered solely by the nurse (n=26, 28%), followed by the patient administering his/her on ESAS (n=14, 15%), then the family (n=8, 9%).

A Pearson chi-square two-tailed test was used to determine that there was a significant difference between who the ESAS was administered by and the physician's diagnosis of delirium (p= .010). If the physician diagnosed delirium, then the ESAS was significantly more likely to be administered by the nurse (44%). As well, delirious patients usually had the ESAS administered with nursing assistance (41%). In the group of patients diagnosed as delirious by the physician, the patient completed the ESAS themselves in 6% of cases, whereas family members never administered the ESAS to their delirious loved ones (Table 9).

Table 9: Comparison between ESAS administration and delirium diagnosed by MD

| ESAS administered by: | Non-delirious (n=78) | Delirious (n=32) |
|---|---|---|
| Nurse | 12 (16%) | 14 (44%) |
| Nurse assisted | 33 (43%) | 13 (41%) |
| Patient | 12 (16%) | 2 (6%) |
| Family | 8 (10%) | 0 (0%) |
| Not available | 13 (17%) | 3 (9%) |

The ESAS scores (n=104) ranged from 13 to 82 out of a minimum score of 9 and a maximum of score of 90, with an average score of 40 (SD=15.16, median=38). Scores

of zero were calculated as missing values. The lower the ESAS scores, the lower the levels of symptom distress.

The ESAS scale is divided into 9 sub-scales: pain, activity, nausea, depression, anxiety, drowsiness, appetite, well being, and shortness of breath. Scores on each sub-scale range from one to 10. Pain and appetite were always marked for every ESAS scale administered. Activity level was missed once; nausea, shortness of breath, and drowsiness each were missed in three cases. However, anxiety, depression, and well being were frequently not marked on ESAS administration (missing 15, 20, and 29 respectively). The highest average ESAS sub-scale score was for activity ($x$ =8, SD=2.68), followed by appetite ($x$ =7, SD=3.19), drowsiness ($x$ =6, SD=3.09) and well being ($x$ =6, SD=3.03). Scores were generally lower for anxiety ($x$ =4, SD=2.87), pain ($x$ =4, SD=2.65), shortness of breath ($x$ =4, SD=3.00), depression ($x$ =3, SD=2.85), and nausea ($x$ =3, SD=2.56).

An independent t-test was used to determine that there is a significant difference in symptom distress between delirious and non-delirious terminally ill cancer patients, as diagnosed by the palliative care physician, on admission to the palliative care unit. Non-delirious patients had higher levels of symptom distress than delirious patients. The same significant difference was demonstrated when three sub-scales of the ESAS (depression, anxiety, and well being) were eliminated from the total ESAS score due to their high frequency of missing values. ESAS scores in this total sub-scale score ranged from 10 to 52 with an average score of 31 (SD=10.25). However, when delirium/confusion was diagnosed by the nurse on admission, there was no significant difference in symptom distress between delirious and non-delirious patients using both the ESAS total score and the ESAS sub-scale total score (Table 10).

Table 10: Symptom distress between delirious and non-delirious patients.

(Dx=diagnosed)

| | Delirious | Non-delirious | F | Sig. (p) |
|---|---|---|---|---|
| Dx by MD (ESAS score) | n=30 x=37.97(11.69) | n=74 x=41.47(16.31) | 4.272 | .041 |
| Dx by MD(sub-scale score) | n=29 x =29.38(7.98) | n=66 x=31.30(11.11) | 3.996 | .049 |
| Dx by RN (ESAS score) | n=21 x=38.43(12.18) | n=83 x =40.9(15.85) | 1.537 | .218 |
| Dx by RN (sub-scale score) | n=20 x =29.30(7.48) | n=75 x =31.0(10.88) | 2.723 | .102 |

**Summary**

The results of the quantitative data analysis have been presented. Demographic data to determine the characteristics of patients were analyzed to reveal an essentially equal number of male and female patients and most patients were older than 71 years of age. Lung cancer was the most common malignancy and patients frequently had metastatic disease to the bone. The length of cancer diagnosis was usually greater than two years. Patients were typically admitted onto the palliative care unit for reasons of fatigue, followed by pain and terminal care. The average length of stay from admission to death was 30 days.

Terminally ill cancer patients admitted onto the palliative care unit were most frequently on Morphine with an average daily dose of narcotic of 197mg and 14mg on average of a PRN narcotic. Patients were also commonly on corticosteroids and benzodiazepines on admission. On average, patients typically were prescribed three other medications and one other PRN medication not including narcotics.

Determining the prevalence of delirium was the first research question asked. Data analysis revealed that 29% of patients admitted onto the palliative care unit were diagnosed with delirium/confusion by the palliative care physician and 21% diagnosed by the nursing staff. A chi-square test determined that nurses were significantly less likely to diagnose delirium on admission than the physician. As well, 35% of patients became delirious during the course of their hospital stay who were not diagnosed as delirious on admission. The average number of days from date of confusion to death was 13 days with a median interval of 8 days.

A comparison was made between the two groups, delirious versus non-delirious, to determine if there was a significant difference in demographic data (gender, age), location of primary tumor, site of metastases, length of cancer diagnosis, and narcotics on admission., the dose of narcotics, number of medications, lab values, and MMSE scores. There was no significant difference in demographic data, or between the total daily dose and PRN dose of narcotic between the two groups, nor was there a significant difference between the total number of other medications and PRN medications administered. There was also no significant difference between the delirious and non-delirious patient's lab values except for sodium levels. However, data analysis determined that there was a significant difference in the MMSE scores between the two groups, delirious patients tended to have lower MMSE scores than non-delirious patients. Patients who were diagnosed as delirious on admission to the palliative care unit were generally treated with neuroleptics as an intervention, followed by opioid rotation. The most common neuroleptic used was Nozinan.

Finally, data analysis revealed that there was a significant difference in symptom distress (using total ESAS scores) between delirious and non-delirious patients to answer the second research question. Non-delirious patients had higher levels of symptom distress than delirious patients when the physician diagnosed delirium but not when the nurse diagnosed delirium. The results were the same using an ESAS sub-scale score where depression, anxiety, and well being were eliminated from the total ESAS score due to their high frequency of missing values. Results in this section also determined that the ESAS was most frequently administered with the nurse's assistance and if patients were diagnosed as delirious by the physician, the ESAS was most frequently administered by the nurse.

# CHAPTER SIX

# DISCUSSION, LIMITATIONS, AND IMPLICATIONS

In this chapter the findings of the study are reviewed and discussed in relation to findings from previous delirium prevalence studies and related research. Limitations of this study are also noted. The results of this research study provide important implications for nursing clinical practice, education, and research so that terminally ill cancer patients' experiencing delirium quality of life may be improved.

## DISCUSSION OF THE FINDINGS

The most striking findings in this study relate to the research questions asked on prevalence of delirium and levels of symptom distress. In this study, the prevalence of delirium/confusion diagnosed by the palliative care physician was 29% and 21% by the nursing staff. Data analysis revealed that nurses were significantly less likely to diagnose delirium upon admission to the palliative care unit (p=.000). Fainsinger et al. (1991) had suggested that without the use of a delirium assessment instrument even experienced palliative care nurse overlook the presence of delirium in 24% of cases.

Results of this study determined that delirious patients tended to have lower levels of symptom distress than non-delirious patients. Previous research studies determined that agitated delirium was interpreted as an indirect expression of pain and increased doses of narcotics and sedatives were given (Fainsinger et al., 1993). However, results from this study may indicate that patients with delirium are not able to perceive and report symptoms accurately as indicated by the Symptom Perception Theory used in this study.

Another unexpected finding was made when comparing the delirious and non-delirious groups and their daily doses of narcotics, number of other medications, and lab values. Delirious patients were frequently on fewer doses of narcotics and prescribed fewer amounts of other medications on admission to the palliative care unit. This finding was unanticipated because delirium is commonly precipitated by opioids, opioid toxicity, and polypharmacy (Massie et al., 1993; Bruera et al., 1992; Stiefel et al., 1992; Bruera et al., 1995). These results suggest that delirium is multifactorial and many patients become delirious due to the dying process. As well, lab values revealed no significant difference between delirious and non-delirious patients except for sodium levels. Sodium levels, including hyponatremia and hypernatremia, have generally only accounted for a low percentage of causes for delirium in research studies (Bruera et al., 1992; Morita et al., 2001). All of these findings are discussed in greater detail in the discussion section.

**Characteristics of Patient Sample**

Many of the characteristics in this patient population were similar to those found in other terminally ill cancer patients who experience delirium/confusion on admission to a palliative care unit. In this study, the length of stay of patients from admission to death median interval was 22 days. This is congruent with other research studies that indicate a median interval from 21 to 25 days (Jenkins et al., 1998; Morita et al., 2001). Essentially terminally ill cancer patients admitted onto a palliative care unit die approximately three weeks after admission, which suggests that patients were admitted for the final stages of their terminal cancer and were able to stay in their homes longer.

Gender is typically divided equally among both sexes and the average age of patients is always over the age of 65 years old. The location of the primary tumor is most

commonly in the lung or gastrointestinal tract with metastases usually in the bone. Not surprising, as lung cancer is the number one cause of cancer death in men and women in North America (Yarbro, Frogge, Goodman, & Groenwald, 2000). Lung cancer may have been over-represented at Riverview Health Centre, as its referral base is the Health Sciences Centre hospital, which deals with most of the lung cancer cases. Morphine is the most frequently used narcotic on admission to a palliative care unit consistent with other studies demonstrating morphine as the most prescribed narcotic prior to admission (Jenkins et al., 1998, 2000). Morphine may be prescribed more frequently in the community as it is a cheaper narcotic and many patients in the community are paying for their prescription medications. This may also explain why many patients were on few medications and PRN medications prior to admission.

The most common reason for admission to the palliative care unit in this study was for fatigue, followed by pain and terminal care. Delirium/confusion was the fifth most frequent reason for admission. A study by Cobb et al. (2000) showed that delirium was frequently the reason for admission to a hospice attributable to hyperactive delirium where patients were agitated and hallucinating and their families were no longer able to cope. As fatigue was the most common reason for admission and a symptom associated with hypoactive delirium, many of these patients may have been delirious but undetected by the nursing staff and/or physician. As well, patients with a hypoactive form of delirium are often sleeping, quiet and easier for families to manage on their own and hence may not need an inpatient admission.

**Prevalence of Delirium/Confusion**

To answer the first research question, both the palliative care physician and the nursing staff diagnoses of delirium/confusion were examined. The diagnosis of delirium/confusion by both the physician and the nursing staff was retrieved from the patients' initial admission progress notes. The prevalence of delirium in terminally ill cancer patients upon admission to the palliative care unit was 29% as diagnosed by the palliative care physician and 21% as diagnosed by the nursing staff. This is consistent with other research studies suggesting a delirium prevalence rate between 20% to 32% in terminally ill cancer patients on admission to a palliative care unit (Gagnon et al., 2000; Sarhill et al., 2001).

However, the prevalence of delirium in this research study is lower than in a study conducted by Lawlor et al. (2000) who found that 42% of advanced cancer patients experienced delirium upon admission to a palliative care unit. The MMSE was used on admission to screen for delirium in this study. As well, 44% of advanced cancer patients had an abnormal MMSE upon admission to a palliative care unit in a study by Pereira et al. (1997). The use of the MMSE as a delirium assessment tool has its limitations, as cognitive impairment diagnosed by the MMSE does not correspond to a formal diagnosis of delirium. Using the MMSE in these studies may have led to a higher prevalence rate of delirium in advanced cancer patients.

Delirium often occurs after admission onto a palliative care unit. The prevalence of delirium during a terminally ill cancer patient's inpatient stay on a palliative care unit tends to be slightly higher than on admission. Delirium may develop in hospital due to a combination of stressors such as the unfamiliar environment, increased risk of infections,

and increased use of opioids or other medications (Cole, 1999; Foreman, 1989). In this study, 35% of patients became delirious/confused after admission to the palliative care unit. These prevalence rates of delirium are congruent with other research studies on delirium prevalence with ranges from 28% to 45% while on a palliative care unit (Fainsinger et al., 1991; Minagawa et al., 1996; Caraceni et al., 2000; Gagnon et al., 2000; Lawlor et al., 2000).

A total of 64% of patients became delirious either on admission or during their hospital stay. This total amount includes patients that developed delirium prior to death. Patients who were delirious on admission may have been admitted just before death as many were admitted for terminal care. Sixty-four percent is a lower prevalence rate when compared with other studies that include delirium prevalence just prior to death. Delirium prevalence ranges from 80% to 90% prior to death were noted in research studies examining delirium prevalence in terminally ill cancer patients (Massie et al., 1983; Bruera et al., 1992; Lawlor et al., 2000; Fainsinger et al., 2000; Morite et al., 2001). However three of these studies used very low sample sizes, from 19 patients to 61 patients which may be an inaccurate estimate of the prevalence of delirium.

The median length of time from the date of admission to the date of confusion was 12 days. There are no research studies examining the length of time from admission to confusion in terminally ill cancer patients admitted onto a palliative care unit. Studies using the elderly population suggest delirium occurs most frequently on the second day of hospitalization and rarely occurs after the first week (Foreman, 1989; Foreman, 1990). Since these studies investigate delirium only in the elderly population, they do not take into account delirium that develops prior to death, which is highly prevalent in the

terminally ill cancer population. Therefore delirium will develop after 7 days of hospitalization on the palliative care unit for patients with terminal cancer.

The average length of time from date of confusion to date of death in this study was 13 days ± 16 days (median = 8 days). Concordant with these findings, Morita et al. (2001) found that delirium occurred an average of 19 days with a median interval of 10 days before death. Bruera et al. (1992) reported patients experiencing delirium an average of 16 days prior to death.

Physician versus Nursing Assessment of Delirium/Confusion

As noted previously, the prevalence of delirium/confusion diagnosed by the palliative care physician was 29% versus 21% by the nursing staff. In 10% of the terminally ill cancer patients admitted onto the palliative care unit, the physician and not the nurse diagnosed delirium/confusion, and 11 delirious patients were undetected by the nurse. This suggests that nurses were significantly less likely to diagnose delirium upon admission to the palliative care unit. Fainsinger et al. (1991) suggested that without the use of a delirium assessment instrument even experienced palliative care nurses overlook the presence of delirium in 24% of cases.

Most of the research examining nurses' assessment of delirium has been done on the hospitalized geriatric population. Inouye, Foreman, Mion, Katz, & Cooney (2001) conducted a prospective study comparing nurse ratings for delirium using the Confusion Assessment Method based on routine clinical observations with researcher ratings based on cognitive testing. Delirium occurred in 16% of 797 hospitalized geriatric patients on admission to a medical-surgical ward. Nurses identified delirium in only 19% of patients compared with 31% by the researchers. A study done by Culp et al. (1997) examined the

prevalence of and nursing staff recognition rates for acute confusion in two long-term care facilities. Data was collected using the MMSE as a baseline for detecting a change in mental status and the Neecham delirium assessment scale daily in the first week and every second day in the second week. The small sample of 37 geriatric patients limits generalizing the study findings. However, the research results obtained suggested a high prevalence of acute confusion in geriatric patients that may go undetected by nurses.

Another study by Williams, Ward and Campbell (1988), compared two standardized delirium assessment scales with nurses observation for disturbed cognitive function in 169 elderly patients recovering from surgical repair of hip fractures in four acute care hospitals. The Short Portable Mental Status Questionnaire was used as a baseline cognitive assessment on admission, the Confusion Rating Scale was used daily to detect delirium, and medical records were reviewed to check the nurses' notes for any documentation of "confusion". Nursing staff may have become sensitized to observe and record for signs and symptoms of acute confusion, since they were all reviewed on the purpose of the study. Results from this study showed that there was an underestimation of cognitive disorder by behavioral observation by nurses when compared to standardized testing. The study stresses the need for clinical testing of mental status and periodic testing throughout patients' hospital stay to identify patients at high risk. Morency, Levkoff, & Dick (1994) concluded that nurses did not recognize behavioral aspects of delirium and that nurses tended to focus more on the orientation of the patient.

Comparing the number of cognitively impaired elderly identified by a standardized mental status exam with the number identified by present nursing techniques was again researched with 182 geriatric patients on four medical-surgical units. This

study by Palmateer and McCartney (1985) compared the standardized assessment scale, the Cognitive Capacity Screening Examination, with the nursing notes on admission only. Nurses in this study missed detecting cognitively impaired elderly 55% to 72% of the time. These investigators concluded that the under-detection of cognitive impairment occurred because nurses did not use standardized methods of cognitive assessment.

**Comparisons Between Groups (Delirious versus Non-delirious Patients)**

In this research study, there were no significant differences in patient gender, age, location of primary tumor, site of metastases, length of cancer diagnosis, and narcotics on admission between delirious/confused versus non-delirious/non-confused terminally ill cancer patients. Other research studies examining patient characteristics between delirious and non-delirious terminally ill cancer patients have also shown no significant difference with relation to gender, age, location of primary tumor, length of cancer diagnosis, and narcotics on admission (Gagnon et al., 2000; Lawlor et al., 2000; Morita et al., 2001). However, some studies indicated that male gender, primary brain tumor, and/or brain metastases were significant risk factors for delirium (Cobb et al., 2000; Caraceni et al. 2000; Sarhill et al., 2001). According to Trzepacz (1996), the pathophysiology of delirium proposes that delirium can develop in patients with space-occupying lesions in the brain. The association of gender and delirium may not be clinically meaningful.

Results of the data analysis compared the average daily dose of narcotic and PRN narcotic (calculated in daily morphine equivalents), the number of 'other medications' (all other medications not including narcotics, benzodiazepines, antipsychotics, anticholinergics, corticosteroids, and antidepressants) and PRN medications, lab values,

and MMSE scores between delirious/confused versus non-delirious/non-confused terminally ill cancer patients upon admission to the palliative care unit.

Delirious patients in this study were on an average of 192mg of narcotic daily and non-delirious patients were on slightly higher doses of 199mg of narcotic daily. The average PRN narcotic daily dose was 14mg, the same amount for both delirious and non-delirious patients. Delirious patients were again on lesser amount of 'other medications', averaging only 2 medications' on admission, while non-delirious patients were on 3 medications. The PRN number of 'other medications' was the same between groups, using only one PRN medication on admission. These results were unexpected as delirium is typically precipitated by opioids, opioid toxicity, and polypharmacy (Massie et al., 1993; Bruera et al., 1992; Stiefel et al., 1992; Bruera et al., 1995). This finding conflicts with results found in a study conducted by Gagnon et al. (2000), which determined that non-delirious patients were on lower doses of daily and PRN opioid (approximately half of the dose of delirious patients). However, the results of this study imply that delirium is multifactorial, not just related to the dose of narcotic or polypharmacy, and many patients become delirious because of multiple organ failure as a result of the dying process. As well, since the use of neuroleptics was the most common intervention when delirium was diagnosed, this may suggest that many patients were dying and the delirium may not have been reversible when diagnosed.

Routine lab work was completed on most patients admitted onto the palliative care unit. There were approximately 15 patients with no lab value results. Data analysis of patient's lab values demonstrated only a significant association in sodium levels between delirious and non-delirious patients ($p = .018$). Two studies examined potential causes of

delirium and found hyponatremia accounted for only 3% of cases of delirium, hypernatremia in less than 1% (Bruera et al., 1992; Morita et al., 2001). Again, these findings are in contrast to many studies in which abnormal lab values resulting in various possible causes of delirium were reported, for example anemia (low hemoglobin), hypercalcemia, infection (increased white blood cell counts), hyper/hypoglycemia, renal failure (increased urea and creatinine), disseminated intravascular coagulation (low platelets), hyperkalemia (increased potassium), and low serum albumin levels (Bruera et al. 1992; Lawlor et al., 2000; Morita et al., 2001).

Patients diagnosed with delirium/confusion on admission to the palliative care unit were frequently treated with neuroleptics to relieve the clinical symptoms of delirium. Methotrimeprazine (Nozinan) was the most commonly used neuroleptic which tends to be more sedating and is typically recommended when sedation is required for severe symptom distress, including agitated delirium, pain, and nausea (Stiefel et al., 1992). Midazolam (Versed) was the second most frequently used neuroleptic which is also very sedating but has less side effects with respect to respiratory depression and cardiovascular compromise (Shury, 2002). This may indicate that many of the patients in this study that were administered Nozinan or Versed were closer to death and therefore terminally sedated. Haldol has always been considered the gold standard for the pharmacological treatment of delirium. However, recent research is starting to show the benefit of the use of atypical antipsychotics, such as Risperidone and Olanzapine, which have a lower rate of extapyramidal side effects (Breitbart et al., 2002; Schwartz & Masand, 2002; Tune, 2002). These new medications may not have been available during the time frame in which the study was reviewed.

Opioid rotation, discontinuing or decreasing a non-opioid medication, treating hypercalcemia, treating infection, and treating dehydration were also utilized as interventions in the management of delirium. Research studies have shown that patients with delirium have a reduced incidence of agitated delirium and/or improve with these interventions (Bruera, Franco, Maltoni, Watanabe, Suarez-Almazor, 1995; Gagnon et al., 2000; Lawlor et al., 2000). These interventions are clinically simple to implement and have low burden on the patient. Progress notes written in the patients' medical charts that received these interventions had noted a reverse in the delirious state. In two cases, delirium in patients was reversed when they were treated for dehydration and hypercalcemia. Delirium was also reversed in a patient who received neuroleptics, had his or hers corticosteroid dose increased, and rotated the opioids he or she was receiving. As well, opioid rotation and neuroleptics reversed delirium in another patient who was admitted onto the palliative care unit with a narcotic dose of 1800mg. There was no improvement in delirious patients who had died soon after.

On admission to the palliative care unit, nurses are expected to routinely administer the MMSE to terminally ill cancer patients in order to get a baseline score for the patient's cognition and to assess for any cognitive impairment. However, there were only 51 MMSEs completed out of the 110 charts. Many reasons were noted on the chart as to why the MMSE was not administered to patients. These reasons included: patient too drowsy or tired, patient unable to speak, patient too vague or confused, hearing impairment, fractured arm, patient unresponsive, or a language barrier prevented administration of the MMSE. One MMSE was not administered because the patient had Alzheimer's disease.

The average score on the MMSE in delirious/confused patients was 20 out of 30 and for non-delirious/non-confused patients 26 out of 30. Results of this study found a significant difference between scores of the MMSE of delirious versus non-delirious patients ($p = .012$). Scores on the MMSE of less than 24 indicate cognitive impairment, and the finding that delirious patients tended to have lower MMSE scores is not surprising. These results are consistent with a study by Minagawa et al. (1996) where the average MMSE score in cognitively impaired terminally ill cancer patients was 6 out of 30 and non-cognitively impaired patients scored an average of 27 out of 30.

**Symptom Distress in Delirious versus Non-delirious Patients**

To answer the second research question, symptom distress scores using the ESAS were compared with the palliative care physician and nurses' assessment of whether patients were delirious or not on admission to the palliative care unit. The Symptom Perception Theory guided the conceptual framework for answering the second research question.

The ESAS is routinely administered to patients to adequately assess patients' levels of symptom distress upon admission to the palliative care unit. Out of 110 charts reviewed, 104 ESASs were completed. The average score on the ESAS was 40 out of maximum score of 90. Lower ESAS scores indicate lower levels of symptom distress. The most distressing symptoms for all patients were activity (also referred to as fatigue), appetite, drowsiness, and well being from that order of most distressing. These results correlate exactly with findings from a study by Jenkins et al. (1998) who also found fatigue, appetite, drowsiness, and well-being as the most distressing symptoms rated in order from most distressing, with an average ESAS score of 41. Another study by Jenkins

et al. (2000) also reported fatigue, appetite, and well being as having the highest average ESAS scores indicating more symptom distress. The results from this study are not surprising as the main reason for admission onto the palliative care unit was for fatigue. Terminally ill patients admitted onto the palliative care unit are typically fatigued, drowsy and tend to have no appetite since they are typically closer to death than the patients still in the community.

Results from the data analysis revealed that there is a significant difference in symptom distress upon admission to a palliative care unit between delirious and non-delirious terminally ill cancer patients when the palliative care physician diagnosed delirium on admission ($p = .041$), but not when the nurse diagnosed delirium ($p = .218$). This study found that non-delirious patients had higher levels of symptom distress than delirious patients. The same significant difference was demonstrated when three sub-scales of the ESAS (depression, anxiety, and well being) were eliminated from the total ESAS score due to their high frequency of missing values. The average ESAS scores without these sub-scales were 31 out of a score of 60. There was still a significant difference when the physician diagnosed delirium ($p = .049$) between delirious and non-delirious patient's levels of symptom distress than when the nurse diagnosed delirium ($p = .102$).

A comparison with the results of this study and findings of other research studies can not be made as there are no other research studies comparing levels of symptom distress between delirious/confused and non-delirious/non-confused terminally ill cancer patients upon admission to a palliative care unit. Research studies comparing delirious patients and levels of pain intensity have suggested that health care providers and

patient's family members tend to overestimate the levels of pain in delirious patients versus non-delirious patients, although patients did not complain of more pain before, during, or after an episode of delirium (Bruera, 1991; Bruera et al., 1992). Patients in the study could not remember having increased pain during their delirious episode. However, a recent research study on patients' recall of their delirium experience suggested that out of 154 hospitalized patients with cancer, 54 patients recalled their delirium experience as highly distressing due to the presence of delusions in both hypoactive and hyperactive sub-types of delirium (Breitbart, Gibson, Tremblay, 2002). Their study also confirmed that delirium is highly distressing to patient's families and nursing staff. This study did not specifically examine patients' levels of symptom distress and patients were not terminally ill.

The results of this study indicate that non-delirious/non-confused terminally ill cancer patients have higher levels of symptom distress than delirious/confused patients upon admission to the palliative care unit. This result may suggest that patients with delirium are not able to perceive and report symptoms accurately since delirium is a global brain dysfunction with disturbed arousal, attention, cognition, and communication. Accurate reporting of symptoms depends on the patient's ability to perceive symptoms normally and communicate the experience appropriately.

The conceptual model used for this study, the Symptom Perception Theory, seeks to explain the processes that affect symptom reporting. This theory suggests that information (both externally and internally) that is perceived is partly dependent on the cognition and traits of the individual. Important steps in this theory are the first step, information input, the second step, the selection of information through attentional

processes, and the third step, detection of somatic sensations. Since delirium is an altered state of consciousness with impaired ability to focus or shift attention, the selection of information through attentional processes would be altered. Therefore if patients are delirious with decreased selective attention to the body, they will have less processing of somatic information and thus a lower detection of somatic sensations. That is, delirious patients may experience lower levels of symptom distress, as they can not detect distressing symptoms in their bodies due to their decreased attention to physiologic bodily process. The fourth step of this model, attribution, refers to the meaning of the somatic information for the individual. Delirious patients may not be able to account for the meaning of their symptoms as delirious patients lack insight into their experience (Fleminger, 2002).

Another reason for delirious patients having lower levels of symptom distress relates to the hypoactive delirium sub-type. In hypoactive delirium, patients present as quiet, withdrawn, lethargic, slow to respond, facial inexpressiveness, and may sleep more often (Johnson, 1999; Camus et al., 2000; Crammer, 2002). As well, patients with a mixed delirium fluctuate between hyperactive and hypoactive states. The mixed sub-type and the hypoactive delirium tend to be more common than the hyperactive delirium (Liptzin & Levkoff, 1992; Lawlor, Gagnon, Mancini, Pereira, & Bruera, 1998; O'Keefe & Lavan, 1999; Sandberg, Gustafson, Brannstrom, & Bucht, 1999; Meagher, O'Hanlon, O'Mahony, Casey, & Trzepacz, 2000). Many patients admitted for terminal care and fatigue may have had a hypoactive sub-type of delirium since hypoactive delirium is especially prevalent just prior to death and patients are generally more physically ill (Liptzin & Levkoff, 1992; Lawlor et al., 1998). Symptom distress may be inaccurately

assessed in delirious patients due to their decreased ability to perceive or report symptoms. Nursing staff may perceive hypoactive delirious patients as having less symptom distress. Since the nurse most frequently completed the ESAS when patients were delirious, nurses may have scored patients lower on the ESAS.

## LIMITATIONS OF THE STUDY

There are limitations to this research study. Although this study examined consecutive medical charts of patients that died on the palliative care unit between September 1999 and January 2000 to avoid a history bias, the design was retrospective. Delirium prevalence relied on the physician and nursing assessment of delirium but no formal delirium assessment scales were used. However, the reliability in the detection of the prevalence of delirium was enhanced as the same palliative care physician admitted all of the patients in this study.

As delirium tends to fluctuate during the day and patients who have a hypoactive form of delirium are at risk of under-detection, especially by the nursing staff. Delirious patients with an agitated, hyperactive delirium are easier to identify. Since the nurse completed most of the ESASs, not the patients themselves, the nurses may have perceived that the hypoactive delirious patients had lower levels of symptom distress. The conceptual model used in this study supports that patients with cognitive impairment have difficulty perceiving and thus reporting symptoms, which may account for the low levels of symptom distress on the ESAS score.

It may be difficult to generalize the study's findings to all terminally ill cancer patients, as there are terminally ill cancer patients in every type of setting, both hospital

and community, and only one palliative care unit was used as the setting in this study. However, the large sample size was able to detect a significant difference between the delirious and non-delirious terminally ill cancer patients. Despite these limitations, this research study provides important program evaluation information on which to base clinical practice guidelines, future research studies, and nursing education.

## IMPLICATIONS OF THE STUDY

### Implications for Nursing Practice

As delirium is highly prevalent and nurses tend to miss the detection of delirium on admission to a palliative care unit, a formal delirium assessment scale should be implemented into the initial nursing assessment of patients on admission. With a delirium assessment tool, nurses could detect delirium quickly and coordinate with other health care team members to initiate a plan of care that promptly treats delirium in order to reduce the symptoms, duration, and potential negative consequences of this disorder. Early diagnosis and treatment of delirium (that is, prior to the development of management problems such as patient aggressive behavior directed at staff and family) would prevent both a disruption in ward routine and an increase in nursing care and supervision which often result in increased hospital costs. The patient's quality of life would be enhanced if the delirium and potential symptom distress is detected early and treated quickly in the initial admission assessment. Patient and family communication could continue at a time when it is especially important for them to discuss life closure issues. Consistent and frequent assessment of delirium using a formal delirium assessment instrument throughout patients' inpatient stay is required to reduce the

incidence and deleterious effects of delirium. It is imperative for palliative care providers to recognize and manage delirium with greater expertise.

Nursing care plans currently provide palliative care nurses with guidelines on how to manage various terminally ill cancer patients' symptoms such as pain, constipation, and nausea and are available on the palliative care unit. However, as there are no nursing care plans for the management of the delirious patient, care plans that focus exclusively on delirious patients need to be proposed and implemented.

Various distressing symptoms occur frequently in terminally ill cancer patients. Presently, nurses assess patients' symptom distress using the ESAS both on admission and daily on this palliative care unit. It would be helpful if patients independently administered their own ESAS so that nurses would have a better sense of the patient's levels of symptom distress. Nurses need to educate patients on how to use the ESAS, as many sub-scales on the ESAS were not filled out, in particular, well being, depression, and anxiety. Nurses need to recognize that delirious patients may have difficulty reporting their symptom distress and so adequate time to spend with the patient may be needed.

**Implications for Nursing Education**

From my own nursing education experience, nursing education provides little information on the care of delirious patients. As a Clinical Education Facilitator with the Faculty of Nursing, I found that nursing students were generally overwhelmed with all aspects of the palliative care course and there often tended to be a focus on pain control. As nurses in this study were unable to detect the presence of delirium as often as the palliative care physician, this indicates a need for continuing education for nurses on delirium in terminally ill cancer patients. Continuing education programs and frequent

seminars on the assessment and management of delirium are necessary to help educate the palliative care nurse. It would be helpful to include a seminar on delirium upon orientation to the palliative care unit.

### Implications for Nursing Research

Further research is needed to fully comprehend and successfully manage delirium in terminally ill cancer patients. As there are no other research studies comparing levels of symptom distress between delirious and non-delirious terminally ill cancer patients on admission to the palliative care unit, more research is required. A stronger research design such as a prospective study would be helpful to increase the validity and generalizability of results for future research.

Educational initiatives should be investigated to enhance the knowledge and clinical skills of palliative care nurses to improve the outcome and quality of life of terminally ill cancer patients. Educational research needs to focus on both nursing assessment and interventions for delirious patients to determine which nursing assessments (including a delirium assessment tool) and interventions are most effective.

## CONCLUSION

This study represents the first study (to my knowledge) conducted comparing symptom distress levels between delirious/confused and non-delirious/non-confused terminally ill cancer patients admitted onto the palliative care unit. The findings of this retrospective research study indicate that there is a significant difference between levels of symptom distress between delirious and non-delirious patients upon admission to a palliative care unit and requires future research studies to examine this difference.

Overall, this study confirms findings from previous studies, using the terminally ill cancer population, that delirium is highly prevalent upon admission to a palliative care unit. It is important that care providers are able to recognize and identify delirious patients and their levels of symptom distress upon admission to a palliative care unit so that interventions to reverse the causes of delirium and management of symptom distress can immediately be implemented.

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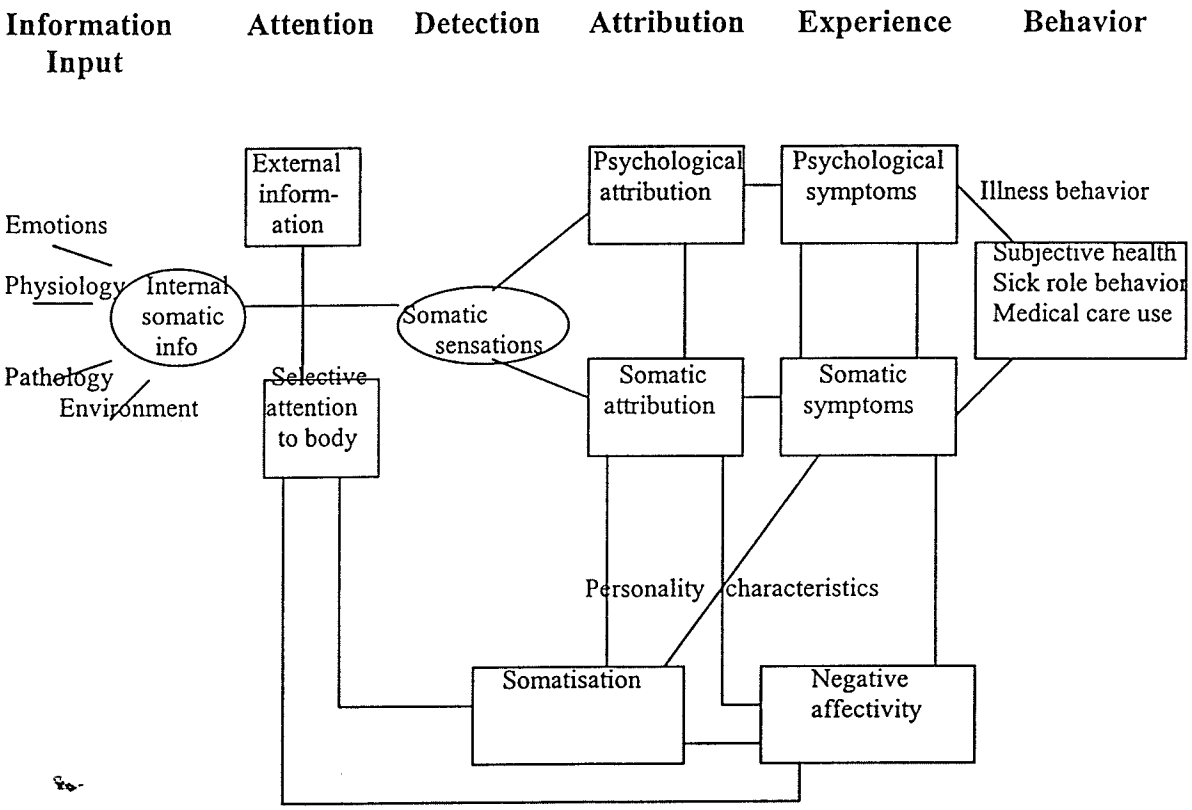
# APPENDIX ONE

# SYMPTOM PERCEPTION THEORY

# SYMPTOM PERCEPTION MODEL



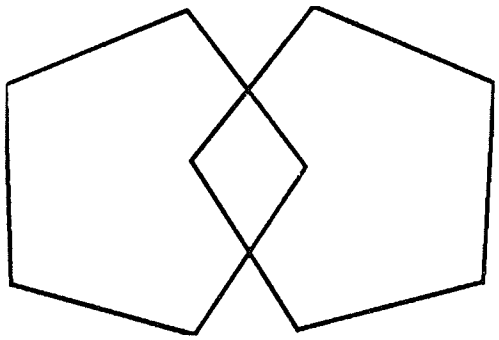
# APPENDIX TWO

## FOLSTEIN MINI MENTAL STATE EVALUATION (MMSE)

# MINI-MENTAL STATE EVALUATION (FOLSTEIN)

| Maximum Score | Client's Score | |
|---|---|---|
| | | Client: _____ Evaluator: _____ Date: _____ |
| 5 | [ ] | **Orientation to Time**<br>Month _____ date _____ year ____ day of week _____ season _____ |
| 5 | [ ] | **Orientation to Place**<br>Home/place _____ street _____ city _____ province _____ country _____ |
| 3 | [ ] | **Registration**<br>Name 3 objects (apple, penny, table); 1 second to say each. Ask the client to repeat all 3 after you have said them. Give 1 point for each correct answer. Then repeat them (up to 3 times) until client learns all 3. Count trials. **Trials:** _____ |
| 5 | [ ] | **Attention and Calculation**<br>Spell "WORLD" backwards. (Spell forward & correct errors first) ___ ___ ___ ___ ___<br>Alternatively do serial 7's. 1 point for each correct. Stop after 5 answers.<br>93 ___ 86 ___ 79 ___ 72 ___ 65 ____<br>Record best score. |
| 3 | [ ] | **Recall**<br>Ask for the 3 objects repeated above.<br>Give one point for each correct.<br>_____ _____ _____ |
| | | **Language** |
| 2 | [ ] | Name a pencil _____ and a watch _____ |
| 1 | [ ] | Repeat the following: "No ifs, ands, or buts" _____ |
| 3 | [ ] | Follow a 3 stage command. "Take this paper in your right hand _____, fold it in half _____, and put it on the floor/bed/table" _____. (3 points). [Use blank piece of paper]. |
| 1 | [ ] | "Do what this says to do": 'CLOSE YOUR EYES' [show bottom of this page]. |
| 1 | [ ] | Write a sentence [on back of this page]. |
| 1 | [ ] | **Visual Construction**<br>Copy design [on back of this page]. |
| 30 | _____ | **Total Score** |
| 30 | | |

# CLOSE YOUR EYES



# APPENDIX THREE

## EDMONTON SYMTPOM ASSESSMENT SCALE (ESAS)

NAME: _____

## SYMPTOM ASSESSMENT

ROOM NO: _____

DATE & TIME: _____

| | | |
|---|---|---|
| No Pain | _____ | Worst Possible Pain |
| Most Activity | _____ | Least Activity |
| Not Nauseated | _____ | Worst Possible Nausea |
| Not Depressed | _____ | Worst Possible Depression |
| Not Anxious | _____ | Worst Possible Anxiety |
| Not Drowsy | _____ | Worst Possible Drowsiness |
| Best Appetite | _____ | Worst Possible Appetite |
| Best Feeling of Well Being | _____ | Worst Feeling of Well Being |
| No Shortness of Breath | _____ | Worst Possible Shortness of Breath |
| Other Problems | _____ | |

**Completed by:** ☐ **Patient**
☐ **Family**
☐ **Nurse**
☐ **Nurse Assisted**

**Edmonton Symptom Assessment System**

# APPENDIX FOUR

## DATA COLLECTION FORM

# DATA COLLECTION FORM

ID NUMBER_____

ADMISSION DATE_____
DATE of DEATH_____
DATE CONFUSION DIAGNOSED_____

GENDER
- Male.....1
- Female.....2

AGE
- 18-35.....1
- 36-50.....2
- 51-60.....3
- 61-70.....4
- 71-80.....5
- 80+.....6

LENGTH OF CANCER DIAGNOSIS (original diagnosis)
- < 3 months.....1
- 3-6 months.....2
- 6 months- 1 year.....3
- 1-2 years.....4
- > 2 years.....5

LOCATION OF PRIMARY TUMOR
- Brain.....1
- Breast.....2
- Lung.....3
- Genitourinary.....4
- Gastrointestinal.....5
- Head & neck.....6
- Hematological.....7
- Lymph.....8
- Other.....9
- Unknown location.....10

METASTASES (circle all that apply)
- Brain.....1
- Lung.....2
- Liver.....3
- Bone.....4
- Other.....5

<u>On Admission</u>:
1)MMSE score_____

2)ESAS total score_____
Done By:
Nurse or NA
Patient
Family

3)Individual symptom scores:
- Pain_____
- Activity_____
- Nausea_____
- Depression_____
- Anxiety_____
- Drowsiness_____
- Appetite_____
- Feeling of well being_____
- Shortness of breath_____

<u>On Admission:</u>
Delirium/confusion diagnosed by palliative care physician?
Yes.....1
No.....2

Delirium/confusion stated in progress notes by nursing?
Yes.....1
No.....2

On Admission:

1)NARCOTICS (circle all that apply)

Morphine.....1
Dilaudid.....2
Fentanyl Patch.....3
Codeine.....4
Other.....5

TOTAL DAILY DOSE OF NARCOTIC (in oral Morphine equivalents/24h)
_____mg

PRN (in oral morphine equiv/24h)_____

2)MEDICATIONS (circle all that apply)

Benzodiazepines.....1
Antipsychotics.....2
Corticosteroids.....3
Anticholinergics.....4
Antidepressants.....5

3)Total number of other medications (not incl. Narcotics/above meds)_____ PRN____

4)LAB VALUES

Calcium_____ Albumin_____ Sodium_____
Potassium_____ Urea_____ Creatinine_____
Glucose_____ WBC_____ RBC_____ Hgb_____ Plts_____
Urine C&S: positive / negative

REASON FOR ADMISSION per palliative MD death summary (circle all that apply)

Pain.....1
Delirium/confusion.....2
Nausea.....3
Constipation.....4
Dyspnea.....5
Fatigue.....6
Anorexia.....7
Terminal care.....8
Other_____

INTERVENTIONS (If diagnosed with confusion/delirium on admission):

Opioid rotation.....1
Hydration (IV or hypodermoclysis).....2
Treatment of infection (antibiotics).....3
Treatment of hypercalcemia (IV pamidronate).....4
Neuroleptic treatment.....5
Haldol / Versed / Nozinan / other
Decreasing or discontinuing non-opioid drug.....6

# APPENDIX FIVE

## LETTER OF APPROVAL FROM THE ETHICAL REVIEW COMMITTEE

UNIVERSITY OF MANITOBA | OFFICE OF RESEARCH SERVICES

ORS
244 Engineering Building
Winnipeg, Manitoba R3T 2N2
Telephone (204) 474-8418
Fax (204) 261-0325
www.umanitoba.ca/vpresearch/ors

# APPROVAL CERTIFICATE

02 April 2002

**TO:** **Sarah Brown**
Principal Investigator

**FROM:** **Lorna Guse, Chair**
Education/Nursing Research Ethics Board (ENREB)

**Re:** **Protocol #E2002:025**
**"Prevalence of Delirium and its Relationship to Symptom Distress in Terminally Ill Cancer Patients"**

Please be advised that your above-referenced protocol has received human ethics approval by the 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.

# APPENDIX SIX

## LETTER OF APPROVAL FOR ACCESS TO RIVERVIEW HEALTH CENTRE


April, 2002

Sarah Brown

Winnipeg, MB
R3P 0J7

Dear Ms. Brown:

Please be advised that the Riverview Health Centre Research Committee reviewed your proposal "Prevalence of Delirium and its Relationship to Symptom Distress in Terminally Ill Cancer Patients" at a meeting held on April 17th, 2002. At that time, the committee approved your request for access to the Centre. It is recommended that you make contact with the Health Information Department (478-6295) for assistance. Please note that a condition of access to RHC is that you provide us with a summary of your findings when available.

If you have any questions, please feel free to contact me at (or ). Best wishes for the successful completion of your study and program.

Sincerely,

Marie Edwards
Education/Research Services

1 Morley Avenue • Winnipeg, Manitoba, Canada • R3L 2P4
Telephone (204) 452-3411 • Fax (204) 287-8718