

PAIN AND AGITATION IN THE DEMENTED LONG TERM CARE RESIDENT

Colin George Zieber

B.Sc., University of Lethbridge, 1996

A Thesis  
Submitted to the School of Graduate Studies  
of the University of Lethbridge  
in Partial Fulfillment of the  
Requirements for the Degree

MASTER OF SCIENCE

School of Health Sciences  
University of Lethbridge  
LETHBRIDGE, ALBERTA, CANADA

© Colin George Zieber, 2003

## ABSTRACT

This study involved 58 persons with dementia living in three rural Canadian long-term care (LTC) facilities. In an attempt to find the relationship between these person's possible pain and levels of agitation, data on five proxy indicators of pain were collected and correlated with scores from the Pittsburgh Agitation Scale (PAS). Results indicated that three of the resident pain measures were significantly correlated with PAS scores. In particular, the palliative consultant pain ratings and the DS-DAT were strongly correlated with total PAS scores, and the five PAS sub-factors. Importantly, the PAS sub-factor of *resistance to care* was strongly correlated with three of the pain variables. Major study implications include the need for increased use of palliative pain consultants in LTC, and the need for nursing staff to realize that when demented residents resist care, it may be a potential clue that the resident is experiencing untreated pain.

## ACKNOWLEDGEMENTS

The author would like to acknowledge his heartfelt appreciation to the following groups and individuals that made this thesis possible:

- 1) My most precious wife Lori Jeanne and beautiful daughters Laurel Victoria and Annika Joy. You have been the inspiration to keep going when the studies ceased to be fun.
- 2) Dr. Bradley Hagen, you are a true student's professor! Your continual encouragement and praise was extremely valuable during these past few years.
- 3) My parents, siblings, in-laws, church family and friends. Thank you for the practical help with meals, editing, childcare, and regular prayers.
- 4) Dr. Chris Armstrong-Esther and Dr. Mark Sandilands for the practical assistance in reviewing the thesis and assisting with the research design.
- 5) Dr. Roland Ikuta, Donna Stelmachovich, Phyllis Baskin, Margaret Brewin, Trudy Harbidge and the Chinook Health Region Seniors Health Team. Thank you for supporting me through this arduous process!
- 6) Continuing Care Managers and Registered Nurses in the three facilities. You were so patient and supportive of the project.
- 7) The whole Palliative Care Team. Particular thanks to LeAnn Popson-Esau, Diane Nummi, and Anne Plesko for your participation in the data collection.
- 8) Sharon Brown for her assistance with the data collection and statistical analyses.

## TABLE OF CONTENTS

|  |      |
|--|------|
| Abstract.....  | iii  |
| Acknowledgements.....  | iv   |
| Table of Contents.....   | v    |
| List of Tables .....   | xiii |
| List of Figures .....  | xv   |
| Chapter One: Introduction .....  | 1    |
| Purpose and Scope .....  | 1    |
| Background to the Study.....   | 2    |
| Chapter Two: Review of Relevant Literature.....                                  | 4    |
| Population of Interest: Individuals with Moderate to Severe Dementia.....        | 4    |
| Overview .....   | 4    |
| Prevalence of Dementia.....  | 5    |
| Prevalence of Dementia in Long Term Care .....                                   | 5    |
| Challenges to Providing Dementia Care.....                                       | 6    |
| Pain Issues.....   | 7    |
| Principles of Pain Assessment .....  | 7    |
| General Challenges to Pain Assessment and Treatment.....                         | 8    |
| Responsibility of Health Professionals<br>in Pain Assessment and Treatment ..... | 8    |
| Ethnicity of the Patient and Pain Treatment .....                                | 8    |
| Ethnicity of the Health Professional and Pain Treatment.....                     | 9    |

|   |    |
|---|----|
| Principles of Pain Treatment in the Elderly .....   | 9  |
| Misconceptions Regarding Pain Assessment and Treatment of<br>Elderly Patients .....         | 9  |
| Non-Medication Approaches to Treating Pain in the Elderly.....                              | 10 |
| Medication Approaches to Treating Pain in the Elderly.....                                  | 11 |
| Pain Assessments in the Elderly and Long Term Care Environment.....                         | 12 |
| Pain Intensity and Dementia .....   | 12 |
| Issues with Pain Assessment and Treatment<br>in the Elderly with Dementia .....             | 15 |
| Prevalence of Pain in Long Term Care.....   | 16 |
| Proxy Pain Assessments by Family and / or Caregivers.....                                   | 16 |
| Use of Self-Report Pain Scales with Persons with Dementia.....                              | 17 |
| McGill Pain Questionnaire .....   | 17 |
| Present Pain Intensity Subscale .....   | 18 |
| Visual Analogue Scale.....  | 19 |
| Additional Self-Report Pain Scales .....  | 20 |
| Use of Observational Pain Behaviour Assessment Scales for<br>Individuals with Dementia..... | 21 |
| Discomfort Scale-Dementia of the Alzheimer Type<br>(DS-DAT) .....                           | 21 |
| University of Alabama-Birmingham Pain Behavior<br>Scale (UAB).....                          | 22 |
| The Issue of Pain and Agitation in Long Term Care .....                                     | 23 |

|   |    |
|---|----|
| Overview of Pain and Agitation in Long Term Care.....                             | 23 |
| Agitation, Education of Staff, and the Long Term Environment .....                | 23 |
| Defining Agitation .....  | 24 |
| Assessing Dementia Related Agitation in the Long Term Environment...25            |    |
| Behavioral Syndromes Scale for Dementia (BSSD) .....                              | 25 |
| Cohen-Mansfield Agitation Inventory (CMAI).....                                   | 25 |
| Pittsburgh Agitation Scale (PAS) .....  | 26 |
| Common Management Approaches for Agitation in Long Term Care .....                | 26 |
| Overall Themes: Pain and Agitation in Dementia.....                               | 27 |
| Recommendations for Assessing Pain in Persons with Dementia<br>and Agitation..... | 28 |
| Summary of Relevant Literature.....   | 29 |
| Proposed Research .....   | 31 |
| Chapter Three: Framework.....   | 32 |
| Definition of Relevant Terms .....  | 32 |
| Research Framework .....  | 33 |
| Identification of Assumptions.....  | 34 |
| Objectives, Questions, and Hypotheses.....  | 36 |
| Objectives .....  | 36 |
| Research Questions .....  | 36 |
| Hypotheses.....   | 37 |
| Chapter Four: Methods and Procedures.....   | 38 |
| Research Design.....  | 38 |

|  |    |
|--|----|
| Descriptive Correlational Design.....                                    | 38 |
| Advantages and Disadvantages of Research Design .....                    | 38 |
| Sample and Setting .....   | 39 |
| Sampling Method.....   | 39 |
| Sampling Criteria.....   | 39 |
| Resident Subjects .....  | 39 |
| Facility Nurse Subjects (Nurses A and B) .....                           | 40 |
| Palliative Nurse Consultant.....   | 40 |
| Sample.....  | 41 |
| LTC Residents .....  | 41 |
| Facility Nurse Subjects (Nurses A and B).....                            | 41 |
| Palliative Nurse Consultant Subjects.....                                | 42 |
| Setting .....  | 42 |
| Ethical Considerations .....   | 43 |
| Background to Ethical Considerations.....                                | 43 |
| Study Specific Ethical Considerations.....                               | 44 |
| Measurement Methods.....   | 45 |
| Overall Need for Triangulation of Data, Methods, and Investigators ..... | 45 |
| Data Triangulation .....   | 45 |
| Method Triangulation .....   | 46 |
| Investigator Triangulation.....  | 46 |
| Measurement of Moderate to Severe Cognitive Impairment.....              | 47 |
| Measurement of Pain .....  | 47 |

|   |    |
|---|----|
| Pain Diagnoses.....   | 48 |
| Analgesic Medications.....  | 49 |
| Facility Nurse Pain Ratings .....                                     | 51 |
| Palliative Nurse Consultant Pain Ratings .....                        | 51 |
| Pain Behaviours .....   | 52 |
| Agitation .....   | 53 |
| Data Collection .....   | 54 |
| Facility Nurses .....   | 54 |
| Chart Reviews.....  | 54 |
| Observations of Behaviour .....                                       | 55 |
| Palliative Consultant Ratings.....                                    | 55 |
| Chapter Five: Results.....  | 57 |
| Research Question #1 .....  | 57 |
| Relationship between Pain Diagnoses and                               |    |
| Total Pittsburgh Agitation (PAS) Scores.....                          | 57 |
| Relationship between Pain Diagnoses and PAS Sub-Scores.....           | 58 |
| Aggregate Analgesic Scores and PAS Scores .....                       | 58 |
| Relationship between Facility Nurse Pain Ratings and PAS Scores ..... | 59 |
| Relationship between Palliative Consultant Pain Ratings and           |    |
| PAS Scores.....   | 64 |
| Relationship between DS-DAT and PAS Scores.....                       | 66 |
| Research Question #2 .....  | 68 |
| Research Question #3 .....  | 68 |

|   |    |
|---|----|
| Research Question #4 .....  | 70 |
| Research Question #5 .....  | 70 |
| Chapter Six: Discussion.....  | 71 |
| Overview.....   | 71 |
| Research Questions and Hypotheses .....   | 71 |
| Research Question #1 .....  | 71 |
| Hypothesis #1.....  | 71 |
| Aggregate Analgesic Scores and Total PAS Scores .....                                   | 72 |
| DS-DAT and Total PAS Scores.....  | 73 |
| Palliative Nurse Consultant Pain Ratings<br>and PAS Scores.....                         | 74 |
| Facility Nurse Pain Ratings and Total PAS Scores .....                                  | 74 |
| Further Implications of the Relationship between<br>Pain Variables and PAS Scores ..... | 74 |
| Hypothesis #2.....  | 75 |
| PAS Sub-Factors and Pain Variables.....   | 76 |
| Correlation Among Pain Variables.....   | 78 |
| Research Question #2 .....  | 79 |
| Hypothesis #3.....  | 79 |
| Research Question #3 .....  | 80 |
| Hypothesis #4.....  | 80 |
| A Further Implication of Palliative Pain Rating Scores.....                             | 81 |
| Research Question #4 .....  | 82 |

|  |     |
|--|-----|
| Hypothesis # 5.....  | 82  |
| Research Question #5 .....   | 83  |
| Hypothesis #6.....   | 83  |
| Overall Implications of Study.....   | 84  |
| Limitations .....  | 85  |
| Representativeness of Sample.....  | 85  |
| Demographic Representation.....  | 85  |
| Rural Facilities .....   | 86  |
| Subjectivity of Assessment Tools.....  | 86  |
| Recommendations for Future Research .....                                    | 87  |
| References.....  | 88  |
| Appendix 1: Letter of Permission to reproduce                                |     |
| <i>Model of multifaceted pain assessment</i> .....                           | 97  |
| Appendix 2: Nurse A consent form .....                                       | 98  |
| Appendix 3: Nurse B consent form .....                                       | 99  |
| Appendix 4: Palliative Nurse Consultant consent form.....                    | 100 |
| Appendix 5: Letter of Appeal to Chinook Health Region Ethics Committee ..... | 101 |
| Appendix 6: Chinook Health Region Research Approval Letter .....             | 103 |
| Appendix 7: University of Lethbridge Research / Ethics Approval.....         | 104 |
| Appendix 8: Chinook Health Region Ethics Committee Approval .....            | 105 |
| Appendix 9: Palliative Consultant Summary Form .....                         | 106 |
| Appendix 10: Data Collection Worksheet.....                                  | 107 |
| Appendix 11: Long Term Care Pain Rating Tool.....                            | 115 |

Appendix 12: Pittsburgh Agitation Scale .....116

**LIST OF TABLES**

Table 1: Correlation between Pain Diagnoses and Total Pittsburgh Agitation Scale (PAS) Scores .....60

Tables 2: Correlation between Pain Diagnoses and Pittsburgh Agitation Scale (PAS) sub-factors of Aberrant Vocalization (AV), Motor Agitation (MA), Aggressiveness (AG), and Resisting Care (RC).....61

Table 3: Correlation between Aggregate Analgesic Score, Total Pittsburgh Agitation Scale (PAS), and Sub-Factor Scores for Aberrant Vocalization (AV), Motor Agitation (MA), Aggressiveness (AG), and Resisting Care (RC).....62

Table 4: Correlation between Facility Nurse (average of Nurses A & B) Pain Rating And Score, Total Pittsburgh Agitation Scale (PAS), and Sub-Factor Scores for Aberrant Vocalization (AV), Motor Agitation(MA), Aggressiveness (AG), and Resisting Care (RC) .....63

Table 5: Correlation between Palliative Nurse Consultant (average of three consultants) Pain Rating and Total Pittsburgh Agitation Scale (PAS), and Sub-Factor Scores for Aberrant Vocalization (AV), Motor Agitation (MA), Aggressiveness (AG), and Resisting Care (RC).....65

Table 6: Correlation between Discomfort Scale-Dementia of the Alzheimer Type (DS-DAT) Total Rating and Total Pittsburgh Agitation Scale (PAS), and Sub-Factor Scores for Aberrant Vocalization (AV), Motor Agitation (MA), Aggressiveness (AG), and Resisting Care (RC) .....67

Table7: Correlation matrix demonstrating the correlation between pain ratings completed  
by Palliative Consultants A, B, and C.....69

## LIST OF FIGURES

|  |    |
|--|----|
| Figure 1: Model of Multifaceted Pain Assessment..... | 35 |
| Figure 2: Aggregate Analgesic Score .....            | 50 |

## **CHAPTER ONE: INTRODUCTION**

### **Purpose and Scope**

The purpose of this chapter is to introduce my Masters thesis, “Pain and Agitation in the Demented Long Term Care Resident.” In this chapter, I outline some of the professional experiences and literature that ‘caught’ my interest in understanding the relationship between various measures of pain and agitation with Long Term Care (LTC) residents with moderate to severe dementia. Furthermore, the purpose and scope of the issue are discussed.

Chapter Two is composed of a systematic and comprehensive review of the literature. Specifically, the literature reviewed includes the prevalence of dementia, general pain issues, pain assessment and treatment of LTC residents with dementia, the assessment and treatment of agitation in LTC residents with dementia, and the link between pain and agitation in LTC residents with dementia. Finally, the gaps in literature and clinical practice regarding assessment and treatment of agitation and pain are identified.

In Chapter Three, the framework of the study is outlined. The framework includes the definition of relevant terms, the research framework based on a model of multifaceted pain assessment, and the research objectives, research questions, and research hypotheses. The methods and procedures for the study are outlined in Chapter Four. The methods of the study include the research design, sampling methods and criteria, description of the subjects, and a description of the three LTC facilities used in the study.

The final component of the methods section is a description of the ethical considerations unique to a study using individuals with dementia as the primary subjects of study. The second part of Chapter Four deals with the procedures involved in measuring the research variables of dementia, pain, and agitation. In addition, a discussion is included regarding the need for triangulation of data, methods, and investigators for this study.

In Chapter Five, the results of the study are presented as they relate to the five research questions posed in Chapter Three. Finally, Chapter Six includes a discussion of the implications of the study as they relate to the research questions and hypotheses outlined in chapter three. Chapter Six also discusses the limitations of the study and results and offers suggestions for nursing practice and future research.

### Background to the Study

At the time I commenced on this course of study, I was working as a Psychogeriatric Nursing Consultant with the Chinook Health Region. My role was to assess (mostly elderly) residents displaying behavioural and psychiatric problems and provide consultative support and education to family and caregivers. The majority of individuals referred for assessment were residents of LTC displaying dementia related behavioural problems. On many occasions, the agitation and aggression was directly related to untreated or under-treated pain in LTC residents with a dementia. When the pain was appropriately treated, the patient's agitation decreased or completely disappeared. One example occurred of a LTC resident who screamed during all meals and became physically aggressive during personal care in the evening. During the course of assessment, the assessor recognized that the remaining teeth were profoundly decayed

and the nerve endings were exposed. Proper dental care was requested and completed with a dramatic improvement in the level of agitation. Additional experiences such as this caused me look for assessment tools to properly assess the pain and agitation that often comes with a dementia. However, this search revealed that few tools or assessment methods are available.

Two important resources that began the process of considering this study were the *model of multifaceted pain assessment* by Warne (1994) in Feldt, Warne, and Ryden (1998) and the Pittsburgh Agitation Scale (PAS) (Rosen et al., 1994). In particular, I began to use the PAS in clinical practice and conducted a small pilot study on a Geriatric Assessment and Rehabilitation Unit. The study assessed whether nursing staff could use the PAS to track agitated behaviours while medication and environmental interventions were changed.

## **CHAPTER TWO: REVIEW OF RELEVANT LITERATURE**

Population of Interest: Individuals with Moderate to Severe Dementia

### *Overview*

When a family is caring for one of its members with dementia, one of the most common reasons for Long Term Care (LTC) placement is escalating physical and/or behavioural needs resulting in a caregiver crisis (Penrod & Dellasega, 2001). Although LTC placement relieves the family or informal caregiver of the direct burden of providing care, the nursing and nursing aid staff attempt to deal with the physical and behavioural needs. Behavioural problems such as screaming, physical aggression, wandering, and resistance to personal care do occur in about 90% of individuals with a dementia (Canadian Medical Association, 1999). The causes of the behavioural problems in a dementia may be the result of one or a multitude of factors such as pain or other medical conditions, environmental triggers, and psychiatric conditions. The difficulty for physicians, nurses, and families is that an individual with moderate to severe dementia cannot properly communicate their need for physical and emotional comfort (Simons & Malabar, 1995). Therefore, it is important that professional caregivers systematically address anticipated physical needs, environmental issues, and psychiatric conditions until such time as these individuals demonstrate some relief (Banazak, 1996). A brief overview of the prevalence of dementia is outlined next in order to indicate the current and future needs for care of this population.

### *Prevalence of Dementia*

Over 3 million Americans (American Psychiatric Association, 1997), about 300 000 Canadians (CMA, 1999), and 25 000 Albertans have a dementia such as Alzheimer's Disease (Alberta Health and Wellness, 2002). Most estimates indicate that a third of these individuals reside in a LTC facility (CMA). In addition, due to the aging of the North American population, the number of individuals with a dementia will triple by the year 2031. The challenge for health professionals and families working with dementia will be to develop successful methods for dealing with the physical and behavioural demands associated with an increased need for dementia care.

### *Prevalence of Dementia in Long Term Care*

Because it is one of the most likely reasons for admission to LTC, dementia affects many of the residents in most LTC facilities (Penrod & Dellasega, 2001). Using the diagnostic criteria for dementia, a review of 2285 Maryland LTC admissions between 1992 and 1995 found that over 50% of new residents suffered from a dementia (Magaziner et al., 2000). Another American study estimated the prevalence of dementia in established LTC residents to be from 70 % - 80% (Rovner, Katz, & Lyketsos, 2000). Dementia profoundly impairs the memory, functional abilities, and communication and comprehension of the affected individual (APA, 1997). Recognizing that a dementia greatly impacts the LTC resident's ability to communicate their needs, a study of 325 LTC residents found that 21% of the residents could not make their needs known to staff or family (Ferrell, Ferrell, & Rivera, 1995). Along with communication issues in providing dementia care, other challenges face the caregiver in a LTC environment providing dementia care.

### *Challenges to Providing Dementia Care*

Sixty percent of Albertans with a dementia are classified as having moderate or severe dementia (Alberta Health and Wellness, 2002). Such individuals are either close to being admitted to LTC or are already living in a LTC facility. The problem of providing care to such individuals is that they demonstrate severe disorientation, physical and verbal aggression, severe language problems or the loss of all communication abilities, and the inability to care for their physical needs (Alzheimer Society of Canada, 2002). Unlike the experience of transient confusion due to a delirium, those with a dementia experience progressive and irreversible functional and cognitive deficits (APA, 1997). According to the systematic approach of Banazak (1996), the physical needs of individuals with a dementia must be assessed and addressed prior to attending to their environmental or psychiatric issues. Banazak did assert that pain may be one of the leading contributing factors to problem behaviours in LTC.

With the projected increase in the numbers of individuals with dementia, care issues will become more important. Furthermore, promoting and maintaining comfort for individuals with a dementia should become the priority of care. As outlined in the following section, pain issues have often been inadequately assessed and treated for many individuals with a dementia. In order to understand the issues of pain with demented residents in LTC, the general issues related to pain assessment and treatment will be reviewed.

## Pain Issues

### *Principles of Pain Assessment*

Unfortunately, pain cannot be directly measured, only inferred through physiologic measures such as heart rate or by observing facial expressions (Porter et al., 1996). Baillie (1993) contends that pain is a truly individual and subjective experience. Pain control experts advocate that the patient must be in control of expressing the intensity of pain and determining the extent of treatment (McCaffery & Pasero, 1999). McCaffery and Pasero suggest that a nurse “works with the patient to set comfort/function goals; the patient must understand that the intent is not to identify the highest pain level the patient can tolerate, but rather to identify how much pain can exist without interfering with function” (p. 74).

A general approach to assessing pain in an individual is to use a tool such as the Initial Pain Assessment Tool as recommended by McCaffery and Pasero (1999). The Initial Pain Assessment Tool requires that ten assessment areas be considered. First, the location, intensity, and quality of the pain are determined in consultation with the affected individual. Second, the onset, duration, variations, and manner of expressing pain are considered. Third, the patient confirms whether any relief has been achieved, what worsens the pain, and the physical, social, and emotional effects of the pain. Finally, the clinician and patient discuss other relevant issues and a pain treatment plan is mutually developed. However, all of these steps require fully functioning verbal and visual abilities of the patient.

### *General Challenges to Pain Assessment and Treatment*

#### *Responsibility of Health Professionals in Pain Assessment and Treatment*

The traditional approach to pain assessment is for the health professional to work with the affected individuals to help them describe their pain. Next, the clinician and patient work collaboratively to develop an effective treatment plan. However, many factors prevent the implementation of such a comprehensive pain assessment and treatment approach. Due to the communication and cultural limitations of some of these patients, health professionals must take more responsibility for ensuring thorough and ongoing pain assessment and treatment for this population. Furthermore, physicians and nurses are being held more accountable for the under-treatment of pain (Pasero & McCaffery, 2001).

#### *Ethnicity of the Patient and Pain Treatment*

One challenge to appropriate pain assessment that physicians and nurses face is the ethnicity of the patient. Ortega (2000) demonstrated that cultural and language barriers can impair proper assessment and treatment of pain. Similar findings were provided by a study in a Los Angeles Emergency Department in which it was found that Caucasian patients were two times more likely to receive analgesics than Hispanic patients (Todd, Samaroo, & Hoffman, 1993). By contrast, a follow-up study by Choi, Yate, Coats, Kalinda, and Paul (2000) in London, England did not find a significant difference between the analgesic medications given to either Bangladeshi or Caucasian patients. However, these researchers did acknowledge ethnic variation in the expression of pain.

### *Ethnicity of the Health Professional and Pain Treatment*

Ethnicity of the nurses and physicians can influence the subjective assessment of a patient's pain. Research on the pain a patient experiences after cardiac bypass surgery by Watt-Watson, Stevens, Garfinkel, Steiner, and Gallop (2001) discovered that only 47% of patients received their prescribed analgesics. In addition, one-third of patients (judged to be cognitively intact prior to surgery) could remember being administered a pain assessment tool. Of particular interest, the study found that one of the greatest barriers to proper pain control may have been the ethnicity of the nurses. Nurses of Southeast Asian decent scored their patient's pain significantly lower than Caucasian colleagues.

Appropriate pain relief measures require a thorough assessment and effective implementation of treatment regimes. A review of pain treatment will outline the medication and non-medication approaches. Particular attention will focus on the pain assessment and treatment needs of the elderly, specifically, residents of LTC with a dementia.

### *Principles of Pain Treatment in the Elderly*

#### *Misconceptions Regarding Pain Assessment and Treatment of Elderly Patients*

Pain control that is unique to the elderly individual is still considered to be a "peripheral focus of gerontological health care, despite the prevalence of pain-related conditions in this population" (Gibson, 1998, p. 10). Gibson contends that six misconceptions impede proper management of pain in the elderly. First, many health care professionals ascribe to the myth that pain is a normal part of aging and that pain perception is dulled by aging

and cognitive impairment. Second, they believe that strong interventions to treat pain in the elderly are not justified due to the individual's advanced age (ageism). Third, many think the treatment of pain in the elderly will have a lower chance of success than pain management in a younger individual. Fourth, health professionals consider pain assessment not worthwhile due to communication and cognitive barriers. Fifth, clinicians fear pain management will result in an elderly individual being addicted to opioid medications. Finally, they fear that proper pain assessment and treatment of elderly individuals will be too labour intensive. Gibson contends that the above misconceptions must be acknowledged and addressed prior to any health professional properly assessing and treating pain in any elderly patient. Weissman and Matson (1999) relate that one of the greatest barriers to proper pain treatment is the fear that the elderly cannot physiologically handle analgesic medications in both short-term and long-term scenarios. However, while analgesic medications are the main approach to treating pain in any age group, many non-medication approaches are useful.

#### *Non-Medication Approaches to Treating Pain in the Elderly*

Weissman and Matson (1999) recommend that non-medication approaches to pain treatment should be used in addition, rather than as a substitute, to medication approaches. Non-medication approaches to pain management in the elderly include music therapy, massage, Transcutaneous Electric Nerve Stimulation (TENS), exercise, acupuncture, and spiritual support. Miller and Talerico (2002) cited a few studies that examined non-medication approaches to treating pain in the elderly. They reported that these approaches were generally found to be minimally effective. Furthermore, nursing staff reported that they seldom used non-medication approaches such as exercise, heat

and cold therapies, massage, music, and conversation. In summary, the majority of research on pain treatment in the elderly has focused upon the use of analgesic medications as opposed to the use of non-medication (complementary) treatment options.

#### *Medication Approaches to Treating Pain in the Elderly*

Prior to initiating a medication approach to pain management in the elderly, a physician or other health professional must thoroughly assess the underlying etiology of the pain. The rationale for this approach to pain assessment is that the medications used and the dosing regimes prescribed will vary greatly depending upon whether the pain is due to a cardiac condition, gastroesophageal reflux, degenerative arthritis, vertebral fracture, or a plethora of cancerous conditions (Feinsod, Prochoda, Anneberg, & Solomon, 2000). Feinsod et al. describe how a medication such as nitroglycerine is used initially for cardiac pain or a combination of analgesics and steroids are used for some cancers. However, after non-medication and non-analgesic approaches are initiated to treat pain in the elderly, the next and main approach is to use analgesic medications.

A unique approach to classifying analgesic medications is to use the World Health Organization's (WHO) Analgesic Ladder (Scottish Intercollegiate Guidelines Network, 2001). Analgesic medications are arranged according to three levels of increasing strength of action to treat mild (Level or Step 1), mild to moderate (Level or Step 2), and moderate to severe (Level or Step 3) pain. Examples of Level 1 medications include paracetamol (acetaminophen), aspirin, and non-steroidal anti-inflammatory drugs (NSAIDs). Codeine is considered a Level 2 analgesic for the treatment of mild to moderate pain. Finally, moderate to severe pain (Level 3) is treated with analgesics such as morphine, fentanyl, hydromorphone, methadone, and oxycodone. The general

guidelines suggest starting with a Level 1 medication for a sufficient trial. If analgesia is not achieved, the physician will prescribe Level 2 and 3 analgesics until relief or significant side effects are observed.

In treating the elderly LTC resident, analgesic medications must be used with caution for the following reasons outlined by Feinsod et al. (1999). Acetaminophen should not be given in doses above 3000mg – 4000mg in a 24 hour period to avoid possible damage to the liver. Aspirin and NSAIDS can cause gastric irritation and ulceration. Opioid medications such as morphine often cause constipation, confusion, and respiratory depression at higher doses. In the LTC environment, the use of opioid analgesics can potentially cause confusion and unsteadiness that will increase the likelihood of falls. Despite these concerns, the health care professional must try all possible treatments to address pain to improve an elderly individual's quality of life.

#### *Pain Assessment in the Elderly and Long Term Care Environment*

##### *Pain Intensity and Dementia*

When a health professional decides on an appropriate treatment for painful conditions, the question of pain tolerance or pain intensity arises. Morrison et al. (1998) acknowledge that similar painful stimuli can impact individuals differently. When individuals with dementia are compared, the assumption is that variability in pain sensation still exists. Using this premise, some researchers have questioned whether the processes of aging and dementia diminish the intensity of pain. Case reports of seemingly pain free abdominal emergencies and supposedly silent myocardial infarctions lead clinicians to question whether an individual with dementia feels a lessened intensity of pain (Closs, 1994). Other anecdotal evidence (Fisher-Morris & Gellatly, 1997) describe

LTC residents with Alzheimer's disease who walked on fractured limbs, experienced hot water burns, grew undetected cancerous tumours, and appear to not be bothered by angina. Despite these incredible stories, Fisher-Morris and Gellatly (1997) do acknowledge that verbal and physical agitation did result in many of the cases. Liu, Raji, Twersky, and Riggs (2000) describe a demented LTC resident with persistent vocal agitation that was later discovered to be suffering with gout.

Recognizing that several researchers contend that an individual with dementia experiences minimal pain intensity, this argument will be considered by assessing the research. Although a dementia interferes with an individual's ability to communicate physical and psychological needs, researchers have attempted to research pain in dementia using language-based measurements. In a study of pain intensity and affect, Scherder, Bouma, Borkent, and Rahman (1999) concluded that demented subjects reported lower pain intensity and affect scores than cognitively intact controls. These findings were potentially confounded due to the verbal nature of the pain assessments conducted on each subject. Similarly, Scherder et al. reported a confounding result that demented and control subjects used equal numbers of analgesics, a possible sign that demented subjects felt pain but could not describe their agony in verbal terms.

Italian researchers Benedetti et al. (1999) conducted an ethically questionable experiment. Subjects with varying degrees of dementia were initially subjected to electric shocks and then had the blood flow temporarily occluded in one arm. Since more subjects with dementia did not vocalize their discomfort as quickly as the number of non-dementia subjects, the authors concluded that pain tolerance increased with worsening dementia.

Porter et al. (1996) studied elderly adults during the collection of blood samples via venipuncture. The researchers studied the heart rate, respiratory sinus arrhythmias, self reported anxiety, and pain using videotaped facial expressions of elderly subjects from the community and LTC residents with dementia. In summary, they found that LTC residents with dementia demonstrated a diminished change in heart rate, more difficulty verbalizing pain and anxiety, and more pronounced facial reactions. The evidence of more pronounced facial reactions in subjects with dementia supports the notion that pain sensation does exist in dementia.

Parmelee (1994) admits that evidence supports the notion that elderly individuals have a decreased sensitivity to painful stimuli. However, factors such as physical and emotional health impact pain perception. Co-morbid diseases, a higher incidence of depression, and behavioural expressions of pain confuse the issue of pain tolerance in LTC residents with dementia (Toomey & Seville, 1994). Research demonstrating that pain is less intense for individuals with a dementia may be countered by research in which non-verbal expressions of pain indicate the prevalence of painful conditions in the elderly. In addition, a growing body of research provides evidence that health professionals can be poor at assessing pain with their demented LTC residents (Marzinski, 1991; Sengstaken & King, 1993).

*Issues with Pain Assessment and Treatment in the Elderly with Dementia*

Although the assessment of pain with cognitively intact individuals relies heavily on a patient's self report (Gaston-Johansson, Johansson, & Johansson, 1999), a LTC resident with dementia has difficulty with sensory losses (hearing and vision) and cognitive factors such as memory, language dysfunction, and comprehension (Feldt, 2000). Furthermore, even if LTC residents with dementia could communicate their needs, many nurses chart less than half of what the patients describe (Marzinski, 1991). Another study illustrated that physicians detected pain in only 17% of LTC residents who were diagnosed with dementia and who had painful conditions (Sengstaken & King, 1993). Even when painful conditions are recognized, the treatment offered to individuals with dementia can be much less than for cognitively intact cohorts.

Morrison and Siu (2000) studied cognitively intact and impaired patients on an acute care unit for treatment of hip fracture. Their study revealed over 40% of intact patients rated their pain as 'severe to very severe'. However, only half of the patients received adequate analgesia. The most surprising result of Morrison and Siu's study was that the cognitively impaired hip fracture patients received a third of the analgesic given to the cognitively intact patients. The authors concluded that the cognitively impaired patients must have experienced significant postoperative pain.

### *Prevalence of Pain in Long Term Care*

A meta-analysis of pain studies in LTC identified pain as a concern in 62 to 79% of residents (Miller & Talerico, 2002). Arthritis, musculo-skeletal disorders (compression fractures), cancers, diabetic neuropathy, cardiac conditions, and ulcers are common painful conditions among LTC residents (Brignell, 1999). Ferrell et al. (1995) discovered that 70% of LTC residents with dementia had arthritis as a medical diagnosis. Cramer, Galer, Mendelson, and Thompson (2000) used the need for analgesic treatment as a measure of potential pain in LTC residents with dementia. Cramer et al. demonstrated that 54% of residents demonstrated one reason for analgesic treatment, 31% two reasons, and 14.7% had three or more reasons for analgesic treatment.

### *Proxy Pain Assessments by Family and / or Caregivers*

Pain assessment in LTC has been briefly discussed in the previous sections. The earlier sections outlined how pain in demented LTC residents can be assessed by reviewing potentially painful medical conditions, reviewing medication records, and linking aggression and agitation to under treated pain. In a 1998 study by Feldt et al. on pain and aggression in LTC residents with severe dementia, nursing assistants and family members were asked, "Do you think R (resident's name) experiences pain from some physical condition?" (p.18). While 76% of residents had at least one painful medical diagnosis, nursing attendants identified pain in 66% of residents while family members identified pain in only 44% of residents. Although this approach is quite simplistic and not common in the literature, it is a useful example of using a caregiver and / or family member to provide a proxy assessment of pain for an individual who cannot communicate their needs.

### *Use of Self-Report Pain Scales with Persons with Dementia*

One of the most common approaches to pain assessment is to use a self-report pain assessment scale (McCaffery & Pasero, 1999). Such an approach to pain assessment involves having the patient provide verbal or visual ratings of the pain intensity, tasks a person with dementia cannot complete (McCaffery & Pasero, 1999). Weissman and Matson (1999) argue that pain assessment with demented LTC residents is complicated due to memory problems, communication deficits, visual and auditory decline, and multiple medical problems. Despite these concerns, some researchers have attempted to use pain assessment scales developed for adults and children on individuals with dementia. The risk of using such scales on individuals with dementia is that they will not accurately measure pain since they rely on subjective reporting, intact cognition, and functional hearing or vision (Closs, 1994).

#### *McGill Pain Questionnaire (MPQ).*

The McGill Pain Questionnaire (MPQ) developed by Melzack (as cited in Miaskowski, 1999) is one of the most widely used verbal instruments for assessing pain. The MPQ asks an individual to point to the most descriptive words from a list of 78 words arranged into 20 groupings (Parmelee, 1994). It has been extensively cited in over 100 studies and translated into several languages (Schofield, 1995). The patient is asked to describe the pain using terms such as “quivering,” “burning,” “aching,” “icy,” “nauseating,” “intense,” or “stabbing” (Miaskowski, 1999, p. 651).

Ferrell et al. (1995) attempted the MPQ on 325 cognitively impaired LTC residents (moderate to severe impairment) and found that 80% could identify several words. A major weakness of the MPQ is the time it takes to complete the tool. Another weakness is

that the MPQ has only been tested in a handful of studies focusing upon elderly individuals (Parmelee, 1994). Most of the criticisms of the MPQ were summarized by Schofield (1995). The MPQ was described as an impractical tool for everyday use since it is time consuming for the tester and subject. Finally, the MPQ requires intact physical and cognitive skills, making it impractical for use with demented LTC residents (Forrest, 1995).

*Present Pain Intensity Subscale (PPI).*

Due to the MPQ's length and reliance upon intact verbal and reasoning ability, a sub-scale of the MPQ, termed the Present Pain Intensity Subscale (PPI), was developed (Feldt, 2000; Parmelee, 1994). The PPI is composed of six words with attached numerical values ranging from no pain = 0 to excruciating = 6. Ferrell et al. (1995) found that this scale demonstrated the highest rate of completion, even with subjects who had a mean Mini Mental Exam score of 12.1/30, considered to be evidence of dementia. The 65% completion rate was higher than the Memorial Pain Assessment Card Subscale (59%), Rand Coop Chart (57%), a verbal 0-10 scale (47%), and the Horizontal (100mm) Visual Analogue Scale (44%). However, the study revealed that almost 33% of subjects could not complete the PPI. This finding supports Parmelee's (1994) assertion that the PPI and similar scales have limited use with demented LTC residents.

Krulewitch et al. (2000) used the Pain Intensity Scale (PIS) developed by Parmelee (1994), a variation of the PPI. It was administered to cognitively impaired, community-dwelling elderly. With a mean Mini Mental Score of 15.7/30, 62% of subjects were able to complete the PIS. Then, the researchers asked the subjects' caregivers to complete the PIS. The completion rate was 97%. As proposed by

Miaskowski (1999), caregivers may provide suitable proxy assessments of pain in cognitively impaired elderly.

*Visual analogue scale (VAS).*

The Visual Analogue Scale (VAS) is another self-report scale used to research pain complaints in persons with dementia (Herr & Mobily, 1993; Ferrell et al., 1995). This scale comes in both horizontal and vertical versions. Interestingly, the vertical VAS was found to be easier for the elderly to complete than the horizontal VAS (Herr & Mobily, 1993; Forrest, 1995). This scale asks the individual to rate their pain by placing a mark or pointing to a spot on a line anchored with the phrases “no pain” and “pain as bad as it could be”(Herr & Mobily, 1993, p. 42). As mentioned earlier, Ferrell et al. (1995) discovered that the VAS had the lowest completion rate with cognitively impaired LTC residents of the five presented pain assessment scales. Thus, when the VAS is used with elderly or cognitively impaired subjects, it faces validity concerns since the VAS requires intact vision and the ability to understand how pain can be abstractly represented on a line (Baillie, 1993).

*Additional self-report pain scales*

Several variations of the PPI and VAS have been developed to assess pain. Examples are the Memorial Pain Card Subscale by Fishman et al. (cited in Ferrell et al., 1995), the Verbal Descriptor Scale, the Pain Thermometer, and the Numeric Rating Scale (Herr & Mobily, 1993). A verbal scale such as the Memorial Pain Card Subscale involves eight randomly arranged verbal descriptors of pain. The subject must rate their pain with a word or phrase such as “moderate,” “mild,” “just noticeable,” “strong,” “no pain,” “excruciating,” “severe,” and “weak” (Ferrell et al., 1995, p.594). All the variations of the

PPI and VAS offer limited clinical value to nurses working in LTC since they require residents to have intact vision and sufficient cognitive abilities to understand abstract concepts (Herr & Mobily, 1993).

Other researchers have used facial features as a measure of pain in the demented LTC resident. Porter et al. (1996) compared elderly with and without cognitive impairment and discovered that their facial reactions varied in response to venipuncture. Cognitively impaired elderly demonstrated more facial expression in response to painful stimuli despite showing a decrease in physiological response such as heart rate. The authors questioned whether the facial expressions represented pain or some other extraneous sensations. Furthermore, Bieri et al. in Herr, Mobily, Kohout, and Wagenaar (1998) used cartoon depictions of seven faces to illustrate pain intensity. The faces depict a range of emotions from happiness to extreme sadness. Similar to the six cartoon faces in Brignell (1999), most face pain scales are designed for children aged three to eight and up (Herr et al., 1998). This approach initially makes sense when working with cognitively impaired elderly. However, Krulewitch et al. (2000) discovered that cognitively impaired elderly only had a completion rate of 53%. Again, visual and cognitive deficits in most LTC residents would prevent a faces scale from having a general clinical benefit. Even if a facial pain scale was used by caregivers for proxy assessments, illnesses such as Parkinson's disease or a stroke could cause involuntary distortion of facial features. Therefore, a facial features scale assessment scale demonstrates minimal value for assessing pain in LTC residents with dementia (Simons & Malabar, 1995).

*Use of Observational Pain Behaviour Assessment Scales for Individuals with Dementia*

Overall, self-report pain scales show minimal clinical benefit for use with the cognitively impaired LTC resident. An emerging approach to pain assessment is to use observed behavioural measures that imply pain is likely present (Brignell, 1999). Numerous researchers have advocated that pain causes demented individuals to demonstrate behaviours such as facial grimaces (Brignell, 1999; Porter et al., 1996), aggressive actions (Feldt et al., 1998), crying (Liu et al., 2000), posture changes and restlessness (Hurley, Volicer, Hanrahan, Houde, & Volicer, 1992), as well as confusion and social withdrawal (Feldt, 2000). While these behaviours cannot be validated with most non-communicative LTC residents, they offer another perspective when assessing pain in the LTC environment (Miaskowski, 1999). Two scales have shown some clinical benefit and will be reviewed.

*Discomfort scale – Dementia of the Alzheimer Type (DS-DAT).*

The Discomfort Scale for Dementia of the Alzheimer's Type (DS-DAT), developed by Hurley et al. (1992), looks at the frequency, intensity, and duration of pain behaviours observed in non-communicative individuals with a dementia. The initial phase of the scale's development involved asking nursing staff to provide terms that described the 'discomfort' experienced by non-communicative LTC residents. Through a process of several trials, the list of terms was reduced from 26 to nine. These included the terms "noisy breathing, negative vocalizations, absence of a look of contentment, looking sad, looking frightened, having a frown, absence of relaxed body posture, looking tense, and fidgeting" (p. 372). The DS-DAT is scored by observing the nine behaviours and noting their frequency, intensity, and duration during a five-minute period of time. From

these assessments, a score of 0 – 27 can be obtained for the frequency. The scale did demonstrate satisfactory inter-rater reliability and content validity. The authors concluded that the DS-DAT should be tried on other populations of non-communicative individuals (e.g., brain injured individuals or stroke patients). One criticism of the DS-DAT is that it is overly complex for routine use by nursing staff due to the need for in-depth training prior to use (Feldt, 2000).

*University of Alabama-Birmingham Pain Behavior Scale (UAB).*

The second scale is the University of Alabama in Birmingham Pain Behavior Scale (UAB) (Richards, Nepomuceno, Riles, & Suer, 1982). This scale consists of ten categories of pain behaviours such as “vocal complaints (verbal), vocal complaints (non-verbal), down-time (time spent lying down per day), facial grimaces, standing posture, body language, use of visible supportive equipment, stationary movement, and medication” (p. 395). Each category is scored 0, 0.5, or 1 for a total possible score of 10. The scale can be quickly completed each day to help clinical staff determine treatment needs and measure effectiveness of the treatment. With trained assessors, inter-rater reliability was very high ( $r = 0.95$ ,  $N=58$ ,  $p \leq 0.01$ ), while test-retest reliability also high ( $r = 0.89$ ,  $N=58$ ,  $p \leq 0.05$ ). The validity was tested using the MPQ and the VAS (0-10). The authors found that the MPQ scores did not correlate with UAB scores while the VAS scores showed a weak relationship. The authors were not surprised with this outcome since chronic pain patients often demonstrate behaviours that are not congruent with their verbal reports (Porter et al., 1996). Richards et al. (1982) concluded by stating that the UAB was a “time friendly” instrument to quantify pain behaviours. The staff found it was a useful tool to teach staff about pain assessment and evaluate treatment interventions.

## The Issue of Pain and Agitation in Long Term Care

### *Overview of Pain and Agitation in Long Term Care*

While pain management for demented residents in LTC is a significant issue, one of the greatest barriers to proper assessment and treatment is that LTC caregivers do not have the skills and training to understand how pain affects an individual with dementia.

Weissman and Mattson (1999) argue that poorly trained and busy nursing attendants primarily staff most LTC facilities. Pain expressed by an individual with dementia is often classified as verbal and/or physical agitation (Buffum et al., 2001; Feldt et al., 1998). These behaviours are clearly shown to be one of the greatest challenges to providing dementia care to residents of LTC (Hagen and Sayers, 1995). In particular, 80% of LTC staff who were interviewed felt that agitated behaviours caused a resident to require more care than other LTC residents (Whall, Gillis, Yankou, Booth, & Beel-Bates, 1992). A study by Sourial, McCusker, Cole, and Abrahamowicz (2001) confirmed that up to 95% of hospital inpatients with a dementia displayed agitated behaviours, similar to the incidence seen in many LTC facilities. Therefore, any discussion about pain assessment and treatment in LTC must also address a simple and reliable method of assessing agitation.

### *Agitation, Education of Staff, and the Long Term Care Environment*

Numerous articles outline the concern with agitated and aggressive behaviour in LTC. This is not surprising given the previously cited information that a dementia is one of the primary reasons for admission to LTC (Penrod & Dellasega, 2001). The dementia is not the issue, but rather the physical and verbal agitation is burdensome to caregivers.

The Canadian Medical Association (1999) reported that almost 90% of individuals with a dementia demonstrate behavioural and psychological disturbances at some point in the course of their disease. One study on agitation in LTC identified that between 70% - 80% of staff working in LTC had been assaulted by nursing home residents (Whall et al., 1992). Wilkinson (1999) described a study where over 50% of cognitively impaired LTC residents demonstrated aggressive behaviours towards the staff. Many of the staff in LTC are nursing aids with minimal training or education (Middleton, Stewart, & Richardson, 1999). Education of the staff in LTC about the causes of agitation and aggression has demonstrated a significant and replicated benefit of decreasing the aggressive behaviours and improving staff satisfaction (Hagen & Sayers, 1995; Middleton et al.; Wilkinson). In particular, the program initiated by Hagen and Sayers involved three education modules covering basic information on dementia, causes of aggression, goals and strategies of care, and protective measures in case of an assault. The overall result was that the aggressive incidents decreased by 50%.

#### *Defining Agitation*

In reviewing the literature on agitation or aggression in a dementia, there is some variability in the actions exhibited by the 'agitated' or 'aggressive' LTC resident. In other words, the terms agitation or aggression can be operationally defined in a variety of ways. Whall et al. (1992) surveyed LTC staff and developed a list of over 30 behaviours such as hitting/slapping, refusing care, and complaining / whining that were defined as being 'disruptive'. Another author classified disruptive behaviours as hyperactive-physical, hyperactive-verbal, hypoactive-physical, and hypoactive-verbal (Bair, Toth, Jonhson, Rosenberg, & Hurdle, 1999). Hagen and Sayers (1995) looked at behaviours such as

kicking, hitting / punching, throwing, spitting, shoving / pushing, scratching / biting, and pinching / grabbing when assessing aggression in a LTC environment.

*Assessing Dementia Related Agitation in the Long Term Care Environment*

As one of the most common and troublesome problems in dementia care, agitation and aggression is of concern to the resident with dementia, other residents, and the family and caregivers (Wilkinson, 1999). Several research initiatives have resulted in observational scales that quantify the behavioural problems in dementia.

*Behavioral Syndromes Scale for Dementia (BSSD)*

A tool developed in 1991, the Behavioral Syndromes Scale for Dementia (BSSD), looks at the main categories of behavioural problems such as disinhibition, apathy and indifference, sundowning, catastrophic reaction, and other clinical features when assessing agitation (Devanand et al., 1992). The BSSD demonstrated robust internal consistency and inter-rater reliability. This tool was designed as a clinical-research tool in capturing the intensity and severity of agitation in dementia. A difficulty of using this tool for LTC residents with dementia is that the BSSD was validated using community dwelling individuals with dementia.

*Cohen-Mansfield Agitation Inventory (CMAI)*

One of the most commonly used agitation assessment forms is the Cohen-Mansfield Agitation Inventory (Cohen-Mansfield, 1999). Although it can be used in the clinical setting, a study looking at pain and agitation in patients with dementia used it for its research utility (Buffum et al., 2001). The CMAI requires that 29 behavioural descriptions be rated using a seven-point scale. Problems associated with this form is the training required to use the scale and the time needed to administer the instrument.

### *Pittsburgh Agitation Scale (PAS)*

One tool for assessing agitation in LTC that attains good validity while being easy to administer is the Pittsburgh Agitation Scale (Rosen et al., 1994; Rosen et al., 1999). This tool classifies agitation as motor and vocal agitation, aggressive behaviours, and resistance to care. It is user friendly and can be reliably completed in less than a minute by a caregiver with minimal training.

### *Common Management Approaches for Agitation in Long Term Care*

In the hopes of improving the quality of life for residents with dementia and caregivers within a LTC facility, any successful approach at alleviating resident agitation will be of benefit. One of the most common approaches to treating dementia related agitation has been the use of psychotropic medications such as anti-depressants, anxiolytics, and anti-psychotics (Alexopoulos, Silver, Kahn, Francis, & Carpenter, 1998). Due to the risks associated with such medications, the United States sought to regulate the use of psychotropic medications in LTC with the Omnibus Budget Reconciliation Act of 1987 (Gurvich & Cunningham, 2000; Rosen et al., 1999). This act stipulated that psychotropic medications be used exceedingly judiciously, and it placed the responsibility for monitoring the medications on the LTC facilities. With limitations on the use of psychotropic medications in LTC due to their negative side effects such as falls and confusion, health professionals are having a closer examination of physical, not psychiatric causes of agitation in dementia. Given the growing evidence that the agitation may have a strong relationship to untreated pain, then pain issues become more of a priority (Haskell, Frankel, & Rorondo, 1997).

A small informal study was conducted to determine if the regular administration of a mild analgesic to LTC residents with agitated behaviours decreased the frequency and severity of these behaviours (Douzjian et al., 2000). Using ten subjects, administration of 650 mg of acetaminophen three times a day resulted in a 63% decrease in the behavioural symptoms and a 75% decline in psychotropic medication use. Such a study corroborates the strong positive correlation found between discomfort or pain measures and agitated or aggressive behaviours in demented LTC residents (Buffum et al., 2001; Feldt et al., 1998).

#### *Overall Themes: Pain and Agitation in Dementia*

In reviewing the research that looks at the issue of pain and agitation for LTC residents with a dementia, several themes emerge:

- 1) To begin with, the number of individuals with a dementia will continue to grow (CMA, 1999). Since behavioural issues such as agitation often lead families to place a loved one with dementia into LTC (Penrod & Dellasega, 2001), the issues of agitation in LTC will continue and possibly worsen. Agitation is a concern for staff in LTC since 70% - 80% of staff have been physically assaulted by a demented resident (Whall et al., 1992).
- 2) Agitation can be assessed using one of the scales developed for LTC residents. Since LTC staff are busy and have minimal formal training, a scale that is user friendly would be of the greatest clinical benefit (Rosen et al., 1994).
- 3) The historical treatment of agitation in LTC is psychotropic medications (Gurvich & Cunningham, 2000; Alexopoulos et al., 1998). Despite the wide spread use of neuroleptics in LTC (Rosen et al., 1999), agitation is still a concern.

4) The essential question is whether the use of psychotropic medications to treat agitation is only addressing the behavioural results of underlying issues such as pain (Feldt et al., 1998). Possibly, untreated or under-treated pain is a greater cause of agitated behaviour in LTC residents with dementia than was previously believed (Douzjian et al., 2000).

*Recommendations for Assessing Pain in Persons with Dementia and Agitation*

One of the greatest issues when assessing pain in persons with a dementia is the individual's inability to communicate their physical needs (Alzheimer Society of Canada, 2002). However, most pain assessment tools rely upon intact communication and comprehension abilities (McCaffery & Pasero, 1999). The Warne Model of Multifaceted Pain Assessment (Feldt et al., 1998) outlines a systematic approach to assessing pain and its relationship to agitation in LTC residents with a dementia. Pain assessment does not use a single tool or information source. Instead, three sources of information are compiled when determining the severity of pain experienced by an individual with dementia.

First, a family member or caregiver is asked for input on the pain experienced by the family member in question. Feldt et al. asked LTC caregivers to rate the pain of residents. Parmelee (1994) used a similar approach in community-dwelling subjects with dementia and their family caregivers. One approach that has not been tried is to compare the pain assessments of LTC caregivers against those of pain consultants.

The second approach advocated by Warne (1994) in Feldt et al. (1998) for assessing pain in LTC residents with dementia is to conduct a comprehensive review of the resident's pain diagnoses, medications, and pain history. When Feldt et al. assessed

the medications, only the number, not the type of analgesics was recorded. As seen in the WHO's Analgesic Ladder, analgesics can vary greatly in their ability to help patients deal with a variety of types of pain (SIGN, 2001).

The final approach of a multifaceted pain assessment of persons with a dementia is to use a behavioural assessment tool to quantify the pain induced behaviour changes (Warne, 1994; in Feldt et al., 1998). Several scales have been proposed such as the Discomfort Scale – Dementia of the Alzheimer Type (DS-DAT) (Hurley et al., 1992) used by Buffum et al. (2001) in a pilot study looking at pain and agitation in 33 LTC residents with dementia. The tool used by Buffum et al. was the Cohen-Mansfield Agitation Index (CMAI) (Cohen-Mansfield, 1999). A positive correlation was found between DS-DAT scores and CMAI scores. Of interest, this study included 32 male subjects and one female. The demographic characteristics seen in Buffum et al. are not indicative of the typical LTC population where approximately 70% of residents are female (Magaziner et al., 2001). As well, the majority of resident subjects (58%) still had intact verbal abilities, an indication that most of the subjects were either mild to moderate in their dementia (Alzheimer Society of Canada, 2002).

#### *Summary of Relevant Literature*

In summary, agitation and aggression is of great concern for current caregivers in dementia care. Families and informal caregivers are often left with no choice but to place a loved one with dementia in LTC to deal with the aggression and agitation that is common in dementia (Penrod & Dellasega, 2001). Not only is agitation a concern for current dementia caregivers, the projected increase in dementia will place additional strain on the family and LTC caregivers.

Another issue in the care of individuals with dementia is proper assessment and treatment of painful physical conditions. An individual with dementia is likely to not receive required analgesic medications (Kaasalainen et al., 1998). This may be due to misconceptions of health professionals that an individual with dementia does not feel pain. Alternatively, physicians and nurses are not equipped to assess and treat pain in persons with dementia.

Even if health professionals attempt to assess the pain experienced by an individual with dementia, the majority of pain assessment approaches are single assessment tools that require a patient to have intact physical and cognitive abilities (Forrest, 1995). However, research has demonstrated that pain results in predictable behavioural changes for an individual with dementia. The behavioural changes appear similar to the symptoms seen with agitation and aggression in a dementia. Therefore, a link between agitation and pain in dementia may provide an alternative means of addressing agitation in the LTC environment.

A novel approach to assessing pain for LTC residents with dementia will require multiple methods of assessing pain. The historical approach of using a single assessment method needs to be challenged by research that investigates the required multiple approaches to pain assessment. A LTC resident with dementia cannot communicate pain needs and must rely on a systematic and comprehensive review of pain variables by trained staff.

Recognizing that staff who are educated to assess pain and agitation are able to intervene much more effectively, the need for reliable and valid, but user-friendly assessment tools will be required. The staff working in LTC are generally busy and have

a low level of training. The use of complex or time-consuming instruments to investigate pain and agitation will result in staff neglecting to properly assess these concerns.

Alternatively, the use of pain consultants in LTC has not been fully researched. Their ability to assist the staff with education and assessment of residents will possibly result in less agitated residents and more confident and satisfied staff.

#### *Proposed Research*

This researcher proposed to use a multi-factorial approach to assessing pain in LTC residents with moderate to severe dementia. As a result of the communication and comprehension limitations arising from a dementia, a multi-factorial approach to pain assessment was used. This research model included pain ratings of facility and palliative consultant nurses. A review of literature revealed no identified studies using palliative or pain consultant nurses in LTC. As well, the analgesic medications are classified according to the strength of effect in alleviating pain. A pain behaviour rating assessed any behaviour changes resulting from pain the resident subjects are experiencing. Finally, the pain producing medical diagnoses were identified.

Regarding the assessment of agitation in LTC residents with dementia, a 'user friendly,' valid, and reliable (requiring minimal training) instrument was used. The assessment of agitation and the multi-factorial measures of pain were correlated to investigate the relationship between agitation and pain in LTC residents with a moderate to severe dementia. It was expected that certain types of agitation such as motor or vocal agitation would be associated with certain measures of pain. Finally, the use of palliative nurse consultants to assess the pain of residents in LTC with dementia was investigated.

## CHAPTER THREE: FRAMEWORK

### Definition of Relevant Terms

Certain terms are used frequently in this report. For the purpose of clarity, specific terms are outlined below:

*Analgesic:* A medication that is taken to decrease or alleviate the physiological symptoms of pain.

*Cognitive Impairment:* An impairment in cognitive functioning that usually involves memory loss, decreased judgement, diminished abstract thinking ability, and a loss of verbal skills and comprehension.

*Dementia:* An irreversible medical condition that has resulted in progressive cognitive impairment with associated functional deficits.

*Facility Nurse:* A registered nurse working in the three Long Term Care sites used in the study. Typically, this term refers to one of the six nurse subjects.

*Functional Assessment and Staging (FAST):* Developed by Dr. B. Reisberg (Reisberg, 1988), a checklist that assists caregivers in determining the functional decline arising from a dementia.

*Global Deterioration Scale(GDS):* Developed by Dr. B. Reisberg, this scale divides the functional decline from a dementia into seven stages. The FAST is based upon the GDS.

*Long Term Care (LTC):* A continuing care or nursing home facility for individuals with profound physical and/or cognitive disabilities.

*Nurse A:* One of the six nurse subjects in the study. She/he rated the cognitive level and pain level of subjects during the day shift (0700-1500 in two of the sites and 0700-1900 in the third site).

*Nurse B:* One of the six nurse subjects in the study. She/he rated the cognitive level and pain level of subjects during the evening shift (0700-1500 in two of the sites and 0700-1900 in the third site).

*Opioid Medication:* An analgesic used for severe pain. Examples of opioid analgesics are codeine, morphine, fentanyl, and demerol.

*Palliative Nurse Consultant:* A registered nurse working with the Chinook Health Region's Palliative Care Team. Five registered nurses comprise the nursing component of the team (One nurse manager and four nursing consultants).

*Principal Investigator:* This term is used to describe Colin Zieber.

*Registered Nurse (R.N.):* A health professional skilled in the assessment and treatment of individuals with medical and psychiatric illnesses using an approach defined as the nursing process.

*Research Assistant:* Term used to describe Sharon Brown, a research assistant employee of the University of Lethbridge School of Health Sciences.

#### Research Framework

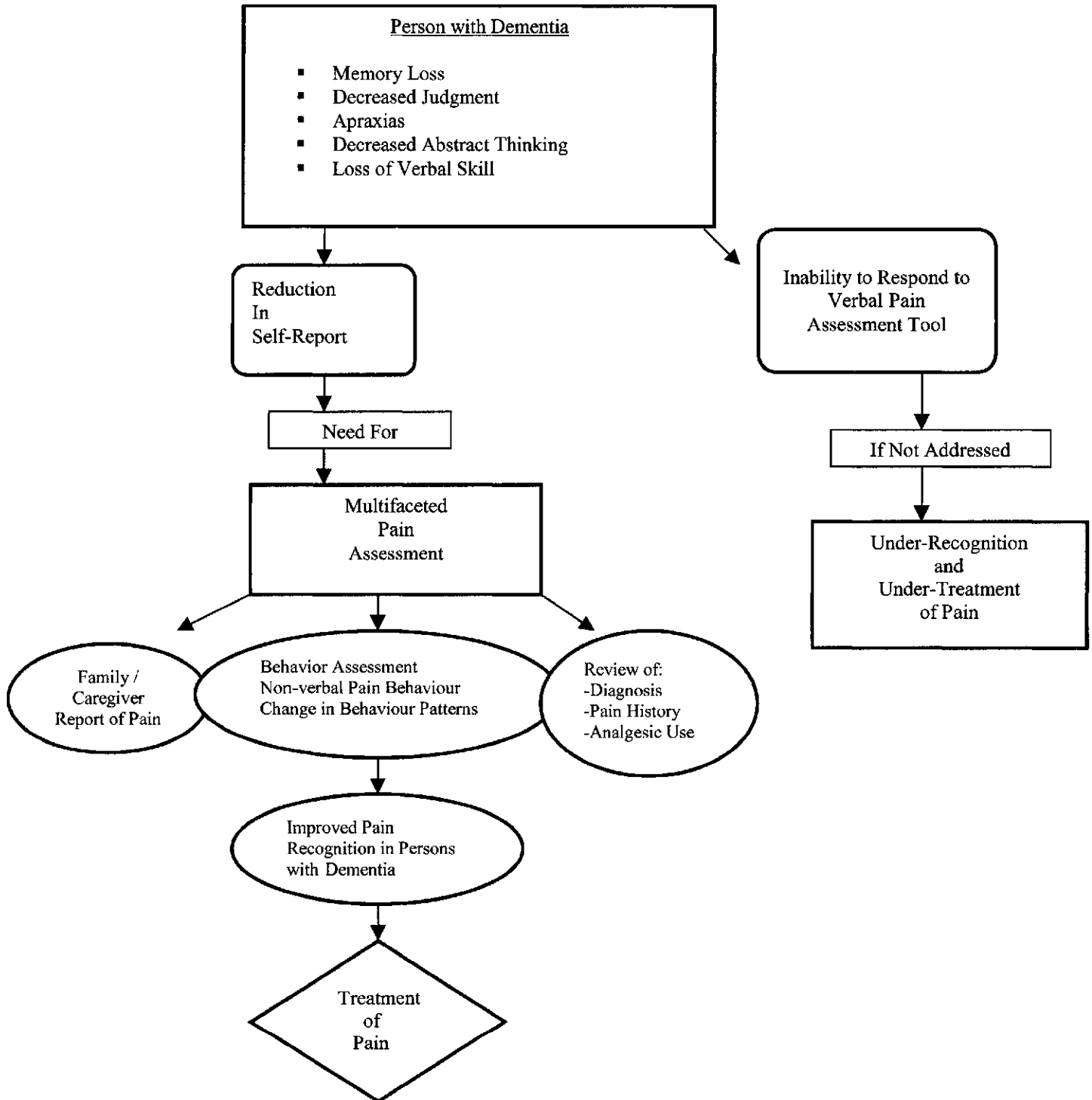
The model that served as the template for this study was the *Model of multifaceted pain assessment* (See Figure 1) by Warne (as cited in Feldt et al., 1998). This conceptual model was developed to address the unique needs of individuals in pain who are cognitively impaired. As well, it was used by Feldt et al. to study the relationship of pain and aggressive behaviour in cognitively impaired LTC residents.

### Identification of Assumptions

For the correct application of the model by Warne (1994), several assumptions about the functional abilities and needs of the population must be understood for a proper application of the unique approaches to assessing and treating pain in the LTC resident with dementia. As outlined in Feldt et al. (1998):

- 1) Standard pain assessment tools and protocols emphasize the use of patient self report to decide upon a treatment response. Warne's model acknowledges that cognitive declines impair an individual from accurately participating in self-report measures.
- 2) Present and past medical diagnoses will help the clinician predict the probable pain the cognitively impaired individual is experiencing.
- 3) The family and/or caregiver can assist in predicting the level of pain a demented loved one is experiencing based upon their observations and the historical pain threshold of the LTC resident.
- 4) Cognitively impaired individuals demonstrate pain through verbal and non-verbal behaviours. These behaviours assist in the assessment of pain and the evaluation of treatment.

Figure 1. Model of Multifaceted Pain Assessment



From "The Experience of Pain in Persons with Cognitive Impairment M. A. Warne, 1994, in "Examining Pain in Aggressive Cognitively Impaired Older Adults," K. S. Feldt, M. A. Warne and M. B. Ryden, 1998, *Journal of Gerontological Nursing*, 24(11), p. 17. Reprinted with permission from the author (See Appendix 1)

## Objectives, Questions, and Hypotheses

### *Objectives*

The objectives of this study were as follows:

1. To examine the relationship between several measures of pain and agitated behaviours in LTC residents with late-moderate to severe dementia.
2. To identify the most common pain diagnoses of the resident subjects.
3. To determine how similar and reliable the pain ratings of facility nurses are for identical residents.
5. To determine how similar and reliable the pain ratings of the palliative nurse consultants are for identical residents.
6. To compare the pain ratings completed by the facility nurses and the pain ratings of palliative nurse consultants for the identical residents.

### *Research Questions*

The research questions were as follows:

1. What is the relationship between resident pain (as measured by pain diagnoses, use of analgesics, pain ratings of facility nurses and palliative nurses, and pain behaviour scores) and total scores (and sub-scores) of the Pittsburgh Agitation Scale?
2. How well do the pain ratings of facility nurses correlate with each other for identical residents?
3. How well do the pain ratings of the palliative nurse consultants correlate with each other for identical residents?

4. How well do the pain ratings of facility nurses correlate with the palliative nurse consultants for identical residents?
5. What are the most common pain diagnoses in the resident sample?

### *Hypotheses*

The hypotheses in this study were as follows:

1. There would be a positive relationship between resident pain scores and resident agitation scores.
2. Higher resident pain scores would be especially associated with higher aberrant vocalization scores.
3. There be a weak yet positive correlation between the resident subject pain ratings completed by the facility nurses.
4. There be a strong yet positive correlation between the resident subject pain ratings completed by the three palliative nurse consultants.
5. There be a weak yet positive correlation between the resident subject pain ratings completed by the facility nurses and the palliative nurse consultants.
6. Arthritis and osteoporosis be the most common pain diagnoses for resident subjects.

## **CHAPTER FOUR: METHODS AND PROCEDURES**

### Research Design

#### *Descriptive Correlational Design*

A descriptive correlational design was chosen for this study. Such a design considers the relationships that exist in naturally occurring situations without any attempt to manipulate or control the variables (Burns & Grove, 2001). The two main research variables under investigation were pain and agitation assessed through chart reviews and observations with no interference from the researcher or facility staff. Specifically, the main variable of pain was defined by considering painful medical diagnoses, pain ratings of facility and palliative consultant nurses, analgesic use, and pain behaviours. Assessment of agitation included vocal agitation, motor agitation, aggressive actions, and resistance to care from nursing staff.

#### *Advantages and Disadvantages of Research Design*

Descriptive correlational studies prove useful when considering numerous relationships over time (Burns & Grove, 2001). Since pain assessment with the elderly is an emerging field of study (Ferrell et al., 1995; Forrest, 1995) a descriptive correlational design was chosen for its utility in formulating hypotheses for later research (Burns & Grove). On the other hand, a correlational design is inadequate to determine causality. Furthermore, a correlational design can only look at factors occurring within a defined group and not differences between unique groups.

## Sample and Setting

### *Sampling Method*

A convenience sample was used for all the three samples represented in the study. The LTC residents with a profound dementia, the facility nurses, and the palliative nurse consultants were used due to their availability and/or willingness. Burns and Grove (2001) describe convenience sampling as “accidental” (p. 374). The term ”accidental” is most likely used since convenience samples cannot distinguish overt and covert biases. Subjects selected in a convenience sample may be completely unrepresentative of the population in question due to the timing and/or location of the sample selection.

Conversely, convenience samples are inexpensive, save time and effort in the recruitment of subjects, and are useful for exploration of new concepts and ideas (Burns & Grove, 2001). Furthermore, convenience samples can be improved by using specific subject criteria, potentially controlling for biases (Norwood, 2000).

### *Sampling Criteria*

The sampling criteria for the three samples in this study are best defined by describing specific inclusion criteria. Using inclusion and exclusion criteria is one method of improving the internal validity of a study (Norwood, 2000). As well, using specific sampling criteria attempts to mimic the characteristics of the target population in the sample, a means to improving the external validity of a study.

### *Resident Subjects*

The resident subjects formed the largest group of subjects in the study. Criteria were established to ensure that only LTC residents with a moderately severe to severe

dementia were studied. The criteria for inclusion into the resident subject group were the following:

1. Older than age 65.
2. Resident of continuing care in one of three rural facilities in the Chinook Health Region.
3. Dementia symptoms (functional) that meet or exceed a 6 using the Functional Assessment Staging Tool (Reisberg, 1988).

*Facility Nurse Subjects (Nurses A and B)*

In order to ensure that only nurses who knew the subject well contributed to the data, the following criteria for Nurses A and B were developed:

1. Registered Nurse with a 0.50 FTE position or greater in one of the three LTC facility sites.
2. Recommended by their manager to participate in the research.
3. Signed consent agreeing to participate in the study (see Appendices 2 and 3).

*Palliative Nurse Consultant*

The criteria for the palliative nurse consultants were based on the following points:

1. Registered Nurse with the Palliative Care Program in the Chinook Health Region.
2. Signed consent agreeing to participate in the study (see Appendix 4).

## *Sample*

### *LTC Residents*

At the time of the data collection, the total number of residents in the three LTC facilities was 164. Initially, 64 subjects were identified and initial data was collected. In the time between initial and final data collection, six of the subjects died, mostly from a flu outbreak. Therefore, 58 subjects remained in the data pool. The resident subjects constituted approximately 37% of the total population of the facilities. The number of resident subjects at each facility was as follows: the first site had 15 resident subjects, approximately 44% of the total number of residents in the facility. Initially, the second site had 21 resident subjects but five passed away during a flu outbreak. With the 16 remaining subjects, 29% of the residents in the facility were subjects. The third site had a total of 28 resident subjects until one passed away before the final data was collected. The 27 resident subjects at this site constituted 39% of the facility population. Reflective of the general population in continuing care facilities, 63.8% of the resident subjects were female while 36.2% were male. The mean age was 83.9 years with a standard deviation of 7.9 years. Resident subjects had resided in LTC for an average of almost 29 months (2 years and five months). The severity of dementia symptoms as rated by the facility nurses was as follows: 30 resident subjects (51.7%) were rated as a 6/7 by both facility nurses. Both nurses rated 22 resident subjects as a 7/7 (38%), and the nurses were differing with their ratings of dementia severity on 6 resident subjects (10.3%).

### *Facility Nurse Subjects (Nurses A and B)*

Minimal demographic information was collected on the facility nurses. A total of seven nurses contributed to the data collection. The original intent was to have two nurses

at each facility, however, one nurse was away during a follow-up visit to the third site and another nurse contributed to the pain assessments. One nurse was male and the other six were female.

#### *Palliative Nurse Consultant Subjects*

A total of five nurse consultants work with the Palliative Care Program in the Chinook Health Region. Three of the nurses agreed to participate in the study. All of the nurses were female. One nurse works in the west of the region, one works in the City of Lethbridge, and the other nurse works in the rural communities to the east and south of Lethbridge.

#### *Setting*

The study used three LTC facilities in rural communities within the Chinook Health Region. The Region operates the three LTC facilities used in the study. All of the facilities have a high number of residents with a diagnosis of dementia. Furthermore, all have a locked dementia unit or whole-facility secure access to ensure that residents who wander are kept securely within the facility.

The first facility is located near the eastern slopes of the Rocky Mountains, close to the British Columbia -Alberta border. The surrounding communities had a mining industry that was once the major employer in the area. The facility houses 60 individuals with cognitive and/or physical deficits. The unique feature of this facility is the ethnic diversity of the residents and staff. Over the past century, immigrants from all over the world came to work in the mining industry.

The residents and staff of the second site have an amazing view of the Rocky Mountains. This facility houses up to 40 residents but six of the beds were on hold. Many

of the 34 residents are life-long members of the Church of Jesus Christ Latter Day Saints. In the late 1800s and early 1900s, a large group of settlers from Utah immigrated north and settled in the area. Many of the early pioneers and their descendants were instrumental in developing irrigation and became successful farmers in southwestern Alberta.

The third setting for the study was a 70 resident facility in a thriving agricultural community.. Within the facility is a secure dementia unit which houses twenty residents. Many of the subjects from this facility were retired farmers.

### Ethical Considerations

#### *Background to Ethical Considerations*

A cornerstone of most pain assessment protocols is the assumption that pain severity and intensity is what the patient claims it to be (McCaffery, 1999). However, when a severely demented LTC resident is considered, their ability to communicate painful feelings and the need for treatment is severely limited (Kovach et al., 2000). A requirement of most research protocols is free and informed consent of the subjects or proxy decision-makers. Informed consent entails answering the questions that the client is competent, has sufficient information to make informed choices, and that consent is completely voluntary (Stelmach, Konnert, & Dobson, 2001).

Gordon (2001) uses the four ethical concepts of autonomy, beneficence, non-maleficence, and justice when considering research with demented subjects. Autonomy is a concern since the demented individual cannot determine the benefit or risk of volunteering for a research project. Beneficence may be a concern where an individual in the late stage of the dementing process may not derive any personal benefit or be able to

understand the projected benefit to others from the research. As long as research is carefully planned to minimize or eliminate the potential for harm to the subjects, then research on demented individuals should proceed. Finally, the concerns regarding justice can be allayed by the presence of a true surrogate decision maker.

#### *Study Specific Ethical Considerations*

In this study, the requirement for informed consent from a surrogate decision-maker was an issue requiring consideration. Although the study proposed using observational data collection tools and chart audits, the Chinook Health Region Ethics Committee initially requested that proxy decision makers provide informed consent for the data to be collected. In Alberta, the only method for becoming a proxy or surrogate decision maker is to apply through the courts to become a guardian or to be named in a Personal Directive that has been enacted (Alberta Government, 1997). To answer the concerns, an audit of the presence or absence of guardians or agents in the three proposed LTC sites was conducted by a Health Analyst with the Chinook Health Region. The result demonstrated that less than 10% of potential subjects had a guardian or agent listed (H. Vint, personal communication, July 26, 2001). Using this information, an appeal was presented to the Chinook Health Region Ethics Committee (see Appendix 5). In addition, the Tri-Council Recommendations (Natural Sciences & Engineering Research Council, 1998) for Human Subject Research and the Health Information Act (Government of Alberta, 1999) Guidelines were provided for the committee. The Health Information Act allows for an ethics committee to recommend to the government that the research may proceed without the requirement of informed consent (Government of Alberta).

The proposed study did receive approval from the Chinook Health Region Research Committee (see Appendix 6) and the University of Lethbridge Research and Ethics Committee (see Appendix 7). Final consent to proceed with the project was received from the Chinook Health Region Ethics committee in the fall of 2001 (see Appendix 8).

### Measurement Methods

#### *Overall Need for Triangulation of Data, Methods, and Investigators*

Assessing pain in a population of LTC residents who have minimal communication and comprehension skills required a unique approach. The literature reviewed several approaches to assess pain with this population. One approach was to use the professional nursing staff to rate the pain experienced by the residents using a pain assessment tool (Kaasalainen et al., 1998). The next approach was to list pain diagnoses as a measure of assumed pain (Feldt et al., 1998; Marzinski, 1991). The final approach was to use behaviours as an inference that pain was a concern (Brignell, 1999; Hurley et al., 1992; Richards et al., 1982). The underlying approach in the selection of data collection tools was to increase the validity of pain measurement. Using suggestions from Banik (1993) and Norwood (2000), approaches for data, methods and investigator triangulation were implemented.

#### *Data Triangulation*

Data triangulation involves collecting information from a variety of sources in the attempt to ensure a comprehensive understanding of a particular subject is achieved. In this study, five sources of data were used to assess the concept of pain in LTC residents with a dementia. Data triangulation was designed to try and communicate the pain felt by a group of subjects who are unable to adequately communicate.

### *Method Triangulation*

Method triangulation involves using a variety of research methods to study a common issue (Norwood, 2000). Both with-in methods and across-methods approaches were used in this study.

With-in methods triangulation uses different strategies but the same method to investigate an issue (Banik, 1993). The facility nurses and palliative nurse consultants used the same assessment tool but completely different methods to rate the pain experienced by resident subjects.

Across-methods triangulation was used when the pain of resident subjects was rated using a seven-point pain rating scale and a pain rating scale. Furthermore, the methods used to collect data involved direct observation, chart review, and ratings based on collected data (secondary analysis).

### *Investigator Triangulation*

Investigator triangulation was also used with the facility nurses and the Palliative Consultants. Banik (1993) describes investigator triangulation as using more than one observer, data collector, or data analyst. For this study, two LTC nurses and three Palliative Consultants were used to arrive at an average pain rating for each of the subjects. A research assistant and the principle investigator were involved in collecting agitation scores, chart information, and pain behaviour ratings. A total of 12 individuals were involved in the data collection for this study. Banik outlines the advantage of using investigator triangulation: “the use of multiple researchers, all of whom have different but complementary knowledge and experience, is useful in avoiding the potential for bias inherent in a single perspective” (p. 49). One potential problem with investigator

triangulation is the potential for decreased reliability in the data collected due to the use of many individuals from slightly different backgrounds and levels of training.

#### *Measurement of Moderate to Severe Cognitive Impairment*

On a general level, cognitive impairment is classified into three levels, mild moderate, and severe. This study examined individuals residing in LTC who had the symptoms of a late moderate to severe dementia. According to the Alzheimer Society of Canada (2002) guidelines, such an individual would exhibit behaviours such as wandering, aggression, and even non-verbal behaviours such as groaning and crying. Severe problems with communication production and comprehension would result. As well, severe memory problems and disorientation would result.

To objectively define moderate to severe cognitive impairment, the FAST based on Reisburg's (1984) GDS was used to determine subjects who were functionally at stage six or seven. Stage six and seven are of particular interest due to the loss of communication production and comprehension seen with the later stages of a dementia.

#### *Measurement of Pain*

In designing this research project, one of the greatest concerns was quantifying the concept of pain with a sample of cognitively impaired residents in LTC facilities. As was outlined earlier, pain assessment for this population required several measures of pain from varying perspectives. Therefore, the research variable of pain was sub-divided into five components, each considering various aspects of pain. Pain diagnoses, analgesic medications, facility nurse pain ratings, palliative nurse consultant pain ratings, and pain behaviours were collected using a variety of tools and methods.

### *Pain Diagnoses*

Based on the article by Feldt et al. (1998), five pain diagnoses were proposed as being the most common reasons for pain in cognitively impaired individuals displaying aggressive behaviours. The diagnoses of arthritis, osteoporosis, history of hip fracture, localized pain (history of headaches, knee pain, abdominal pain, or pain from contractures), and a history of cancer were collected from the charts of the resident subjects. Other authors have proposed common pain diagnoses for the elderly or LTC resident. Cramer, Galer, Mendelson, and Thompson (2000) compiled a list of 17 painful diagnoses common with LTC residents. Of the 17 diagnoses, arthritis (41.7%), bone fracture (12.4%), and cancer (4.7%) were among the most common. Ferrell, Ferrell, and Rivera (1995) found that arthritis (70%), history of an old fracture (13%) and neuropathy (10%) were the most common pain diagnoses among 325 randomly selected LTC residents with a dementia. While the above studies looked at other indicators of pain, Feldt et al. was unique in identifying specific diagnoses that are especially linked to aggressive behaviours in a LTC environment.

The information regarding pain diagnoses was collected from the admission medical form completed by the admitting physician. As well, the Chinook Health Region uses the Minimum Data Set 2.0 Database in all Continuing Care Facilities. Every three months, the data are reviewed and revised by one of the on-site registered nurses. Although Feldt et al. (1998) discovered that the diagnoses of arthritis and osteoporosis were the most common, the medical diagnoses were treated as equal when considering the number of painful diagnoses for each resident subject.

### *Analgesic Medications*

According to the WHO, analgesic medications are categorized as Level I, II, or III depending upon the type and severity of pain treated by each medication (Miller & Talerico, 2002). Examples of Level I medications are acetaminophen, aspirin ASA, and ibuprofen. Level I medications are recommended for the relief of mild pain. Codeine is a Level II analgesic and is used for moderate pain. Finally, a medication such as morphine is a Level III analgesic for the relief of severe pain.

Analgesic medication information was collected from the resident subject's chart. To ensure the analgesic information reflected the medication levels and the different reasons for analgesic treatment, an aggregate analgesic score was created. Some consideration was given to the three levels of the WHO Analgesic Guidelines as a method of scoring the types of regularly scheduled medications prescribed for each resident subject. After discussion with the Palliative Team in the Chinook Health Region, the WHO guidelines appeared to be specifically geared towards cancer pain. As well, a scale with only three options did not offer enough variation. Therefore, a six-point scale was created to quantify the analgesics used by residents (see Figure 2).

A zero aggregate pain score indicated that no regularly prescribed analgesics were given to a resident subject. A score of one indicated that acetaminophen or a non-steroidal anti-inflammatory (NSAID) medication was regularly prescribed. Two on the aggregate pain score indicated that both acetaminophen and a NSAID were prescribed. A score of three indicated that an opiate medication such as codeine, morphine, demerol, or

Figure 2 – Aggregate Analgesic Score

| AGGREGATE ANALGESIC SCORE*   |
|--|
| 0 = No analgesic medications   |
| 1 = Either acetaminophen <u>or</u> NSAID*  |
| 2 = Both acetaminophen <u>and</u> NSAID  |
| 3 = Only opiate* medication  |
| 4 = Opiate analgesic and acetaminophen <u>or</u> NSAID   |
| 5 = Opiate analgesic and acetaminophen <u>and</u> NSAID  |
| *Note: All analgesics are regularly scheduled, not PRN, NSAID = non-steroidal anti-inflammatory drug, Opiate medications include morphine, demerol, codeine, and fentanyl. |

fentanyl was prescribed for the resident subject. Four indicated that an opiate and either acetaminophen or a NSAID were prescribed. Finally, an aggregate score of five indicated that an opiate, acetaminophen, and a NSAID were to be given to a resident subject on a regular basis.

#### *Facility Nurse Pain Ratings*

A requirement for the facility nurses and palliative consultant nurses completing the pain assessments was that a common tool be used. However, each group used different information in completing the pain ratings.

Facility nurse ratings were completed during the morning and evening shifts in each of the three LTC sites. Nurse A was asked to observe the resident subject while answering the question: “Using your professional judgement and considering your observations, please rate your assessment of the resident’s pain level according to the following scale.”

The scale used was the Long Term Care Pain Assessment Tool – Verbal Description (Janssen, 2000) (see Appendix 11). Each nurse’s response was recorded on the Data Collection Worksheet. Finally, the process was repeated with Nurse B during the evening shift. The two nurse responses for each resident were then averaged on the Data Collection Worksheet (see Appendix 10).

#### *Palliative Nurse Consultant Pain Ratings*

Palliative nurse consultants used the same Long Term Care Pain Assessment Tool: Verbal Description (Janssen, 2000). In order to provide their pain ratings, the palliative consultants were provided with demographic information on the resident subjects, pain behaviour ratings, and medication information. All identifying information was eliminated from the medication and demographic information. After reviewing the

summarized information on the Palliative Summary Sheet (see Appendix 9), the palliative nurse consultants were asked to answer the following request: “Based on the client information presented to you, please use your professional judgement to rate the pain experienced by the client”.

### *Pain Behaviours*

Pain behaviours were captured using the nine pain behaviours outlined in Hurley et al. (1992). Through a process of repeated trials, Hurley et al. developed the Discomfort Scale-Dementia of the Alzheimer Type (DS-DAT). The scale has a maximum score of 27. The advantage of the DS-DAT is that it attempts to quantify behaviours that are associated with discomfort in an individual with dementia (Buffum et al., 2001). While the validity and reliability of the DS-DAT reported by Hurley et al. (1992) is good ( $r = .86 - .89$ ), Miller and Talerico (2002) report on research that questions the reliable replication of observations with three of the items on the DS-DAT. Despite these concerns, the DS-DAT was used due to its ease of use and its use in a pilot study looking at the relationship between discomfort and agitation in patients with dementia (Buffum et al.).

The research assistant and/or the principal investigator conducted the observations while the resident subjects were awake. The pain behaviours include noisy breathing, negative vocalization, content facial expression, sad facial expression, frightened facial expression, frown, relaxed body language, tense body language, and fidgeting. After observing the resident subject for up to five minutes to ensure that the behaviour observed was part of the normal behavioural routine, a score from 0 – 3 was recorded on

the Data Collection Form based on the frequency, intensity, and duration of the behaviours.

### *Agitation*

One of main variables of study is agitation. In this study, agitation is based upon the criteria of the Pittsburgh Agitation Scale (PAS) (Rosen et al., 1994). The PAS is composed of four separate observation measures such as aberrant vocalization, motor agitation, aggressiveness, and resisting care (see Appendix 12). Each of the four sub-components of agitation is scored separately to comprise a total PAS score and separate sub-scores. During the development of the PAS, the inter-rater reliability in a nursing home setting was +0.93. On a psychogeriatric unit, the reliability was +0.82. Rosen et al. (1999) assessed the PAS against a comprehensive research tool to assess behaviours (Neurobehavioral Rating Scale) and found that the PAS demonstrated a sensitivity and specificity of between 78% and 95% in identifying agitation ranging from mild agitation to disruptive behaviours. Despite the acceptable reliability, validity, sensitivity, and specificity, the main reason for choosing the PAS was due to its astonishing ease of use. A proper PAS assessment will take less than a minute (Rosen et al. 1999).

The principal investigator and/or the research assistant completed the PAS at the same time the DS-DAT assessments were completed. Behaviour during the morning shift was summarized and rated from 0 – 4. Again, in the early evening, the behaviour up to bedtime was summarized and rated from 0 – 4. A total score for the PAS was obtained as well as sub-scores for each of the four measures of vocalization, motor agitation, aggressiveness, and resisting care.

### *Data Collection*

The initial step of the data collection process was to create, revise, and perfect the Data Collection Worksheet (see Appendix 10). It was coded to coincide with SPSS coding procedures for later data analysis. Many other steps occurred to ensure that the Data Collection Worksheet was completed with the correct information.

#### *Facility Nurses*

On the day of data collection at each LTC site, the facility nurses participating were initially requested to sign a consent form agreeing to participate in the study (see Appendix 9). Then, the nurse was introduced to the two tools she/he was required to complete: 1) FAST (Reisburg, 1984) to determine the eligibility of a resident subject and 2) a pain rating using the Long Term Care Pain Assessment Tool – Verbal Description (Janssen, 2000). The nurse was given the opportunity to review and practice with the tools. Once the facility nurses were familiar with the tools, they walked through the facility with the principle investigator and/or the research assistant identifying potential resident subjects. Importantly, the facility nurses were only able to rate residents they directly observed.

#### *Chart Reviews*

After completing the assessments with Nurse A in the morning, the principal investigator and/or the research assistant conducted a chart review to document demographic information and medication information. Only if Nurse B rated the potential resident subject as meeting a FAST criteria of 6 or 7 did the resident continue as a subject.

In order to ensure that the demographic and medication information was correct, the information was audited and verified using the Chinook Health Region electronic

health record as accessed by the principal investigator. Some incorrect information regarding the age, sex, and length of stay of a resident subject was discovered and corrected.

#### *Observations of Behaviour*

The DS-DAT (Hurley et al., 1992) and the PAS (Rosen et al., 1994) were conducted at the same time for ease of collection and to ensure consistency of behaviour. All assessments were conducted while the residents were awake. The location of assessment varied from a resident's room to a common area. The majority of the first behavioural assessments were completed prior to or after lunch time. The second assessments were conducted after the supper break, often during the time when nursing staff were getting the residents ready for bed. DS-DAT assessments were conducted after observing the resident for up to five minutes, according to the recommendations from Hurley et al. (1992). The PAS was then completed in less than a minute, as outlined by Rosen et al., 1999).

Two assessments of the facility nurse pain ratings, DS-DAT scores, and the PAS scores were taken. After the second assessment was completed (evening shift assessment), it was summarized and averaged with the initial (morning shift) assessment to provide a general daily perspective of the overall pain, discomfort, and agitation a resident subject experienced throughout the day.

#### *Palliative Consultant Ratings*

The videoconference system for the Chinook Health Region was booked for three hours and two consultants gathered in Lethbridge. A third consultant was located in Pincher Creek, 100 km west of Lethbridge. All three consultants had packages containing

a consent form, a FAST scale (Reisburg, 1984), a list of the Stages in Alzheimer Disease (Alzheimer Society of Canada, 2002), a DS-DAT (Hurley et al., 1992), and a Long Term Care Pain Assessment Tool – Verbal Description (Janssen, 2000). As well, each consultant was given 58 Palliative Summary Sheets (see Appendix 11) and medication summaries randomly arranged to ensure that summaries from a particular facility were not grouped together. The palliative consultants completed the consent forms, received instruction on the tools and were given the opportunity to practice. Then, the consultants reviewed the information for the 58 resident subjects and provided a pain rating for each.

## CHAPTER FIVE: RESULTS

Following the data collection, the information was entered into a computer. From this database of information, research results in the form of demographic and correlational information were generated using SPSS. For the purpose of clearly communicating the research findings, the results will be presented in relation to the research questions posed in the Framework Section.

*Research Question # 1: What is the relationship between resident pain (as measured by pain diagnoses, use of analgesics, pain ratings of facility nurses and palliative nurses, and pain behaviour scores) and total scores (and sub-scores) of the Pittsburgh Agitation Scale?*

*Relationship between Pain Diagnoses and Total Pittsburgh Agitation Scale (PAS) Scores*

The Pittsburgh Agitation Score was compared to the total number of medical diagnoses and to each sub-diagnosis such as arthritis, osteoporosis, a history of hip fracture, localized pain, and a history of cancer. A maximum total score for the PAS would be 16, based on a 4/4 on each of the four PAS sub-factors such as aberrant vocalization, motor agitation, aggressiveness, and resisting care (Rosen et al., 1994). Furthermore, the Total PAS score would be an average of the two PAS scores collected on each resident subject. An inspection of the total number of pain diagnoses listed for each resident subject and the total PAS score shows the relationship was non-significant ( $r = .138$ ,  $N=58$ ,  $p \leq 0.01$ ). The correlation coefficients between the sub-diagnoses and the total PAS score are all non-significant as summarized in Table 1.

### *Relationship between Pain Diagnoses and PAS Sub-Scores*

The individual pain diagnoses and total PAS scores were not significantly related and the sub-factors of the PAS were similarly unrelated to pain diagnoses. The correlations between pain diagnoses and the PAS sub-factors of aberrant vocalization, motor agitation, aggressiveness, and resisting care are summarized in Table 2.

### *Aggregate Analgesic Scores and PAS Scores*

In order to quantify the analgesic medications used by each resident subject, an aggregate analgesic score was created. Following a review of the medication records of each resident subject, a score was given based on the type of regularly scheduled analgesics prescribed for each resident subject. A zero aggregate pain score indicated that no regularly prescribed analgesics were given to a resident subject. A score of one indicated that acetaminophen or a non-steroidal anti-inflammatory (NSAID) medication was regularly prescribed. Two on the aggregate pain score indicated that both acetaminophen and a NSAID were prescribed. A score of three indicated that an opiate medication such as codeine, morphine, demerol, or fentanyl was prescribed for the resident subject. Four indicated that an opiate and either acetaminophen or a NSAID were prescribed. Finally, an aggregate score of five indicated that an opiate, acetaminophen, and a NSAID were to be given to a resident subject on a regular basis.

The correlation between the aggregate analgesic score and the total PAS score was not statistically significant ( $r = .130$ ,  $N=58$ ,  $p \leq .332$ ). Furthermore, the aggregate analgesic score and the sub-factors of the PAS such as motor agitation, aggressiveness, and resisting care were similarly un-correlated. The only exception was the correlation

between the aggregate analgesic score and the average aberrant vocalization score. All the correlations are summarized in Table 3.

*Relationship between Facility Nurse Pain Ratings and PAS Scores*

One of the main questions in this study was how well the pain ratings of the facility nurses would correlate with measures of agitation. Using the Long Term Care Pain Assessment Tool – Verbal Description (Janssen, 2000), facility nurses A and B were asked to rate the pain experienced by each resident subject. Ranging from an assessment that the resident is experiencing ‘no pain’ to ‘pain as bad as it could be,’ seven possible ratings of pain could be assigned to each resident subject. Similar to the PAS scores, the facility nurse pain ratings were averaged to reflect the general overall pain rating for a day and evening shift. The correlation between the facility pain ratings (average of data from Nurses A and B) and total and sub-PAS scores are summarized in Table 4.

Table 1. *Correlation between Pain Diagnoses and Total Pittsburgh Agitation Scale (PAS) Scores*

---

| Pain Diagnoses           | Correlation with Total PAS Score |
|--------------------------|----------------------------------|
| Number of Pain Diagnoses | .138                             |
| Arthritis                | .102                             |
| Osteoporosis             | .076                             |
| History of Hip Fracture  | .084                             |
| Localized Pain           | -.069                            |
| History of Cancer        | .063                             |

---

N = 58 for all correlations.

Table 2. Correlation between Pain Diagnoses and Pittsburgh Agitation Scale (PAS) sub-factors of Aberrant Vocalization (AV), Motor Agitation (MA), Aggressiveness (AG), and Resisting Care (RC)

---

|                         | AV     | MA     | AG     | RC     |
|-------------------------|--------|--------|--------|--------|
| <u>Pain Diagnoses</u>   |        |        |        |        |
| Total Pain Diagnoses    | - .013 | .037   | .070   | .090   |
| Arthritis               | - .070 | .099   | .086   | .121   |
| Osteoporosis            | - .023 | - .011 | .138   | .047   |
| History of Hip Fracture | - .035 | -.081  | .043   | .108   |
| Localized Pain          | .123   | -.007  | - .223 | - .108 |
| History of Cancer       | - .032 | .047   | .029   | - .078 |

---

N = 58 for all correlations.

Table 3. *Correlation between Aggregate Analgesic Score, Total Pittsburgh Agitation Scale (PAS), and Sub-Factor Scores for Aberrant Vocalization (AV), Motor Agitation (MA), Aggressiveness (AG), and Resisting Care (RC)*

---

|                           | Total PAS | AV    | MA    | AG   | RC   |
|---------------------------|-----------|-------|-------|------|------|
| Aggregate Analgesic Score | .130      | .269* | -.066 | .090 | .055 |

---

N = 58 for all correlations.

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

Table 4. *Correlation between Facility Nurse (average of Nurses A & B) Pain Rating and Total Pittsburgh Agitation Scale (PAS) and Sub-Factor Scores for Aberrant Vocalization (AV), Motor Agitation (MA), Aggressiveness (AG), and Resisting Care (RC)*

---

|                            | Total PAS | AV   | MA    | AG   | RC     |
|----------------------------|-----------|------|-------|------|--------|
| Facility Nurse Pain Rating | .279*     | .065 | -.114 | .190 | .447** |

---

N = 58 for all correlations.

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

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

### *Relationship between Palliative Consultant Pain Ratings and PAS Scores*

Palliative Nurse Consultants in the Chinook Health Region are trained in the assessment of pain. Although the three consultants who participated in the research project were blind to the identities of the resident subjects, they were given a summary of the resident's demographic information (age, gender, length of stay in LTC), pain behaviour ratings using the Discomfort Scale – Dementia of the Alzheimer Type, and medications. Using this information, the Palliative Consultants were asked to rate the resident subjects' pain using the Long Term Care Pain Assessment Tool – Verbal Description (Janssen, 2000), the same tool used by the facility nurses. A summary of the correlations between the total PAS and sub-factor scores is provided in Table 5.

Table 5. *Correlation between Palliative Nurse Consultant (average of three consultants) Pain Rating and Total Pittsburgh Agitation Scale (PAS) and Sub-Factor Scores for Aberrant Vocalization (AV), Motor Agitation (MA), Aggressiveness (AG), and Resisting Care (RC)*

---

|                                   | Total PAS | AV     | MA    | AG   | RC     |
|-----------------------------------|-----------|--------|-------|------|--------|
| Palliative Consultant Pain Rating | .489**    | .402** | .313* | .229 | .507** |

---

N = 58 for all correlations.

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

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

### *Relationship between DS-DAT and PAS Scores*

The Discomfort Scale-Dementia of the Alzheimer Type is a pain behaviour scale developed by Hurley et al. (1992). It takes into account the frequency, intensity, and duration of the pain behaviours seen in non-communicative individuals with a dementia. Nine behaviours are assessed over a five minute period and scored from 0 – 3. The behaviours are noisy breathing, negative vocalizations, absence of a look of contentment, looking sad, looking frightened, having a frown, absence of relaxed body posture, looking tense, and fidgeting. The scores were obtained during the morning and evening shifts and the two scores averaged. Several of the behaviours are similar to the sub-factors of the Pittsburgh Agitation Scale (PAS) such as aberrant vocalization, motor agitation, aggressiveness, and resisting care. A summary of the correlation between DS-DAT total scores and PAS total and sub-factor scores are provided in Table 6.

Table 6. *Correlation between Discomfort Scale – Dementia of the Alzheimer Type (DS-DAT) Total Scores and Total Pittsburgh Agitation Scale (PAS) and Sub-Factor Scores for Aberrant Vocalization (AV), Motor Agitation (MA), Aggressiveness (AG), and Resisting Care (RC)*

---

|                       | Total PAS | AV     | MA     | AG    | RC     |
|-----------------------|-----------|--------|--------|-------|--------|
| DS-DAT<br>Total Score | .511**    | .418** | .357** | .276* | .463** |

---

N = 58 for all correlations.

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

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

*Research Question #2: How well do the pain ratings of facility nurses correlate with each other for identical residents?*

Nurse A and B were different staff at each site and three sites were involved. As a result of the unique characteristics of each site and attempting to compare the two ratings on each client at each site, the correlation between Nurse A and B at each site was calculated.

The correlation between the pain ratings of resident subjects by Nurse A and B at Facility A was non-significant ( $r = .241, N=16, p = .369$ ). Similarly, the correlation for the same assessment of resident subjects at Facility B was non-significant ( $r = -.016, N=27, p = .938$ ). On the other hand, the pain assessments completed by Nurse A and B for each resident subject at Facility C demonstrated a significant correlation ( $r = .500, N=15, p = .058$ )

*Research Question #3: How well do the pain ratings of the palliative nurse consultants correlate with each other for identical residents?*

The Palliative Consultant pain ratings for each resident subject were strongly correlated with each other. The strength of the correlations indicated a consistency in the pain ratings from this group. A correlation matrix is shown in Table 7.

Table 7. Correlation matrix demonstrating the correlations between pain ratings completed by Palliative Consultants A, B, and C.

| <u>Correlation Matrix</u> |                             |                             |                             |
|---------------------------|-----------------------------|-----------------------------|-----------------------------|
| <i>Spearman's rho</i>     | Palliative A<br>Pain Rating | Palliative B<br>Pain Rating | Palliative C<br>Pain Rating |
| Palliative A Pain Rating  | 1.000                       | .862**                      | .771**                      |
| Palliative B Pain Rating  | .862**                      | 1.000                       | .780**                      |
| Palliative C Pain Rating  | .771**                      | .780**                      | 1.000                       |
|                           |                             |                             |                             |

N = 58 for all correlations.

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

*Research Question #4: How well do the pain ratings of facility nurses correlate with the palliative nurse consultants for the identical residents?*

When the average of the two facility nurse pain ratings were compared to the average of the three Palliative Consultant ratings, the correlation was found to be moderate and statistically significant ( $r = .373$ ,  $N=58$ ,  $p \leq .01$ ) While the relationship between the ratings of each group was not as strong as the reliability of the Palliative Consultant group, however, the correlation was  $.373$ , significant at the 0.01 level.

*Research Question #5: What are the most common pain diagnoses in the resident sample?*

A potential of five pain diagnoses could be used to classify each resident subject. Arthritis, osteoporosis, a history of hip fracture, localized pain, and a history of cancer were recorded based upon chart information. In this study, localized pain was the most common pain diagnosis at 79.3%; 48.3% of resident subjects had a diagnosis of arthritis. Osteoporosis was listed 43.1% of the time on a resident's chart, resident subjects who had a history of hip fracture 22.4% of the time, and those with a history of cancer 10.3% of the time. Therefore, the two most common pain diagnoses in this resident group were localized pain and arthritis.

## CHAPTER SIX: DISCUSSION

### Overview

The purpose of this chapter is to summarize and synthesize the primary findings of the study as they relate to the research questions outlined in chapter three (Framework). As well, the hypotheses derived from the research questions will be reviewed and relevant findings discussed in comparison to previous research. This chapter will also consider the implications of the results and their application to nursing practice. Several overall recommendations for future nursing study will conclude the chapter.

### Research Questions and Hypotheses

#### *Research Question #1: Relationship between Resident Pain and Pittsburgh Agitation Scale (PAS) Scores*

*Hypothesis #1: A Positive Relationship will exist between Pain Variables and PAS Scores*  
*Pain diagnoses and total PAS scores*

The general hypothesis that all pain variables will be positively correlated with total Pittsburgh Agitation Scale (PAS) (Rosen, 1994) scores was not supported by the results. However, the relationship between agitation and resident pain is quite variable depending upon the specific measure of pain used. Specifically, a very weak or slightly negative relationship exists between total agitation scores and the pain diagnoses of arthritis, osteoporosis, history of hip fracture, history of cancer, and localized pain. A

comparison of the pain diagnoses and the agitation sub-factors of aberrant vocalization, motor agitation, aggression, and resistance to care showed the resulting correlation to be all statistically non-significant.

The weak relationship between pain diagnoses and agitation scores is puzzling in comparison to the results of Feldt et al. (1998). Although Feldt et al. used a different agitation measure (Ryden Aggression Scale – Form 2), they demonstrated a positive and strong correlation between the presence of arthritis and/or two or more pain diagnoses and higher aggression scores. Possibly, the agitation/aggression measure used by Feldt et al. is much more sensitive to agitation behaviours resulting from the pain diagnoses common in LTC residents with dementia.

*Aggregate analgesic scores and total PAS scores.*

The relationship between aggregate analgesic scores and total agitation scores was not statistically significant. This result should be expected since a higher analgesic score would indicate the presence of stronger pain treatment. Providing the physician has prescribed analgesic treatment that corresponds to the severity of pain experienced by the resident, it is fair to assume that the agitation score would decrease. Only if a resident was receiving stronger pain medication, but still experiencing pain, would the agitation score and aggregate analgesic score be high. For this reason, the future use of analgesic medications as a measure of pain is not recommended. Analgesic medication use is not a valid measure of pain. When agitation is a concern with a LTC resident, the medications must be reviewed and adjusted in a systematic manner (Liu et al., 2000).

Although requiring further research, a radical approach to using medication information in pain assessment and treatment in LTC might be to initially treat agitation with analgesics. A traditional approach to treating some forms of agitation and aggression in LTC is to use psychiatric medications such as anxiolytics, anti-depressants, and anti-psychotics (Alexopoulos et al., 1998). Psychotropic medications still have some benefit in specific situations. However, a pilot study by Douzjian et al. (2000) showed that small doses of a mild analgesic decreased agitation and the need for psychiatric medications in ten LTC residents. In the expert consensus guidelines for dealing with dementia related agitation (Alexopoulos et al.), the initial recommendation is for clinicians to assess for physical issues such as pain. At one of the three LTC facilities, the unit manager indicated that the nursing staff regularly recommend to physicians that residents with agitation be given a mild analgesic to hopefully deal with any discomfort or pain. In this study, 79.3% of subjects were prescribed an analgesic medication on a regular basis.

*DS-DAT and total PAS scores.*

The relationship between Discomfort Scale – Dementia of the Alzheimer Type (DS-DAT) (Hurley et al., 1992) scores and total agitation scores was (strongly) statistically significant. The Pittsburgh Agitation Scale (PAS) (Rosen et al., 1994) and DS-DAT share some common behavioural characteristics such as motor restlessness and vocal agitation. The results confirm earlier research that a LTC resident with moderate to severe dementia will demonstrate pain through behaviours such as facial grimaces (Brignell, 1999; Porter et al., 1996), aggression (Feldt et al.), crying (Liu et al., 2000), and posture changes and restlessness (Hurley et al.). The presence of pain behaviours in a LTC resident with dementia must alert a clinician to consider pain as a probable cause.

Given the strength of relationship between DS-DAT and PAS measures, the clinician must also consider pain when a LTC resident becomes ‘agitated.’ A change or worsening in behaviour for a LTC resident with dementia is a warning sign that a possible physical problem (pain) has arisen (Banazak, 1996). A radical, but realistic approach for LTC nurses and physicians is to make the terms agitation and aggression synonymous with the question “is the resident in pain or physical discomfort?”

*Palliative nurse consultant pain ratings and PAS scores.*

A positive relationship that was statistically significant was demonstrated with the agitation scores and the pain ratings of the palliative nurse consultants. The pain ratings were strongly correlated with total PAS (Rosen et al., 1994) scores demonstrating a possible role for palliative consultant nurses in the assessment of agitation in LTC residents with dementia.

*Facility nurse pain ratings and total PAS scores*

The correlation between facility nurse pain ratings and total PAS (Rosen et al., 1994) scores was statistically significant (at the 0.05 level). Although the strength of correlation between the facility nurse pain ratings and total PAS scores was not as strong as with the palliative nurse consultants, the result confirms that facility and palliative consultant nurses are both able to identify pain related agitation.

*Further Implications of the Relationship between Pain Variables and PAS Scores.*

The variation in relationship between the pain variables and PAS scores should not be viewed as a negative outcome of the study. These results more strongly support the

need for comprehensive assessment of agitation and pain issues in LTC residents with dementia (Banazak, 1996; Feldt et al., 1998). For example, if a single variable of pain such as pain diagnoses had been used in this study, then no relationship between pain and agitation would be demonstrated. On the other hand, the study by Buffum et al. (2001) used the DS-DAT (Hurley et al., 1992) to demonstrate that a relationship exists between agitation and discomfort. In this study, the strength of relationship between the PAS (Rosen et al., 1994) and DS-DAT (Hurley et al.) was strong. Based on the results of this study, Buffum et al. were fortunate to choose a pain/discomfort variable that demonstrated a relationship with measures of agitation. Similarly, a nurse working in LTC would be prudent to use more than one method of assessing the underlying cause of resident agitation.

*Hypothesis #2: Higher resident pain scores will be strongly correlated with higher aberrant vocalization scores*

A review of the results showed the PAS sub-factor of aberrant vocalization (AV) to be negatively correlated to total pain diagnoses. While not negatively correlated to AV scores, the relationship with facility nurse pain ratings was statistically non-significant. On the other hand, the palliative consultant pain ratings and aggregate analgesic scores were significantly correlated with AV scores. Furthermore, the DS-DAT (Hurley et al., 1992) and AV scores were significantly correlated. In keeping with the results demonstrated with the correlation between pain variables and total PAS (Rosen et al., 1994) scores, pain diagnoses, aggregate analgesic scores, and facility nurse pain ratings were statistically non-significant. However, a further discussion comparing AV to the other PAS sub-factors of motor agitation, aggression, and resistance to care will further

support or not support the hypothesis that AV most strongly correlated with pain variables.

Anecdotal experience has shown that one of the main clues of untreated or undertreated pain in a LTC resident with dementia is vocal agitation. I was involved in a case of a LTC resident with severe dementia that always screamed during the meal times and particularly in the evening during personal care. After some investigation, it was discovered that the resident's teeth were very decayed and were causing great pain. After dental extraction, the vocal agitation subsided. Liu et al. (2000) describe a LTC resident with dementia that persisted with vocal agitation despite environmental and psychiatric intervention, until gout, a painful arthritic/inflammatory condition, was treated. Given these examples, it was surprising to discover that vocal agitation, as measured by the PAS, would demonstrate the strongest relationship with all the pain variables.

*PAS sub-factors and pain variables.*

The correlation between the five pain variables and the four sub-factors of the PAS, aberrant vocalization (AV) did not demonstrate the strongest relationship with most pain variables. Aside from the strongest relationship between aggregate analgesic score and AV, the PAS sub-factor of resistance to care (RC) demonstrated the strongest relationship to pain variables. In particular, a statistically significant correlation was found between facility nurse pain ratings, palliative nurse consultant pain ratings, DS-DAT scores, and RC scores. Motor agitation, another of the PAS sub-scores is significantly correlated with palliative consultant pain ratings and DS-DAT scores.

Finally, the final PAS sub-score of aggression is significantly correlated with DS-DAT scores.

Based upon some of the anecdotal evidence that generated the initial interest in this study and the descriptive example of vocal agitation in Liu et al. (2000), it was surprising that vocal agitation was not more strongly associated with the study pain variables. One possible explanation for this result is the inclusion of resident subjects with both moderate and severe levels of dementia. Stages six and seven on the Global Deterioration Scale (Reisburg, 1984) account for individuals with a dementia who demonstrate severe comprehension and communication impairment. However, a functional difference exists between individuals who are either a stage six or seven. Possibly, the stronger relationship between resistance to care and the pain variables was a reflection of the remaining functional abilities of the resident subjects with a moderate dementia (51.7% of resident subjects classified as moderate, 10.3% classified as moderate – severe, and 38% classified as severe). In comparison, the individual with vocal agitation described in Liu et al. (2000) and all the subjects in Feldt et al. (1998) were classified as having severe dementia.

One of the most surprising but significant findings of this study was the discovery that the pain variables were (generally) most strongly correlated with the PAS (Rosen et al., 1994) sub-factor of resistance to care. In light of the previous discussion regarding the moderate dementia classification of many resident subjects in this study, resistance to care may become an agitation marker or characteristic of this stage of dementia. In addition, the demonstration of resistance to care in moderate dementia may signal possible untreated or under-treated pain.

A nurse or physician working with LTC residents should continue to respond to vocal agitation in a systematic and thorough manner (Banazak, 1996). Using the PAS (Rosen et al., 1994), future research may want to investigate the unique agitation features of each stage of dementia.

*Correlation among pain variables.*

The scores for the pain variables of pain diagnoses (arthritis, osteoporosis, history of hip fracture, localized pain, and history of cancer), aggregate analgesic medications, facility nurse pain ratings, palliative nurse consultant pain ratings, and pain behaviour ratings were correlated with each other. The palliative consultant pain ratings demonstrated the strongest relationship with other pain variables. In order of decreasing statistical strength with other pain variables, aggregate analgesic, DS-DAT, and facility nurse pain ratings demonstrated a decrease in the overall statistical significance with other pain variables. Finally, the variable of pain diagnoses demonstrated the lowest statistical correlation with the other four pain variables.

One possibility to explain the poor correlation between pain diagnoses and other pain variables is that the pain diagnoses may have been influenced by measurement error (Norwood, 2000). The resident subject chart information was used to collect the pain diagnoses. This information was collected under the assumption that the physician and/or facility nurse had conducted a thorough and comprehensive assessment of each resident subject. Based on previous research, the possibility exists that resident subjects suffering with painful diagnoses were never fully assessed nor was the information recorded on their charts (Kaasalainen et al., 1998; Sengstaken & King, 1993). Liu et al. (2000) presented an anecdotal experience where a LTC resident with dementia displayed

persistent vocal agitation until a systematic assessment process identified gouty arthritis. Unfortunately, the LTC resident described by Liu et al. persisted with vocal agitation, despite psychotropic medications and environmental interventions for months until receiving appropriate treatment. This discussion is not a condemnation of the staff and physicians working with the resident subjects; it is a reasonable assumption based upon research and anecdotal experience.

*Research Question #2: Correlation between Facility Nurses' Pain Ratings*

The facility nurses were chosen to collect data on the pain experienced by the resident subjects for several reasons. First, facility nurses in the LTC facilities are expected to have a good understanding of the medical status and medications of all the residents. Second, averaging the ratings of Nurse A and Nurse B would provide an 'average' view of the pain experienced by the resident subject. Third, previous literature has demonstrated that nurses and physicians are poor at rating the pain experienced by LTC residents with dementia (Sengstaken & King, 1993). Comparing the pain ratings of facility nurses against the ratings of palliative consultant nurses would provide a unique perspective on pain assessment in the LTC environment.

*Hypothesis #3: There will be a weak and positive correlation between the resident subject pain ratings completed by the facility nurses*

The correlation between Nurse A and B at each facility varied widely. This variation may be due to the higher number of resident subjects at one facility (N=27). Furthermore, at that facility, three nurses rather than two were used possibly adding to the variation in the pain ratings.

Facility nurse pain ratings were collected at different times of the day under varying conditions. Two nurses at each facility (Taber had three nurses) rated the pain of the resident subjects at that facility. A total of seven facility nurses in three facilities were involved in the pain rating of the 58 resident subjects. The fact that pain ratings of subjects were conducted at different times, under different conditions, and by multiple of nurses would factor against the facility nursing pain ratings being strongly correlated. However, despite these potential confounding variables, the intent of using multiple nurses to rate the pain of residents on the two shifts (morning and evening) was to provide an average or 'general picture' of the resident subjects' pain over the course of a day.

*Research Question #3: Correlation between Palliative Nurse Consultant Pain Ratings*

The correlation between Palliative Consultant A, B, and C were all strongly significant. This is most likely due to the consistent training and strong team that has formed with the four nurse consultants.

*Hypothesis #4: There will be a strong and positive correlation between the resident subject pain ratings completed by the three palliative nurse consultants*

One possible factor may have contributed to the strong reliability of the pain ratings provided by the palliative nurse consultants. The Chinook Health Region palliative consultant team receives regular and consistent education on the assessment of pain and discomfort, medication approaches to treating pain, and critical thinking skills (M. Brewin, personal communication, March 10, 2003). The comprehensiveness and uniformity of training may have helped ensure the consistency of pain ratings. Even on

individuals the palliative consultants never physically assessed, the pain ratings would be relatively consistent.

Furthermore, the strong reliability of the palliative consultant pain ratings lends support for the need for comprehensive education on pain assessment and treatment of elderly individuals. In particular, elderly individuals with a dementia have the greatest need for improved pain assessment and treatment due an inability to properly communicate their needs. Numerous studies have clearly demonstrated that most health professionals are poor at assessing and treating pain in the LTC environment. Marzinski (1991) and Sengstaken and King (1993) identified that physicians and nurses are very poor at identifying potential pain in LTC residents with a dementia. Myths include ideas such as “pain is a normal part of aging”, “pain treatment in the elderly is less successful than treatment with younger patients”, and “pain assessment of elderly individuals is too labour intensive” are common among health professionals (Gibson, 1998). Health professionals working in LTC must take steps to improve their understanding regarding the unique approach to assessing and treating pain in LTC residents with dementia.

*A further implication of palliative pain rating scores.*

While Palliative Consultants in the Chinook Health Region are busy handling the needs of clients in acute and community care, very little time is left to assist LTC nursing staff in assessing and treating the pain of residents. However, the very strong relationship identified between the Palliative Consultant pain ratings, the other pain variables, and agitation scores identifies a need for such expertise in dealing with agitation and discomfort in LTC residents with dementia. The role of Palliative or Pain Consultants in LTC may need to be expanded for general education and consultation in difficult cases. A

search for articles on 'Pain Consultants in LTC / Nursing Homes,' 'Palliative Consultants in LTC / Nursing Homes,' and 'Pain Consultants and the Elderly' turned up no articles for some searches and no relevant articles for other searches. Therefore a paucity of research exists into the use of pain consultants in LTC.

*Research Question #4: Correlation between the Pain Ratings completed by the Facility Nurses and the Palliative Nurse Consultants*

The correlation between the averaged pain ratings of the facility nurses and palliative nurse consultants was statistically significant. Although the facility nurses knew the resident subjects well and the palliative consultants never did meet the resident subjects, the pain ratings were correlated in a statistically significant manner.

*Hypothesis #5: There will be a weak and positive correlation between the resident subject pain ratings completed by the facility nurses and the palliative nurse consultants*

One of the main identified gaps in research was the need to study the use of pain or palliative nurse consultants in pain assessment and treatment of LTC residents with dementia. The hypothesis that facility and palliative consultant nurses would demonstrate a weak correlation between the pain rating scores for each resident was proven false. Important to note, statistical agreement between the pain ratings of both nursing groups illustrates that palliative nurse consultants are likely to arrive at a similar pain rating as a nurse who has the benefit of knowing most aspects of the LTC resident's medical status. Such a result occurred without the palliative nurse consultant observing the resident. A summary of resident information was provided to the palliative nurse consultant. Palliative nurse consultant pain ratings were much more strongly correlated with the

other pain variables and also with the Pittsburgh Agitation Scale (PAS) (Rosen et al., 1994) scores. This finding is a unique confirmation of research that identified how poorly health professionals (physicians and nurses) assess pain in their LTC residents with dementia (Marzinski, 1991; Sengstaken & King, 1993).

*Research Question #5: Common Pain Diagnoses of Resident Subjects*

The current study was composed of 58 subjects with an average age of 83.9 years. Furthermore, 63.8% of subjects were female. A comparison of the painful diagnoses identified in this study revealed that localized pain was the most common at 79.3%, arthritis was listed in 48.3% of subjects, osteoporosis was a factor in 43.1%, a history of hip fracture in 22.4%, and a history of cancer in 10.3% of the subjects.

*Hypothesis #6: Arthritis and osteoporosis will be the most common pain diagnoses for resident subjects*

In the study by Feldt et al. (1998), arthritis and a history of hip fracture were the two most common medical diagnoses. Arthritis was listed 44.7% of the time while a history of hip fracture was listed 42.1% of the time. Localized pain was identified in 34.2% of subjects, osteoporosis in 18.4%, and cancer in 13.0%. The demographic characteristics of the 38 subjects indicated that 81.6% were female and the average age was 86.9 years. The residents in this study were classified with localized pain (79.3%) and arthritis (48.3%) as the two most common pain diagnoses.

An explanation for the difference between the results in this study and those of Feldt et al. (1998) is to consider the historical issue of poor pain assessment practices in LTC (Marzinski, 1991). As discussed earlier in this chapter, when a resident subject was

admitted to LTC, a potentially poor or incomplete pain assessment would result in the pain diagnoses not reflecting the true pain status of the resident.

A more tangible explanation for the difference between the pain diagnoses reported by Feldt et al. and this study is a clear difference in the severity of dementia between the two groups of subjects. As discussed earlier in this chapter, all the subjects in Feldt et al. were classified as having severe dementia. The resident subjects in this study were mostly classified as having moderate dementia.

#### *Overall Implications of Study*

Three general implications are an important result of this study:

- 1) Pain assessment of LTC residents with dementia requires multiple measures of pain. However, some measures of pain used in this study are poor at detecting pain or must be applied in a different manner to improve the results. Specifically, analgesic medications should not be used as a measure of pain in a LTC resident with dementia. Finally, the pain ratings of the facility nurses do correlate with agitation scores.
- 2) The relationship between palliative nurse consultant pain ratings and facility nurse pain ratings, other pain variables, and agitation scores identifies a strong need for education and training regarding pain and dementia in LTC. Although palliative nurse consultants do not have much exposure to current LTC residents, the training and education they did receive on general pain assessment and treatment approaches resulted in strong outcomes with this study. Further research into the use of pain consultants in LTC for pain consultation and education of staff on pain issues in LTC would thus be useful.

3) The strong relationship between agitation scores, as measured by the PAS, and the pain variables of palliative nurse consultant pain ratings and the pain behaviour rating (DS-DAT) add evidence to previous research that a relationship exists between agitation in dementia and pain. An implication of future education and research in LTC is that agitation in dementia will alert nurses and physicians to the strong possibility of untreated or under-treated pain. A unique finding of this study is the prominence of resistance to care as a main feature of agitation. The relationship between pain variables and resistance to care warrants further study.

#### Limitations

##### *Representativeness of Sample*

The sample in this study was representative of the general demographic features of gender and age seen in the general LTC population. However, the use of rural facilities may limit the application of results to urban settings. More realistically, the study results may further the understanding about the unique features of rural LTC residents.

##### *Demographic Representation*

This study was comprised of 58 subjects who were classified as moderate to severe in their functional and cognitive abilities. All subjects demonstrated severe communication and comprehension abilities. The average age of subjects was 83.9 years and females comprised 63.8% of the resident subjects. The average length of stay in LTC was 29 months.

Two studies were used as a comparison to this study. The study by Feldt et al. (1998) assessed the link between pain and aggression in LTC residents with severe

dementia. Feldt et al. assessed 38 subjects who were classified with “severe cognitive impairment” (p. 18). The average age was 86.9 years, 81.6% of subjects were female, and the median length of stay was 53 months. The study by Buffum et al. (2001) looked at discomfort and agitation. It had 33 subjects an average age of 78.5 years with a mean Global Deterioration Scale (Reisberg, 1984) score of 4.8/ 7 (mild – moderate dementia). Of concern, the Buffum et al. study was composed of 32 males and one female. Such a result is the converse of the usual demographics seen in LTC where approximately 70% of residents are female (Magaziner et al., 2001).

#### *Rural Facilities*

One of the unique features of this study was that the resident subjects all resided in three rural LTC facilities. In the comparable studies by Feldt et al. (1998) and Buffum et al. (2001), subjects were all from urban American LTC facilities. Rural facilities were chosen in this study due to a professional interest in rural health issues. Furthermore, smaller LTC facilities found in most rural communities may have some novel approaches to dementia care. While the occupational, ethnicity, and previous location information was not collected on the subjects in this study, it may be fair to assume that many of the resident subjects were farmers, ranchers, coal miners, or former residents of a small rural community. This may limit the generalizability of the findings to urban LTC settings. On the other hand, the findings do contribute to research on rural health issues.

#### *Subjectivity of Assessment Tools*

Most of the measures of cognitive/functional ability, pain assessment, and agitation relied upon the observation of the principal investigator, nursing staff, or

research assistant. Observational scales such as the Pittsburgh Agitation Scale (Rosen et al., 1994) and the Discomfort Scale – Dementia of the Alzheimer Type (Hurley et al., 1992) are subject to the subjective interpretation of the observer. In order to mitigate any validity issues, the use of a limited number of trained observers was utilized. However, even this approach influences the reliability of the findings (Norwood, 2000).

#### Recommendations for Future Research

Although theoretical research is important for nursing practice in LTC, the real need for LTC residents with dementia is an improved quality of life. As outlined in the literature review, a decrease in the agitation and aggression of LTC residents' results in an increased quality of work life for LTC staff. Two main research issues that may affect the greatest improvement in LTC resident quality of life are as follows:

- 1) Evaluating the effectiveness of using pain consultants in LTC for consulting residents and educating LTC staff.
- 2) Further research on the behavioural clues that signal pain issues in dementia. Such research may further investigate the use of agitation and aggression measures developed for LTC residents to assess the severity of pain experienced by LTC residents with moderate to severe dementia. In particular, the presence of resistance to care may serve as a prominent clue of pain issues in dementia.

## REFERENCES

- Alberta Health & Wellness. (2002). *Alzheimer Disease and other dementias: Strategic directions in healthy aging and continuing care in Alberta*. Edmonton, Alberta, Canada: Alberta Health and Wellness.
- Alzheimer Society of Canada. (2002). Alzheimer Disease: Stages of the disease. *The three stages*. Retrieved November 17, 2002 from <http://www.alzheimer.ca/english/disease/stages-3stages.htm>
- American Psychiatric Association. (1997). Practice guideline for the treatment of patients with Alzheimer's disease and other dementias of late life. *American Journal of Psychiatry*, 154(5)(Suppl.), S1-S39.
- Baillie, L.(1993). A review of pain assessment tools. *Nursing Standard*, 7(23), 25-29.
- Bair, B., Toth, W., Johnson, M. A., Rosenberg, C., & Hurdle, J. F. (1999). *Journal of Gerontological Nursing*, 25, 13-21.
- Banazak, D. A. (1996). Difficult dementia: Six steps to control problem behaviours. *Geriatrics*, 51, 36-42.
- Banik, B. J. (1993). Applying triangulation in nursing research. *Applied Nursing Research*, 6, 47-52.
- Benedetti, F., Vighetti, S., Ricco, C., Lagna, E., Bergamasco, B., Pinessi, L., & Rainero, I. (1999). Pain threshold and tolerance in Alzheimer's disease. *Pain*, 80, 377-382.
- Brignell, A. (1999). Assessing pain in the non-cognizant elderly. *Canadian Nursing Home*, 10(4), 4-8.
- Burns, N., & Grove, S. K. (1997). *The practice of nursing research: Conduct, critique, & utilization* (4<sup>th</sup> ed.). Toronto, ON: Saunders.

- Buffum, M. D., Miaskowski, C., & Sands, L. (2001). A pilot study of the relationship  
Between discomfort and agitation in patients with dementia. *Geriatric Nursing*,  
22, 80-85.
- Canadian Medical Association. (1999). Management of dementing disorders:  
Conclusions from the Canadian Consensus Conference on dementia. *Canadian  
Medical Association Journal*, 160, s1-s15.
- Choi, D. M., Yate, P., Coats, T., Kalinda, P., & Paul, E. A. (2000). Ethnicity and  
prescription of analgesia in an accident and emergency department: Cross  
sectional study. *British Medical Journal*, 320, 980-981. Retrieved February, 13,  
2001 from PubMed central at <http://www.pubmedcentral.nih.gov/b.cgi>
- Closs, S. J. (1994). Pain in the elderly patients: a neglected phenomenon? *Journal of  
Advanced Nursing*, 19, 1072-1081.
- Cohen-Mansfield, J. (1999). Measurement of inappropriate behavior associated with  
dementia. *Journal of Gerontological Nursing*, 42-51
- Cramer, G. W., Galer, B. S., Mendelson, M. A., & Thompson, G. D. (2000). A drug use  
evaluation of selected opioid and nonopioid analgesics in the nursing facility  
setting. *Journal of the American Geriatrics Society*, 48(4), 398-404.
- Devanand, D. P., Brockington, C. D., Moody, B.J., Brown, R.P., Mayeux, R.,  
Endicott, J. & Sackeim, H. A. (1992). Behavioral syndromes in Alzheimer's  
Disease [supplement 2]. *International Psychogeriatrics*, 4, 161-184.

- Douzjian, M., Wilson, C., Shultz, M., Tapino, J., & Blanton, V. (1998). A program to use pain control medication to reduce psychotropic drug use in residents with difficult behavior. *Annals of Long Term Care: Clinical Care and Aging (Online)*, 6(4), 1-7. Retrieved January 21, 2001, from:  
<http://www.mmhc.com/nhm/articles/NHM9804/Douzjian.html>
- Feinsod, F. M., Prochoda, K. P., Anneberg, L. A., & Solomon, W. (2000). The medical director's role in pain management for residents in long-term facilities. *Annals of Long-Term Care: Clinical Care and Aging*, 8, 43-48. Retrieved May 12, 2000 from <http://www.mmhc.com/nhm/articles/NHM0010/feinsod.html>
- Feldt, K. S. (2000). Improving assessment and treatment of pain in cognitively impaired nursing home residents. *Annals of Long Term Care: Clinical Care and Aging (Online)*, 8(9), 36-42. Retrieved December 5, 2000, from:  
<http://www.mmhc.com/nhm/articles/NHM0009/feldt.html>
- Feldt, K. S., Warne, M. A., & Ryden, M. (1998). Examining pain in aggressive cognitively impaired older adults. *Journal of Gerontological Nursing*, 24(11), 14-22.
- Ferrell, B. A., Ferrell, B. R., & Rivera, L. (1995). Pain in the cognitively impaired nursing home patient. *Journal of Pain and Symptom Management*, 10(8), 591-598.
- Fisher-Morris, M. & Gellatly, A. (1997). The experience and expression of pain in Alzheimer patients. *Age and Ageing*, 26(6), 497-500.
- Forrest, J. (1995). Assessment of acute and chronic pain in older adults. *Journal of Gerontological Nursing*, 21(10), 15-20.

- Gaston-Johansson, F., Johansson, F., & Johansson, N. (1999). Undertreatment of pain in the elderly: Causes and prevention. *Annals of Long-Term Care*, 7, 190-196.  
Retrieved January 21, 2001 from  
<http://www.mmhc.com/nhm/articles/NHM9905/Gaston.html>
- Gibson, M. C. (1998). Improving the pain control for the elderly patient with dementia. *American Journal of Alzheimer's Disease*, 13, 10-14.
- Gordon, M. (2001). Should we conduct research on persons with dementia? *Geriatrics and Aging*, 14-15
- Government of Alberta (1999). *Health Information Act*. Edmonton, Alberta, Canada: Queens Printer.
- Gurvich, T., & Cunningam, J. A. (2000). Appropriate use of psychotropic drugs in nursing homes. *American Family Physician*, 61, 1437-1446.
- Hagen, B. F., & Sayers, D. (1995). When caring leaves bruises: The effects of staff Education on resident aggression. *Journal of Gerontological Nursing*, 21, 7-16.
- Haskell, R. M., Frankel, H. L., & Rotondo, M. F. (1997). Agitation. *AACN Clinical Issues*, 8(3), 335-350.
- Herr, K. A. & Mobily, P. R. (1993). Comparison of selected pain assessment tools for use with the elderly. *Applied Nursing Research*, 6(1), 39-46.
- Herr, K. A., Mobily, P. R., Kohout, F. J., & Wagenaar, D. (1998). Evaluation of the faces pain scale for use with the elderly. *The Clinical Journal of Pain*, 14(1), 29-38.
- Hurley, A. C., Volicer, B. J., Hanrahan, P. A., Houde, S., & Volicer, L. (1992). Assessment of discomfort in advanced Alzheimer patients. *Research in Nursing & Health*, 15, 369-377.

- Kaasalainen, S., Middleton, J, Knezacek, S., Hartley, T., Stewart, N., Ife, C., & Robinson, L. (1998). Pain and cognitive status in the institutionalized elderly: Perceptions and interventions. *Journal of Gerontological Nursing, 24(8)*, 24-31.
- Kovach, C. R., Weissman, D. E., Griffie, J., Matson, S., & Muchka, S. (1999). Assessment and treatment of discomfort for people with late-stage dementia. *Journal of Pain and Symptom Management, 18(6)*, 412-419.
- Krulewitch, H., London, M. R., Skakel, V. J., Lundstedt, G. J., Thomason, H., & Brummel-Smith, K. (2000). Assessment of pain in cognitively impaired older adults: A comparison of pain assessment tools and their use by non-professional caregivers. *Journal of the American Geriatrics Society, 48(12)*, 1607-1611.
- Liu, D. D, Raji, M., Twersky, J., & Riggs, A. (2000). Case report: Disruptive vocalization due to gout in an elderly nursing home resident with dementia. *Annals of Long Term Care, 8(5)*, 66-70.
- Magaziner, J., German, P., Itkin Zimmerman, S., Hebel, J. R., Burton, L., Gruber-Baldini, A. L., May, C., & Kittner, S. (2000). The prevalence of dementia in a state-wide sample of new nursing home admissions aged 65 and older. *Gerontologist (Online), 40(6)*, 663-672. Retrieved on April 1, 2001, from: <http://www.gerontologist.gerontologyjournals.org>
- Marzinski, L. R. (1991). The tragedy of dementia: Clinically assessing pain in the confused nonverbal elderly. *Journal of Gerontological Nursing, 17(6)*, 25-28.
- McCaffery, M. & Pasero, C. (1999). *Pain: Clinical manual*. St. Louis, MO: Mosby.

- Miaskowski, C. (1999). Pain and discomfort. In J. Takano Stone, J. F. Wyman, & S. A. Salisbury (Eds.), *Clinical gerontological nursing: A guide to advanced practice* (2<sup>nd</sup> ed.), (pp.647-663). Toronto, Ontario, CANADA: W.B. Saunders.
- Middleton, J. I., Stewart, N. J., & Richardson, J. S. (1999). Caregiver distress: Related to disruptive behaviors on special care units versus traditional long-term care. *Journal of Gerontological Nursing*, 25, 11-19.
- Miller, L. L., & Talerico, K. A. (2002). Pain in the older adult. In J. J. Fitzpatrick (Ed.), *Annual review of nursing research* (pp. 63-88). New York, NY: Springer.
- Morrison, R. S., Ahronheim, J. C., Morrison, R., Darling, E., Baskin, S. A., Morris, J., Choi, C., & Meier, D. E. (1998). Pain and discomfort associated with common hospital procedures and experiences. *Journal of Pain and Symptom Management*, 15(2), 91-101.
- Morrison, R. S., & Siu, A. L. (2000). A comparison of pain and its treatment in advanced dementia and cognitively intact patients with hip fracture. *Journal of Pain and Symptom Management*, 19(4), 240-248.
- Natural Sciences & Engineering Research Council. (1998). *Tri-Council policy statement: Ethical conduct for research involving humans*. Retrieved January 31, 2001 from: <http://nserc.ca/news/p980917.htm>.
- Norwood, S. L. (2000). *Research strategies for advanced practice nurses*. Upper Saddle River, NJ.: Prentice Hall Health.

- Ortega, R. A. (2000). Ethnic variability in the treatment of pain.[Electronic version].  
*American Journal of Anesthesiology*, 26, 429-432. Retrieved on February 4, 2001  
 from [http://www.pain.com/library/detail.cfm?Articles\\_id=3258](http://www.pain.com/library/detail.cfm?Articles_id=3258)
- Parmelee, P. A. (1994). Assessment of pain in the elderly. In M. P. Lawton & J. Teresi  
 (Eds.), *Annual review of gerontology and geriatrics*. (pp.281-301). New York,  
 NY: Springer.
- Pasero, C., & McCaffery, M. (2001). The undertreatment of pain: Are providers  
 accountable for it? *American Journal of Nursing*, 101, 62-64.
- Penrod, J., & Dellasega, C. (2001). Caregivers' perspective of placement: Implications  
 for Practice. *Journal of Gerontological Nursing*, 27, 28-36.
- Porter, F. L., Malhotra, K. M., Wolf, C. M., Morris, J. C., Miller, J. P., & Smith, M. C.  
 (1996). Dementia and response to pain in the elderly. *Pain*, 68, 413-421.
- McGraw-Hill Healthcare. (1998). The expert consensus guidelines: Treatment of  
 agitation in older persons with dementia. *Postgraduate Medicine*, 1-89.
- Reisberg, B. (1984). Alzheimer's disease: Stages of cognitive decline. *American Journal  
 of Nursing*, 84, 225-228.
- Reisberg, B. (1988). Functional assessment staging (FAST). *Psychopharmacological  
 Bulletin*, 24(4), 653-659.
- Richards, J. S., Nepomuceno, C., Riles, M., & Suer, Z. (1982). Assessing pain behavior:  
 The UAB pain behavior scale. *Pain*, 14, 393-398.

- Rosen, J., Bobys, P. D., Mazumdar, S., Mulsant, B. H., Sweet, R. A., Yu, K., Kollar, M., & Pollock, B. G. (1999). OBRA regulations and neuroleptic use: Defining agitation using the Pittsburgh Agitation Scale and the Neurobehavioral Rating Scale. *Annals of Long-Term Care*, 7, 429-436.
- Rosen J, Burgio L, Kollar M, Cain, M., Allison, M., Fogleman, M., Michael, M., & Zubenko, G. S. (1994). The Pittsburgh Agitation Scale: A user friendly instrument for rating agitation in dementia patients. *American Journal of Geriatric Psychiatry* 1994; 2:52-59.
- Rovner, B. W., Katz, I. R., & Lyketsos, C. G. (2000). Neuropsychiatry in nursing homes. In C. E. Coffey & J. L. Cummings (Eds.). *Textbook of geriatric neuropsychiatry*. (pp.891-903). Washington, DC: American Psychiatric Press.
- Scherder, E., Bouma, A., Borkent, M., & Rahman, O. (1999). Alzheimer patients report less pain intensity and pain affect than non-demented elderly. *Psychiatry*, 62, 265-272.
- Schofield, P. (1995). Using assessment tools to help patients in pain. *Professional Nurse*, 10(11), 703-706.
- Scottish Intercollegiate Guidelines Network (2001). Control of pain in patients with Cancer: Section 6: Choice of analgesia for cancer pain. Retrieved on February 24, 2003, from <http://www.sign.ac.uk/guidelines/fulltext/44/section6.html>
- Sengstaken, E. A. & King, S. A. (1993). The problem of pain and its detection among geriatric nursing home residents. *Journal of the American Geriatrics Society*, 41(5), 541-544.

- Simons W. & Malabar, R. (1995). Assessing pain in elderly patients who cannot respond verbally. *Journal of Advanced Nursing*, 22, 663-669.
- Sourial, R., McCusker, J, Cole, M., & Abrahamowicz, M. (2001). Agitation in demented patients in an acute care hospital: Prevalence, disruptiveness, and staff burden. *International Psychogeriatrics*, 13, 183-197.
- Stelmach, L, Konnert, C., & Dobson, K. (2001). Obtaining informed consent from continuing care residents: Issues and recommendations. *Canadian Journal on Aging*, 20, 385-406.
- Todd, K. H., Samaroo, N., & Hoffman, J.R. (1993). Ethnicity as a risk for inadequate emergency department analgesia. *Journal of the American Medical Association*, 269, 1537-1539.
- Toomey, T. C., & Seville, J. L. (1994). Assessing functional impairment in elderly patients with chronic pain. *Topics in Geriatric Rehabilitation*, 10(1), 58-66.
- Watt-Watson, J., Stevens, B., Garfinkel, P., Streiner, D., & Gallop, R. (2001). Relationship between nurses' pain knowledge and pain management outcomes for their postoperative cardiac patients. *Journal of Advanced Nursing*, 36, 535-545.
- Weissman, D. E. & Matson, S. (1999). Pain assessment and management in the long-term care setting. *Theoretical Medicine*, 20, 31-43.
- Whall, A. L., Gillis, G. L., Yankou, D., Booth, D. E. & Beel-Bates. (1992). Disruptive Behavior in elderly nursing home residents: A survey of the nursing staff. *Journal of Gerontological Nursing*, 18, 13-17.
- Wilkinson, C. L. (1999). An evaluation of an educational program on the management of assaultive behaviors. *Journal of Gerontological Nursing*, 25, 6-11.

Appendix 1

**From:** Karen Feldt [feldt002@umn.edu]  
**Sent:** Monday, February 24, 2003 9:00 AM  
**To:** Zieber, Colin  
**Subject:** Re: Request for permission to reproduce a figure.

Dear Colin,

Yes you are welcome to reproduce the Model of multifaceted pain assessment.  
Please be sure to cite the Journal of Gerontological Nursing as the source.

Best wishes with your important research!  
Sincerely,

Karen S. Feldt, PhD, RN, GNP  
Associate Professor  
University of Minnesota School of Nursing  
6-101 Weaver Densford Hall  
308 Harvard St. S.E.  
Minneapolis, MN 55455  
phone: 612-624-7653 fax: 612-626-2359  
email: feldt002@umn.edu

At 03:42 PM 2/22/03 -0700, you wrote:

Hello. I would like to request permission from you and/or Mary A. Warne to reproduce a figure from your article "*Examining Pain in Aggressive Cognitively Impaired Older Adults*". Journal of Gerontological Nursing, 1998, 24(11): 14-22. Specifically, I am interested in using the *Model of multifaceted pain assessment* developed by Warne in 1994 but is unpublished until included in the 1998 article.

To give you some background, I am a Registered Psychiatric Nurse completing my M.Sc. with the University of Lethbridge's Health Sciences - Nursing Program. As well, I oversee three of the rural Community Care Offices in the local health region. My M.Sc. research project looked at pain and agitation in severely demented LTC residents. The tools I used were the Pitts. Agitation Scale, DS-DAT, chart reviews, and pain assessments by facility nurses and blind assessments by palliative consultant nurses.

Thank you.

Colin Zieber, R.P.N., B.Sc.

Appendix 2

Nurse A: Consent Form

**Pain and Agitation Study**

Site (Please Circle):                  CNP                  Taber                  Cardston

I \_\_\_\_\_ freely consent to participate in this research project coordinated by Colin Zieber as a partial fulfilment of his Masters of Science Program through the University of Lethbridge. The responses provided by me will be based upon my professional opinion as a Registered Nurse or Registered Psychiatric Nurse.

I also recognize that I have the right to withdraw participation at any time without any negative effect occurring from the Chinook Health Region or my supervisors.

\_\_\_\_\_  
(Signature)

\_\_\_\_\_  
(Date)

Appendix 3

Nurse B: Consent Form

**Pain and Agitation Study**

Site (Please Circle):           CNP           Taber           Cardston

I \_\_\_\_\_ freely consent to participate in this research project coordinated by Colin Zieber as a partial fulfilment of his Masters of Science Program through the University of Lethbridge. The responses provided by me will be based upon my professional opinion as a Registered Nurse or Registered Psychiatric Nurse.

I also recognize that I have the right to withdraw participation at any time without any negative effect occurring from the Chinook Health Region or my supervisors.

\_\_\_\_\_  
(Signature)

\_\_\_\_\_  
(Date)

Appendix 4

University of Lethbridge / Chinook Health Region

Palliative Nurse Consultant - Consent Form

**Pain and Agitation Study**

I \_\_\_\_\_ freely consent to participate in this research project coordinated by Colin Zieber as a partial fulfilment of his Masters of Science Program through the University of Lethbridge. The responses provided by me will be based upon my professional opinion and experience as a Registered Nurse.

I also recognize that I have the right to withdraw participation at any time without any negative effect occurring from the Chinook Health Region or my supervisors.

\_\_\_\_\_  
(Signature)

\_\_\_\_\_  
(Date)

Appendix 5

September 4, 2001

Mr. Thane Olsen  
Ethics Review Committee  
Chinook Health Region  
c/o 960 - 19th Street South  
Lethbridge, Alberta  
T1J 1W5

Dear Mr. Olsen:

RE: RESEARCH STUDY: "The relationship between pain and agitation in long-term care residents with moderate to severe dementia."

At your suggestion in your letter of July 9<sup>th</sup>, I am writing to seek the guidance and support of the CHR Regional Ethics Committee regarding approval the committee granted my research study ("The Relationship Between Pain and Agitation in Long-term Care Residents with Moderate to Severe Dementia) at its June 20<sup>th</sup> meeting. As you may recall, the committee granted approval of the study with the proviso that the study would only recruit residents who have a duly appointed guardian or an agent pursuant to a properly enacted Personal Directive. At that time, it was also suggested that if a problem arose with this proviso, that I was welcome to re-approach the Committee for some further discussion.

Over July and August, I was able to make a number of inquires regarding the three sites where I intend to conduct my research (Crownsnest Pass, Taber and Cardston (Grandview), and it appears that less than 10% of the 149 residents have legal guardians. The true numbers of enacted Personal Directives are unknown but are believed to be quite small. This information was gathered through the Minimum Data Set (MDS) assessments completed on all Continuing Care Residents within Chinook Health Region (CHR) facilities. Therefore, it appears that given the proviso suggested by the CHR Regional Ethics Committee on June 20<sup>th</sup>, I am currently unable to proceed with this valuable research project. I am writing to request that the committee review and re-consider the research team's original request that the research be allowed to proceed without the requirement for informed consent (from the dementia victim's family member and/or third party decision-maker). The research team believes we have three legitimate rationale for this request:

1) First and foremost, our request is in keeping with the ethical guidelines suggested by the Tri-Council Guidelines for Human Subject Research -- the ethical guidelines set out as the ethical standards for all research involving human subjects in Canada (and research funded by Canada's three largest national research funding agencies). In particular, our request is in keeping with a number of specific Tri-Council policies that address the issues of informed consent, the use of secondary (pre-existing) data, and the conduct of research involving persons with incompetent individuals (such as those with a severe dementia). Specifically, sections 2.1.c, 3.3, 3.4, and 5.3 of the Tri-Council recommendations (please see attachments) for ethical review committees would support our request to waive the requirement to obtain informed consent from guardians of severely demented persons in this proposed study because:

a) the research involves no risk to the subjects, yet stands to make significant benefits to

the subjects and improving the care they receive,

- b) the waiver is unlikely to adversely affect the rights and welfare of the subjects,
- c) the research could not practicably be carried out without the waiver alteration,
- d) family members will be provided with pertinent information after the study,
- e) the study involves no therapeutic intervention, nor is anything being done to the subjects or asked of them,
- f) the study only involves the collection of pre-existing data, and confidential observations from nursing staff (secondary use of data).

2) Our request is also in keeping with the Health Information Act of Alberta, which states that pre-existing health information – such as that used in this proposed study – can be used for the purposes of research *without the individuals' consent*, as long as the research has been approved by a research ethics committee (please refer to page 4 of the enclosed Health Information Act Summary Document).

3) Finally, it is important to reiterate that this research project – with the proposed waiving of the requirement to obtain informed consent – has been given considerable review and approval by my entire research committee consisting of experienced researchers (Dr. Brad Hagen, Dr. Roland Ikuta, Dr. Chris Armstrong-Esther, and Dr. Mark Sandilands), and has also been given careful review and ethical approval by another Human Research Subjects Ethical Review Committee, at the University of Lethbridge. This committee, like all human subjects ethical review committees, granted its approval on the basis of the Tri-Council recommendations.

I would be grateful if the committee, in light of this new information, could please carefully review the requirement for informed consent from a legal guardian and/or agent with a personal directive for the purposes of this research proposal, so that this valuable research project may proceed.

I would also like to thank you and the committee for the support you have shown me and this important research project to date, and appreciate the opportunity to further discuss this project with the committee.

Sincerely,

Colin G. Zieber

cc: Dr. B. Hagen  
Dr. R. Ikuta  
Dr. C. Armstrong – Esther  
Dr. M. Sandilands



Appendix 6

Corporate Office  
960 – 19 Street South  
LETHBRIDGE, AB T1J 1W5  
Telephone (403)382-6009 / Fax 382-6011

---

**MEMORANDUM**

**TO:** Colin Zieber, Psychogeriatric Consultant, Community Outreach Team  
Brad Hagen, Associate Professor, School of Health Sciences, U of L

**FROM:** Paul Hasselback, M.D., M.Sc., F.R.C.P.C. *M*  
Chair, Research Committee

**DATE:** June 6, 2001

**RE:** The Relationship between Pain and Agitation in Long Term Care Residents  
with Moderate to Severe Dementia - Study

The CHR Research Committee reviewed the above named study at their meeting on June 5, 2001. Thank you for attending and providing input into the discussions.

The Committee approved the study, subject to clarification of the recruitment process and acceptance of both the CHR and U of L Ethics Committee

To ensure that we maintain up-to-date records of research ongoing within the organization, we would appreciate receiving an update in approximately four months after the initiation of the project. At that time you will receive communication from us requesting such an update.

On behalf of the research committee, I wish you well in the implementation of the study.

cc: Trudy Harbridge/ Donna Stelmachovich/ Dr. Roland Ikuta  
Marg Brewen/ Dr. Rob Wedel  
U of L research office

Appendix 7

# Memo

**To:** Colin Zieber, Health Sciences  
**From:** Margaret McKeen, Administrative Assistant, Research Services  
**Date:** June 15, 2001  
**Subject:** Human Subject Research Approval

Your Master's human subject research protocol entitled, "The relationship between pain and agitation in long-term care residents with moderate to severe dementia" has been approved on behalf of the Human Subject Research Committee.

Margaret McKeen  
Margaret McKeen  
Research Services

mm



Appendix 8

**CORPORATE OFFICE**

---

**CORPORATE OFFICE**

960 - 19 St. South  
Lethbridge, AB  
T1J 1W5  
Phone: (403) 382-6009  
Fax: (403) 382-6011

**CARDSTON**

Cardston Hospital  
Community Health Office  
Grandview Nursing Home

**COALDALE**

Community Health Office

**CROWSNEST PASS**

Crowsnest Pass Hospital  
Community Health Office

**FORT MACLEOD**

Fort Macleod Hospital  
Community Health Office  
Special Development Unit

**LETHBRIDGE**

Lethbridge Regional Hospital  
Community Health Offices  
Children's Centre

**MAGRATH**

Magrath Hospital  
Community Health Office

**MILK RIVER**

Milk River Hospital

**PICTURE BUTTE**

Picture Butte Health Centre  
Community Health Office

**PINCHER CREEK**

Pincher Creek Hospital  
Community Health Office

**RAYMOND**

Raymond Hospital  
Community Health Office

**TABER**

Taber Hospital  
Community Health Office

**VAUXHALL**

Community Health Office

**WARNER**

Community Health Office

September 21, 2001

Colin Zieber  
Graduate Student  
University of Lethbridge

Dear Mr. Zieber

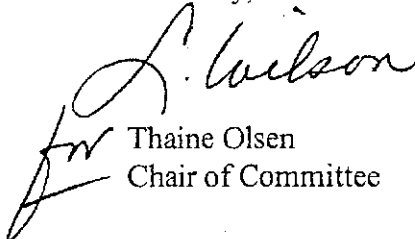
**Re: Relationship Between Pain and Agitation in Long Term Care Residents  
with Moderate to Severe Dementia**

Thank you for your presentation at the September 19<sup>th</sup>, 2001 Regional Ethics Committee meeting. I am pleased to confirm that the Committee made a motion to remove the proviso made in the motion at the June 20<sup>th</sup>, 2001 Ethics Committee meeting. This proviso read "that only those residents are recruited who have a duly appointed guardian or an agent pursuant to a properly enacted Personal Directive".

Attached is a list of the Committee members present at the September 19<sup>th</sup> meeting.

Good luck with this project.

Sincerely,



Thaine Olsen  
Chair of Committee



Appendix 10

Data Collection Worksheet: Pain and Agitation Study

1. **Participant Identifier #** : \_\_\_\_\_
2. CHR Facility Code    1 = CNP                      2 = Cardston                      3 = Taber
3. FAST Score (*Nurse A*)                      \_\_\_\_\_
4. FAST Score (*Nurse B*)                      \_\_\_\_\_
5. FAST Score (Average of A & B)                      \_\_\_\_\_
6. Gender:                      1 = Female                      2 = Male
7. Age    \_\_\_\_\_
8. Length of Stay (Months)    \_\_\_\_\_

**From MDS Assessment:** *[Based upon criteria outlined in Feldt, Warne, and Ryden (1998)].*

9. Arthritis                      1 = Yes                      0 = No
10. Osteoporosis                      1 = Yes                      0 = No
11. Hx of Hip #                      1 = Yes                      0 = No
12. Localized Pain                      1 = Yes                      0 = No
13. History of Cancer                      1 = Yes                      0 = No
14. Number of Pain Dx:    \_\_\_\_\_
15. Pain Rx (Reg)                      1 = Yes                      0 = No
16. Pain Rx (PRN)                      1 = Yes                      0 = No

Type of Pain Medication: [As outlined in Cramer, Galer, Mendelson, & Thompson (2000)]  
Regularly Scheduled and / or PRN in past 72 Hours

- |     |                             |         |        |
|-----|-----------------------------|---------|--------|
| 17. | Acetaminophen               | 1 = Yes | 0 = No |
| 18. | NSAID                       | 1 = Yes | 0 = No |
| 19. | Opioid Analgesic            | 1 = Yes | 0 = No |
| 20. | Opioid Equivalence          | _____   |        |
| 21. | Benzodiazepine Medications: | 1= Yes  | 0= No  |
| 22. | Antipsychotic Medications:  | 1= Yes  | 0= No  |
| 23. | Nurse A Pain Rating: _____  |         |        |

QUESTION: Using your professional judgement and considering your observations, please rate your assessment of the resident's pain level this shift according to the following scale:

- 1 = No Pain
- 2 = Slight Pain
- 3 = Mild Pain
- 4 = Moderate Pain
- 5 = Severe Pain
- 6 = Extreme Pain
- 7 = Pain as bad as it could be

24. Nurse B Pain Rating: \_\_\_\_\_

QUESTION: Using your professional judgement and considering your observations, please rate your assessment of the resident's pain level this shift according to the following scale:

- 1 = No Pain
- 2 = Slight Pain
- 3 = Mild Pain
- 4 = Moderate Pain
- 5 = Severe Pain
- 6 = Extreme Pain
- 7 = Pain as bad as it could be

25. Average Nurse A & B \_\_\_\_\_

**Pittsburgh Agitation Scale:** *[As outlined in Rosen et al. (1994)].*

**Nurse A:**

|     |                        |       |   |   |   |   |
|-----|------------------------|-------|---|---|---|---|
| 26. | Aberrant Vocalization: | 0     | 1 | 2 | 3 | 4 |
| 27. | Motor Agitation:       | 0     | 1 | 2 | 3 | 4 |
| 28. | Aggressiveness:        | 0     | 1 | 2 | 3 | 4 |
| 29. | Resisting Care:        | 0     | 1 | 2 | 3 | 4 |
| 30. | Total Rater #1:        | _____ |   |   |   |   |

**Nurse B:**

|     |                        |       |   |   |   |   |
|-----|------------------------|-------|---|---|---|---|
| 31. | Aberrant Vocalization: | 0     | 1 | 2 | 3 | 4 |
| 32. | Motor Agitation:       | 0     | 1 | 2 | 3 | 4 |
| 33. | Aggressiveness:        | 0     | 1 | 2 | 3 | 4 |
| 34. | Resisting Care:        | 0     | 1 | 2 | 3 | 4 |
| 35. | Total Rater #2:        | _____ |   |   |   |   |

36. **Average Aberrant Score:** \_\_\_\_\_

37. Average Motor Score: \_\_\_\_\_

38. Average Aggressive Score: \_\_\_\_\_

39. Average Resisting Care Score: \_\_\_\_\_

40. Average Totals: \_\_\_\_\_

41. Average from Nurse A & B: \_\_\_\_\_ (Questions 30 & 35)

Discomfort Scale – Dementia of the Alzheimer’s Type

*[As outlined in Hurley, Volicer, Hanrahan, Houde, and Volicer (1992)].*

**Nurse A:**

|     |                               |          |          |           |            |            |            |            |
|-----|-------------------------------|----------|----------|-----------|------------|------------|------------|------------|
| 42. | Noisy Breathing:              | 0        | 1        | 2         | 3          |            |            |            |
| 43. | Negative Vocalizations:       | 0        | 1        | 2         | 3          |            |            |            |
| 44. | Content Facial Expression:    | 0        | 1        | 2         | 3          |            |            |            |
| 45. | Sad Facial Expression:        | 0        | 1        | 2         | 3          |            |            |            |
| 46. | Frightened Facial Expression: | 0        | 1        | 2         | 3          |            |            |            |
| 47. | Frown:                        | 0        | 1        | 2         | 3          |            |            |            |
| 48. | Relaxed Body Language:        | 0        | 1        | 2         | 3          |            |            |            |
| 49. | Tense Body Language:          | 0        | 1        | 2         | 3          |            |            |            |
| 50. | Fidgeting:                    | 0        | 1        | 2         | 3          |            |            |            |
| 51. | Total Nurse A:                | _____    |          |           |            |            |            |            |
|     | Total Calculated              | 1= 0 - 3 | 2= 4 - 7 | 3= 8 - 11 | 4= 12 - 15 | 5= 16 - 19 | 6= 20 - 23 | 7= 24 - 27 |

**Nurse B:**

|     |                               |       |   |   |   |
|-----|-------------------------------|-------|---|---|---|
| 52. | Noisy Breathing:              | 0     | 1 | 2 | 3 |
| 53. | Negative Vocalizations:       | 0     | 1 | 2 | 3 |
| 54. | Content Facial Expression:    | 0     | 1 | 2 | 3 |
| 55. | Sad Facial Expression:        | 0     | 1 | 2 | 3 |
| 56. | Frightened Facial Expression: | 0     | 1 | 2 | 3 |
| 57. | Frown:                        | 0     | 1 | 2 | 3 |
| 58. | Relaxed Body Language:        | 0     | 1 | 2 | 3 |
| 59. | Tense Body Language:          | 0     | 1 | 2 | 3 |
| 60. | Fidgeting:                    | 0     | 1 | 2 | 3 |
| 61. | Total Nurse B:                | _____ |   |   |   |

Total Calculated

- 1= 0 - 3
- 2= 4 - 7
- 3= 8 - 11
- 4= 12 - 15
- 5= 16 - 19
- 6= 20 - 23
- 7= 24 - 27

Nurse A & B

|     |                                       |       |   |   |   |
|-----|---------------------------------------|-------|---|---|---|
| 62. | Average Noisy Breathing:              | 0     | 1 | 2 | 3 |
| 63. | Average Negative Vocalizations:       | 0     | 1 | 2 | 3 |
| 64. | Average Content Facial Expression:    | 0     | 1 | 2 | 3 |
| 65. | Average Sad Facial Expression:        | 0     | 1 | 2 | 3 |
| 66. | Average Frightened Facial Expression: | 0     | 1 | 2 | 3 |
| 67. | Average Frown:                        | 0     | 1 | 2 | 3 |
| 68. | Average Relaxed Body Language:        | 0     | 1 | 2 | 3 |
| 69. | Average Tense Body Language:          | 0     | 1 | 2 | 3 |
| 70. | Average Fidgeting:                    | 0     | 1 | 2 | 3 |
| 71. | Average Total:                        | _____ |   |   |   |

Total Calculated

1= 0 - 3

2= 4 - 7

3= 8 - 11

4= 12 - 15

5= 16 - 19

6= 20 - 23

7= 24 - 27

**Palliative Consultant Questions:**

72. Based on the information presented to you, do you think that you have previous clinical involvement with this client?

Yes = 1

No = 0

Question: Based on the client information presented to you, please use your professional judgement to rate the pain experienced by the client.

73. Palliative A Rating: \_\_\_\_\_

- 1 = No Pain
- 2 = Slight Pain
- 3 = Mild Pain
- 4 = Moderate Pain
- 5 = Severe Pain
- 6 = Extreme Pain
- 7 = Pain as bad as it could be

74. Based on the information presented to you, do you think that you have previous clinical involvement with this client?

Yes = 1

No = 0

75. Palliative B Rating: \_\_\_\_\_

- 1 = No Pain
- 2 = Slight Pain
- 3 = Mild Pain
- 4 = Moderate Pain
- 5 = Severe Pain
- 6 = Extreme Pain
- 7 = Pain as bad as it could be

76. Based on the information presented to you, do you think that you have previous clinical involvement with this client?

Yes = 1

No = 0

77. Palliative C Rating: \_\_\_\_\_

1 = No Pain

2 = Slight Pain

3 = Mild Pain

4 = Moderate Pain

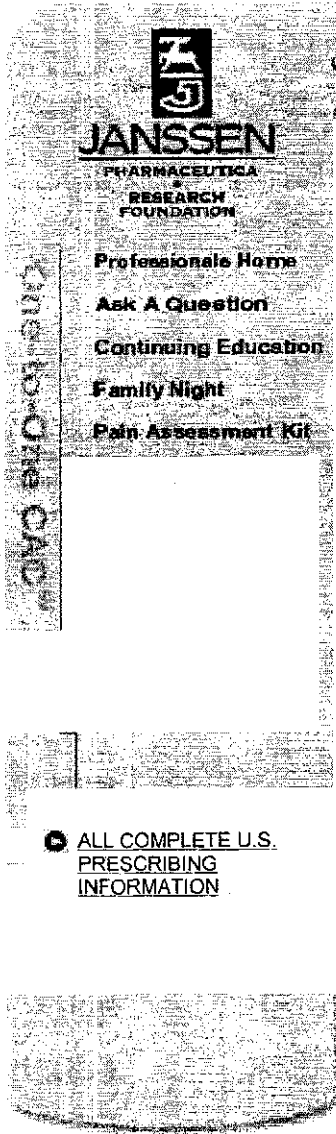
5 = Severe Pain

6 = Extreme Pain

7 = Pain as bad as it could be

78. Average Palliative A, B, & C: \_\_\_\_\_

Appendix 11



▶ Long-Term Care Pain Assessment Tool

**Verbal Description**

Select the words on the scale that best describes the pain  
An additional browser window will display the selected scale to print.

|         |             |           |               |             |              |                            |
|---------|-------------|-----------|---------------|-------------|--------------|----------------------------|
| No pain | Slight pain | Mild pain | Moderate pain | Severe pain | Extreme pain | Pain as bad as it could be |
|---------|-------------|-----------|---------------|-------------|--------------|----------------------------|

**Privacy Policy | Legal Notices**

[About Janssen](#) [Janssen News](#) [Products](#) [Career Opportunities](#) [Feedback](#) [Sitemap](#)  
© Janssen 2000. This site originates in the United States.



## Appendix 12

### \* PITTSBURGH AGITATION SCALE

Please Use Scoring Sheet

Circle only the highest intensity score for each behaviour group that you observed during this rating period. Use the anchor points as a guide to choose a suitable level of severity. (Not all anchor points need be present. Choose more severe level when in doubt).

#### BEHAVIOUR GROUPS

##### Aberrant Vocalization

(repetitive requests or complaints, non-verbal vocalizations, e.g., moaning, screaming)

##### Motor Agitation

(Pacing, wandering, moving in chair, picking at objects, disrobing, banging on chair, taking other's possessions. Rate "intrusiveness" by normal social standards, not by effect on other patients in milieu. If "intrusive" or "disruptive" due to noise, rate under "Vocalization".)

##### Aggressiveness

(Score "0" if aggressive *only* when resisting care)

##### Resisting Care

(Circle associated activity)

Washing

Dressing

Eating

Meds

Other \_\_\_\_\_

Were any of the following used during this rating period because of behaviour problems?  
(Circle interventions used)

Seclusion

PRN meds (specify)

Restraint

Other interventions \_\_\_\_\_

#### INTENSITY DURING RATING PERIOD

0. Not present
1. Low volume, not disruptive in milieu, including crying
2. Louder than conversational, mildly disruptive, redirectable
3. Loud, disruptive, difficult to redirect
4. Extremely loud, screaming or yelling, highly disruptive, unable to redirect

0. Not present
1. Pacing or moving about in chair at normal rate (appears to be seeking comfort, looking for spouse, purposeless movements)
2. Increased rate of movements, mildly intrusive, easily redirectable
3. Rapid movements, moderately intrusive or disruptive, difficult to redirect
4. Intense movements, extremely intrusive or disruptive, not redirectable verbally

0. Not present
1. Verbal threats
2. Threatening gestures; no attempt to strike
3. Physical toward property
4. Physical toward self or others

0. Not present
1. Procrastination or avoidance
2. Verbal gesture of refusal
3. Pushing away to avoid task
4. Striking out at caregiver

\* Reproduced from Rosen et al. (1994). The Pittsburgh Agitation Scale; A user-friendly instrument for rating agitation in dementia patients. *The American Journal of Geriatric Psychiatry*, 2, 52 – 61, with permission for clinical and research purposes.