

PAIN AND PAIN MANAGEMENT IN A MEDICAID WAIVER PROGRAM

By

Elizabeth Annette Byma

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ABSTRACT

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Background/Purpose: Poor older adults are a vulnerable population at increased risk for cancer, pain, poor pain management and pain management outcomes. There is no known research that has examined the differences in pain, pain management and pain management outcomes or the transfer of HCBWP participants to nursing homes between persons with and without a diagnosis of cancer among Medicaid-enrolled, older adults participating in Home and Community-Based Waiver programs (HCBWP). Research examining pain, pain management and pain management outcomes among older adults has been cross-sectional. Longitudinal research would be better able to examine the associations among pain, pain management and pain management outcomes overtime and how pain, pain management and pain management outcomes associate with the admission of older adult HCBWP participants to nursing homes.

Conceptual Model: Based on the Symptom Management Theory, the pain experience, pain management strategies and pain management outcomes are associated with the domains of person and health and illness. The pain experience, pain management strategies, pain management outcomes and domains of person and health and illness are conceptualized as impacting the admission of older adult HCBWP participants to nursing homes.

Methods: The study was a secondary analysis of data from the Minimum Data Set Home Care (MDS-HC), the State of Michigan Cancer Surveillance Data and Michigan Medicaid paid claims files and was of a longitudinal design. The sample was comprised of 4054 older adult HCBWP participants Generalized Estimating Equations, logistic regression and survival analysis methods were used.

Results: Older adult HCBWP participants who were female, had a higher comorbid conditions score or higher score for behaviors indicative of depression were more likely to experience daily pain over time. Older adult HCBWP participants who were African American, older age, or cognitively impaired were less likely to report daily pain over time. Cancer was not associated with daily pain over assessment time points. Older adult HCBWP participants with daily pain and in the initial phase of diagnosis of cancer were less likely to be prescribed non-opioid pain medications and adjuvant pain medications than older adult HCBWP participants without daily pain. Pain, age, race, sex, cognitive functioning, behaviors indicative of depression and comorbid conditions were associated over time with prescribed pain medications and physical functions. Behaviors indicative of depression was significantly associated with perceived pain control, such that as the measure of behaviors indicative of depression increased, the likelihood of pain control occurring decreased. Finally, diagnosis of cancer was not significantly associated with admission to a nursing home. Older adult HCBWP participants with daily pain were less likely to be admitted to a nursing home. Older adult HCBWP participants who had a higher measure of comorbid conditions, were cognitively impaired or were white had an increased hazard of being admitted to a nursing home.

Conclusion: Diagnosis of cancer was not significantly associated with the pain experience, pain management outcomes and admission to a nursing home among older adult HCBWP participants and a limited association with prescribed pain medications. The prescription of pain medication was most consistently associated with the measure of pain. Pain had a negative association with the admission of older adult HCBWP participants to a nursing home and a positive association with physical functioning over time.

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Dedication

This dissertation is dedicated to my family:

My dear husband Gary and our two precious children Maggie and Aaron, my parents, my sisters and their families: I could not have completed this dissertation or any of the doctoral program without your constant love, encouragement and support.

A special dedication in memory of my mother-in-law Ann Lillian Werkema Byma, R.N. Her prayers and pride in my accomplishments meant the world to me. She was so proud to be a registered nurse, and was still interested in all matters nursing long after she gave up her career to be a pastor's wife and mother of five.

I wish she was still here to see me complete this dissertation and graduate.

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Chapter 1

The proportion of the United States population that is 65 and older will increase from 12.4% in 2007 to 20% in 2030 (Administration on Aging, 2007). Older adults are at increased risk of developing cancer when compared to younger populations as more than 60% of cancers diagnosed and 70% of cancer-related deaths occur in older adults (Bourbonniere & Van Cleave, 2006; Yancik & Ries, 2000). Therefore, the impending increase in the size of the older adult population will likely bring a marked increase in the number of persons diagnosed with cancer as well as cancer survivors (Erikson, Salsberg, Forte, Bruinooge, & Goldstein, 2007; Smith, Smith, Hurria, Hortobagyi, & Buchholz, 2009).

An increased number of older adults with cancer or surviving cancer will result in an increase in older adults experiencing pain related to cancer or its treatment. Research has found that older adults with cancer are more likely to experience pain when compared to older adults without cancer (Buchanan, Barkley, Wang, & Kim, 2005; Reyes-Gibby, Aday, Todd, Cleeland, & Anderson, 2007; Rodin, 2008). The presentation of pain among older adults, however, is much more complicated than simply if one does or does not have cancer. Pain occurs in older adults not only because of cancer and its treatment, but also because of the presence of comorbid conditions that are commonly associated with increased age and pain such as arthritis, diabetes and peripheral vascular disease (Bruckenthal & D'Arcy, 2007; Davis & Srivastava, 2003; Freedman, 2002).

The presence of comorbid conditions not only causes pain among older adults but also hinders the resolution of pain due to provider reluctance to manage pain aggressively due to fears of opioid side effects and drug interactions with medications prescribed for comorbid conditions (Duncan, Forbes-Thompson, & Bott, 2008; Goldstein & Morrison, 2005; McNeill,

Reynolds, & Ney, 2007). Pain management among older adults may be hampered by the reluctance of older adults to report pain as well as cognitive impairment which inhibits the production of and assessment of verbal reports of pain (Delgado-Guay & Bruera, 2008; Goldstein & Morrison, 2005). In summary, older adults are at risk of pain due to the increased presence of cancer and other diseases that are associated with pain (Bruckenthal & D'Arcy, 2007; Davis & Srivastava, 2003; Freedman, 2002). Older adults who experience pain are at risk for perceiving that their pain is not assessed and managed appropriately for a variety of patient and system-related reasons and are therefore likely to experience poor pain management outcomes (American Geriatrics Society Panel on Persistent Pain in Older Persons, 2002).

Poor pain management outcomes among older adults include anxiety, depression, decreased social interaction, sleep disturbances, impaired physical function, agitation, delirium, decreased appetite, delayed healing, lower quality of life and higher health care utilization and costs (American Geriatrics Society Panel on Persistent Pain in Older Persons, 2002). Pain is a frequent deterrent to quality of life among older adults (Deane & Smith, 2008) and therefore, pain, pain management and pain management outcomes among older adults are important for health care providers and researchers to address.

Previous research studies that have examined the issues of pain, pain management and pain management outcomes among older adults have several limitations that the study will address. First, the research has been primarily focused on community-dwelling and nursing home settings and has not fully examined pain, pain management and pain management outcomes in other older adult populations (Bryant, Grigsby, Swenson, Scarbro, & Baxter, 2007; Shega, Hougham, Stocking, Cox-Hayley, & Sachs, 2006; Walke, Byers, McCorkle, & T.R., 2006; Won et al., 2004; Zyczkowska, Szczerbinska, Jantzi, & Hirdes, 2007). An alternative to nursing home

placement for older adults is the Medicaid Home and Community Based Waiver Program (HCBWP). The HCBWP allows Medicaid-eligible older adults to receive care services in their homes instead of being admitted to a nursing home for similar care services. Services covered under waiver programs may include homemaker services, respite care, adult day care, environmental modifications, transportation, medical supplies, personal emergency response system, private duty nurse, counseling, home delivered meals, physical and occupational therapy and personal care supervision (Shugarman, Fries, & James, 1999). Despite prevalence of pain among HCBWP participants of 53-69% (Fries, James, & Aliaga, 2004; L. Li & Conwell, 2007) very little else is known about pain, pain management and pain management outcomes among older adult HCBWP participants or differences between pain, pain management and pain management outcomes among older adult HCBWP participants with and without a diagnosis of cancer.

The issues of pain, pain management and pain management outcomes among older adult HCBWP participants and differences in pain, pain management and pain management outcomes between older adult HCBWP participants with and without a diagnosis of cancer are of concern to nursing. Because of their Medicaid eligibility, HCBWP participants are assumed to be impoverished and poverty is associated with an increased risk of developing cancer as well as experiencing poor pain management (Green et al., 2003; Ward et al., 2004b). Therefore, not only are older adult HCBWP participants at risk of pain, poor pain management and cancer because of their increased age, they are also considered at risk of pain and cancer due to their poverty. As such, older adult HCBWP participants are at risk for pain and poor pain management and poor pain management outcomes “above and beyond” other older adults. Research is needed to examine pain, pain management strategies and pain management outcomes in this older adult

population as well as differences in pain, pain management strategies and pain management outcomes between HCBWP participants with and without a diagnosis of cancer.

A second limitation in previous research that has examined pain, pain management and pain management outcomes among older adults is that previous research has been primarily cross-sectional (Jakobsson, Klevsgard, Westergren, & I.R., 2003; Walke, et al., 2006; Won, et al., 2004; Zyczkowska, et al., 2007). Pain, pain management and pain management outcomes have strong temporal (time-related) components and occur as a series of events (Henly, Kallas, Klatt, & Swenson, 2003). Temporal aspects of pain consist of variation of pain over time, how frequently pain occurs, as well as the duration of pain (Jensen, 2003). Pain management can include either short or long-acting pain medications, treating pain that may be either sporadic or continuous across time (American Pain Society, 2005; NCI, 2010b). Pain management outcomes are the end results of care (Patrick, 1997) and are assessed after the provision of pain management interventions (Humphreys & et al., 2008). The assessment of pain management outcomes is timed to occur after an intervention has had an effect. For example, pain management guidelines recommend that the level of pain is reassessed after a dose of pain medication has had time to act, based on pharmacokinetics (American Pain Society, 2005; NCCN, 2010; NCI, 2010b). In summary, pain, pain management and pain management outcomes occur over time and therefore, longitudinal research may be a better choice than cross-sectional research to examine relationships among pain, pain management and pain management outcomes over time among older adults with and without a diagnosis of cancer.

Healthcare services for older adults can be viewed as a continuum, moving from community to institutionalization (L. Li & Zullo, 2003; Williams, 2001). Longitudinal research will allow for analyses of how pain, pain management and pain management outcomes may

influence the admission of older adult HCBWP participants to nursing homes. As the goal of the HCBWP is to prevent or delay nursing home admission (Fries, Shugarman, Morris, Simon, & James, 2002), knowledge gained about the impact of pain, pain management and pain management outcomes on the admission of older adults to nursing homes and differences between participants with and without a diagnosis of cancer would be beneficial for guiding the development of care strategies for assisting older adults in staying in the community and avoiding institutionalization.

In this study, associations between pain, pain management and pain management outcomes among older adult HCBWP participants with and without cancer over time in the HCBWP were systematically explored. Additionally, an analysis of the influence of pain, pain management and pain management outcomes on the admission of older adult HCBWP participants to a nursing home was completed.

The purpose of Chapter 1 was to provide a brief overview of the pain, pain management and pain management outcomes experienced by older adult, HCBWP participants aged 65 and older as an introduction to the study. Differences in pain, pain management, and pain management outcomes among older adults with and without a diagnosis of cancer will be described. An overview of the predictors of admission to a nursing home will be presented. Research questions developed from this overview and a synopsis of the proposal will be presented at the conclusion of this chapter.

Pain among Older Adults

Pain is "...an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage" (International Association for the Study of Pain, 2009, para. 36). Pain is highly subjective, being "...whatever the experiencing

person says it is, existing whenever he/she says it does” (McCaffery & Beebe, 1989, p. 7)

Individual-related characteristics contribute to the multidimensional nature of pain (American Pain Society, 2005; Armstrong, 2003; Dodd et al., 2001; Humphreys & et al., 2008) and are associated with the experience of pain among older adults.

Individual characteristics such as sex and race assist in explaining differences in the pain among older adults. Female older adults are more likely to experience pain than males (Reyes-Gibby, Aday, et al., 2007; Soldato et al., 2007; Thomas, Peat, Harris, Wilkie, & Croft, 2004). Regarding race, while Horgas, Yoon, Nichols and Marsiske (2008) found no difference in pain presence, intensity, locations and durations between black and white older, community dwelling older adults, Teno, Kabumoto, Wetle, Roy and Mor (2004) reported that African American nursing home residents were less likely to experience daily, excruciating pain than white nursing home residents. In comparison, Reyes-Gibby, Aday and Cleeland (2002) found that among community-dwelling older adults, more Hispanics than Whites, Blacks and American Indians were often bothered by pain. Additional research is needed to clarify associations between race and pain among older adults.

Differences in pain among older adults may be explained in part by age-related changes in nerve physiology and function, resulting in diminished endogenous opioid mechanisms and pain modulation (R. R. Edwards, Fillingim, & Ness, 2003; Washington, Gibson, & Helme, 2000), reduced tolerance of and increased response to higher intensity experimental pain stimuli (Gibson & Helme, 2001) and slower resolution of post-injury hyperalgesia (increased sensitivity to pain) (Zheng, Gibson, & Helme, 2000). Therefore, the neuro-physiological changes older adults experience may lead to an increased and prolonged response to injury and pain stimuli, thereby placing older adults at risk of pain that persists or in need of extended pain management.

Another health-related characteristic of older adults associated with pain is the presence of conditions associated with pain. Depression is comprised of both emotional and physical symptoms, with pain as a physical symptom (Delgado, 2004). Therefore, depression may be a possible source of pain among older adults and associations between pain and depression must be accounted for in research examining pain among older adults. In addition to depression being a possible source of pain, depression and pain are associated with one another such that an increased number of depressive symptoms has been shown to predict worsening levels of pain among community dwelling older adults (Rosso, Gallagher, Lubrosky, & Mossey, 2008). Older adults with pain are more likely to have recognized depression (L. Li & Conwell, 2007), have a higher rate of developing a new onset of depression and have a slower resolution of depression than older adults without pain (Geerlings, Twisk, Beekman, Deeg, & van Tilburg, 2002). Therefore, pain is associated with depression among older adults, with the presence of one increasing the likelihood of occurrence and worsening the prognosis of the other (Geerlings, et al., 2002; L. Li & Conwell, 2007).

Physical conditions associated with pain, such as arthritis, diabetes and cancer are more likely to occur in older adults than in younger populations and place older adults at risk for pain (Bruckenthal & D'Arcy, 2007; Davis & Srivastava, 2003; Freedman, 2002). For example, diabetes may contribute to demyelization of peripheral nerves from decreased blood supply which may result in ectopic and spontaneous nerve discharges (Backonja, 2003; Pasero, 2004). Arthritis is common among older adults, affecting about 50% of community-dwelling older adults (Blyth et al., 2008; Zyczkowska, et al., 2007) with over half of older adults with arthritis reporting pain (Reyes-Gibby, et al., 2002). The effect of comorbid conditions on pain is not only singular, i.e. the specific effect of a disease, such as diabetes on pain, but also one of the

combined effect of multiple comorbid conditions, with a higher number of comorbid conditions associated with an increased presence of pain (Mao et al., 2007; Reyes-Gibby, Aday, et al., 2007). The additional effect of comorbid conditions on cancer is a specific concern in regards to older adults, as a diagnosis of cancer is likely to be made in the context of pre-existing health conditions (Yancik, Ganz, Varricchio, & Conley, 2001).

Unfortunately, older adults bear a disproportionate burden of cancer in the United States (Yancik, et al., 2001). Older adults comprise 60% of the population of persons diagnosed with cancer (Yancik & Ries, 2000) and are more likely to have pain at the time of diagnosis than younger populations (Freedman, 2002; McNeill, et al., 2007). Pain has been noted to be one of the most distressing symptoms in patients with cancer (Laird, Colvin, & Fallon, 2008; Valeberg et al., 2008). Pain may occur due to the cancer itself or to its treatment (Chang, Janjan, Jain, & Chau, 2006). For example, a tumor may compress a nerve and cause pain, or chemotherapy may alter nerve function, resulting in pain. Older adults with cancer are more likely to experience pain when compared to older adults without a history of cancer in both community and nursing home settings (Buchanan, et al., 2005; Reyes-Gibby, Aday, et al., 2007; Rodin, 2008). In summary, cancer, depression and the presence of other comorbid conditions increase the risk of pain among older adults.

While comorbid conditions common to older adults place older adults at risk of pain, the presence of cognitive impairment lessens the likelihood that the presence of pain among older adults is recognized (Procter & Hirdes, 2001; Reynolds, Hanson, DeVellis, Henderson, & Steinhauser, 2008; Sengupta, Bercovitz, & Harris-Kojetin, 2010). The presence of pain is acknowledged by a patient's verbal report of pain or pain-related behaviors made by the patient in response to stimuli perceived to be painful (NANDA, 2005; Sykes, Fallon, & Patt, 2003).

Cognitive impairment may diminish the ability of patient to verbally report pain (Bruckenthal, 2008; Helme & Gibson, 2001) and may therefore result in less pain being reported among older adults. Pain prevalence among cognitively impaired older adults is routinely less than pain prevalence among cognitively intact older adults, after controlling for diseases known to likely produce pain (Procter & Hirdes, 2001; Reynolds, et al., 2008; Sengupta, et al., 2010). In summary, older adults with cognitive impairments are less likely than cognitively intact older adults to be able to make verbal reports of pain and therefore, less pain is attributed to cognitively impaired older adults than cognitively intact older adults.

In conclusion, individual characteristics such as sex, race, age and presence of depression, cancer, comorbid conditions and cognitive impairment are associated with pain among older adults and influence the production and perception of pain as well as the ability of the patient to report pain. The patient report of pain or pain behaviors are then used for the pain assessment. As the goal of pain assessment is to direct pain management, an inadequate pain assessment will contribute to poor pain management among older adults.

Pain Management among Older Adults

Pain management begins with pain assessment (Dodd, et al., 2001). Because the assessment of pain is primarily based on a person's verbal self-report of pain, characteristics unique to older adults may affect the self-report of pain, resulting in under-reporting of pain among older adults (Bruckenthal, 2008; Helme & Gibson, 2001) resulting in inadequate pain management. Older adults may expect pain to be part of aging and disease processes and therefore, may underreport their pain (Delgado-Guay & Bruera, 2008; Goldstein & Morrison, 2005). Age and disease-related changes in the production and sensation of pain may influence the older adult's perception of painful stimuli and alter the older adult's ability to accurately

convey reports of pain. (Bruckenthal, 2008; Gibson & Helme, 2001). Pain may be challenging for healthcare providers to accurately assess in older adults with cognitive changes or communication difficulties if pain-related behaviors must be assessed in place of verbal reports of pain (Delgado-Guay & Bruera, 2008; Goldstein & Morrison, 2005). Assessments of pain prevalence among cognitively impaired older adults are routinely less than pain prevalence among cognitively intact older adults, after controlling for diseases known to likely produce pain (Procter & Hirdes, 2001; Reynolds, et al., 2008). In summary, characteristics of older adults may result in underreported pain and a poorer pain assessment. Pain management is based on pain assessment and if the pain assessment is poor, pain management may therefore be poor as well.

Older adults are at risk for inadequate pain management (American Geriatrics Society Panel on Persistent Pain in Older Persons, 2002; Landi et al., 2001). Older adults often have complex clinical presentations of symptoms, including pain, as they may have multiple, co-occurring chronic diseases (Duncan, et al., 2008; Goldstein & Morrison, 2005; McNeill, et al., 2007). Health care providers may have concerns about pain medication interactions with other medications prescribed for chronic diseases and may limit their pain medication prescribing patterns, negatively affect a patient's pain management (Duncan, et al., 2008; Goldstein & Morrison, 2005; McNeill, et al., 2007). Providers may be more concerned about opioid side-effects in older adults and may therefore not prescribe opioids to older adults (Duncan, et al., 2008; Goldstein & Morrison, 2005; McNeill, et al., 2007). As noted in the previous section, cognitively impaired older adults report less pain than cognitively intact older adults (Procter & Hirdes, 2001; Reynolds, et al., 2008). Cognitive impairment impacts not only the reporting and therefore the assessment of pain, but also pain medication use among older adults with cognitive

impairment. Older adult nursing home residents with cognitive impairment and pain receive less pain medications when compared to cognitively intact older adult nursing home residents with pain (Reynolds, et al., 2008).

In addition to the prescribing of medication by clinicians for pain management, hospice services are also used among older adults for pain management and palliative care. Hospice, as a health care service provider, provides palliative rather than curative care and coordinates the provision of medical, emotional and spiritual care for terminally ill patients (life expectancy of less than 6 months) and their families (Hospice Association of America, 2006). Although hospice services are often associated with cancer care, older adults with other terminal diseases (heart failure, chronic obstructive pulmonary disease (COPD) and dementia and Alzheimer disease) may also receive hospice services for symptom management (Locher, Kilgore, Morrissey, & Ritchie, 2006; Rodin, 2008).

The provision of hospice services can take place in the home, nursing homes, hospitals or hospice centers (Hospice Association of America, 2006). Only a small percentage of older adult nursing home residents who would benefit from hospice services receive them (Buchanan, et al., 2005; Duncan, et al., 2008). Despite its limited use in nursing homes, hospice services has been shown to provide high quality end of life care and result in positive outcomes, such as reduced hospitalizations and improved pain management (Stevenson & Bramson, 2009). There is no known research which has examined the provision of hospice services within a HCBWP or associations between the pain experience and hospice services. As HCBWP are an alternative to nursing home care, knowledge is needed regarding the use of hospice services among older adults and to make comparisons regarding hospice use between HCBWP participants with and without cancer.

In conclusion, older adults are at high risk for poor pain management and limited hospice service use. Pain management among older adults is influenced by both characteristics unique to older adults that affect patient reporting of pain and assessment of pain and therefore the ability of healthcare providers to manage pain and complex clinical presentation of older adults with comorbid conditions. Pain that is poorly managed may result in poor pain management outcomes.

Pain Management Outcomes among Older Adults

Pain management outcomes consist of the end results of pain management. In research literature, pain control is an outcome of interventions directed toward pain and equated with a decrease in or improvement of pain levels, functional impairments and frequency due to pain interventions (Christine Miaskowski et al., 2002; Oliver, Kravitz, Kaplan, & Meyers, 2001; Shvartzman et al., 2003). Research examining pain management among older adults in both community and nursing home settings has noted that pain is poorly controlled due to under assessment and treatment (Landi, et al., 2001; Teno, et al., 2004; Won, et al., 2004). In summary, pain control is an outcome of pain management and equated with a decrease in or improved values of pain severity levels, functional impairments and frequency due to pain interventions (Christine Miaskowski, et al., 2002; Oliver, et al., 2001; Shvartzman, et al., 2003) and among older adults, pain is poorly controlled (Teno, et al., 2004; Won, et al., 2004).

Outcomes of pain management include the measure of physical function, as a goal of pain management is improvement of physical functioning (Turk et al., 2003). Physical functioning is the physical ability of a person to engage in various activities, ranging from simple mobility to complex activities requiring adaptation to the environment (Bennett, Winters-Stone, & Nail, 2006). Pain has been shown to have a significant, negative effect on physical

functioning and activities of daily living among older adults (Bryant, et al., 2007; Helme & Gibson, 2001; Onder et al., 2006; Reyes-Gibby, et al., 2002; Soldato, et al., 2007). Among older adults with cancer, pain, fatigue and insomnia were significant and independent predictors of a change in physical functioning from pre-diagnosis physical functioning levels to 8 weeks after initial treatment (B. Given, Given, Azzouz, & Stommel, 2001). Adult long-term cancer survivors 55 and older, with long-term survivorship defined as diagnosed more than 4 years prior, were more likely than adults 55 and older without a diagnosis of cancer to experience pain and diminished mobility and activity of daily living limitations (Keating, Norredam, Landrum, Huskamp, & Meara, 2005). In summary, pain is a predictor of change in physical functioning among older adults in general and older adults with cancer receiving cancer treatment. Aging adults with cancer are more likely than aging adults without a diagnosis of cancer to have diminished physical function. Thus, pain and differences between older adults with and without a diagnosis of cancer is important to address and manage as pain management may preserve and/or improve the physical function of older adults.

In conclusion, older adults are at risk of poor pain management outcomes. Pain management outcomes include pain control and physical function. Older adults with pain are at risk for poor pain control and diminished physical functioning.

Significance of Study

Older adults, aged 65 and above are at risk for experiencing pain, poor pain management and poor pain management outcomes (American Geriatrics Society Panel on Persistent Pain in Older Persons, 2002; Landi, et al., 2001). For the purpose of this study, older adults are adults 65 and older, as 65 is the age at which adults are eligible for Medicare services (Centers for Medicare & Medicaid Services, 2008). Older adults are at risk for experiencing pain as diseases

often associated with pain, such as arthritis, diabetes and cancer which occur at higher rates in older populations (Bruckenthal & D'Arcy, 2007; Davis & Srivastava, 2003; Freedman, 2002). Older adults with cancer are more likely to experience pain when compared to older adults without a history of cancer in both community and nursing home settings (Buchanan, et al., 2005; Reyes-Gibby, Aday, et al., 2007; Rodin, 2008). Older adults are at risk for poor pain management due to inadequate recognition and treatment of pain caused by diminished patient cognitive performance, patient beliefs in pain being part of aging and provider fear of opioid side-effects and medication interactions (Bruckenthal, 2008; Delgado-Guay & Bruera, 2008; Duncan, et al., 2008). Pain and poor pain management are frequent and powerful deterrents to quality of life in older adults (American Geriatrics Society Panel on Persistent Pain in Older Persons, 2002; Deane & Smith, 2008).

The importance of research addressing pain, pain management and pain management outcomes has been noted by nursing leadership and U.S. government research agencies (American Nurses Association, 2010; National Institute of Nursing Research, 2006a, 2006b). Historically, nurses have been responsible for providing comfort and alleviating suffering from pain. The nursing profession's focus on the alleviation of pain continues to be at the forefront of practice and research directives. Nurses are to address issues such as physical comfort, discomfort and pain via nursing interventions (American Nurses Association, 2010). Research examining pain had been prioritized by the National Institute of Nursing Research (NINR) in order to improve patient quality of life (National Institute of Nursing Research, 2006a, 2006b). The NINR has emphasized research addressing the elimination of disparities to ensure that all persons benefit from health care strategies (National Institute of Nursing Research, 2006b) such as pain management. Older adult HCBW participants experience disparities in regards to pain

due to their poverty and therefore, an increased risk of cancer, pain, poor pain management and poor pain management outcomes (Green, et al., 2003; Ward et al., 2004a). Finally, the Institute of Medicine has noted that addressing the physical comfort needs of patients is an important component of patient centered care, which should be a primary focus of health care providers (Institute of Medicine, 2001).

In summary, the importance of this research which addresses longitudinal associations of pain, pain management and pain management outcomes among older adult HCBWP participants and differences in pain, pain management and pain management outcomes between older adults HCBWP participants with and without a diagnosis of cancer, is supported. The research also examines the impact of pain, pain management and pain management outcomes on the admission of older adult HCBWP participants to a nursing home.

The results of this descriptive research will contribute to science by providing information regarding the pain experience, pain management strategies and pain management outcomes of a vulnerable and at-risk population that has not been thoroughly examined: poor older adults with and without cancer. The results of this research can then serve to inform policies regarding the assessment of pain, the provision and reimbursement of pain management strategies as well as the quality of care received in HCBWPs in order to prevent or delay nursing home placement among older adult HCBWP participants.

Research Questions

The following research questions were developed to be addressed in this longitudinal research study.

- 1) How does the pain experience differ between older adult HCBWP participants in regards to diagnosis of cancer over time? How is the relationship between the pain experience

and diagnosis of cancer affected by sex, age, race, comorbid conditions, depression and cognitive functioning over time?

- 2) How does the pain experience of older adult, HCBWP participants relate to pain management strategies and pain management outcomes and how does this relationship differ in regards to diagnosis of cancer over time? How is the relationship between the pain experience, pain management strategies, pain management outcomes and diagnosis of cancer affected by sex, age, race, comorbid conditions, depression and cognitive functioning over time?
- 3) How do the pain experience, pain management strategies and pain management outcomes of older adult, HCBWP participants predict the admission and time to admission of older adult HCBWP participants to a nursing home over time and how does this relationship differ in regards to diagnosis of cancer while accounting for sex, age, race, comorbid conditions, depression and cognitive functioning?

Purpose of Study

The primary purpose of this study is to examine longitudinal differences in the pain experience, pain management strategies and pain management outcomes among older HCBWP participants with respect to diagnosis of cancer while participating in the HCBWP. The secondary purpose of this study is to determine what differences exist in how the pain experience, pain management strategies and pain management outcomes among older adult, HCBWP participants associates with the admission of older adult HCBWP participants to a nursing home, with respect to diagnosis of cancer, over the course of time while participating in the HCBWP. This study will not determine if pain experienced by HCBWP participants is acute,

chronic, or cancer-related as this is beyond the scope of the project and of the dataset that will be used. Instead, pain is viewed in general terms, encompassing all types of pain.

Following the previous overview, in Chapter 2, the revised symptom management model (Dodd, et al., 2001; Humphreys & et al., 2008) will be discussed and conceptual definitions for each variable provided. In Chapter 3, a review of the literature describing pain, pain management, pain management outcomes and predictors of nursing home admission, as well as the influence of cancer, among older adults will be presented. Study methods and planned analysis will be described in Chapter 4. Research findings are presented in Chapter 5. Implications for clinical practice, study limitations and future direction for nursing research based on this research are discussed in Chapter 6.

Chapter 2

The purpose of Chapter 2 is to present the conceptual model that was developed for this study as well as provide definitions for the concepts within the model. The symptom management theory (SMT) which was initially developed by the School of Nursing at the University of California in San Francisco (Larson et al., 1994) and revised by Dodd and colleagues (2001) and Humphreys and colleagues (2008) (See Figure 1) was selected as a guide for the development of the conceptual model for the study (Figure 2).

The SMT was created to be utilized with any symptom experienced by patients. Dodd and colleagues (2001) defined a symptom as a "...subjective experience reflecting changes in the biopsychosocial functioning, sensations or cognition of the individual" (p 669). Within the SMT model, the domains of person, health and illness and environment are shown to be in continuous interaction with each other as well as with the dimensions of symptom experience, symptom management strategies and pain management outcomes.

For the purposes of this study, the SMT model (Dodd, et al., 2001; Humphreys & et al., 2008) was adapted to focus on the differences in the pain experience, pain management strategies, pain management outcomes and admission of older adult HCBWP participants to a nursing home in regards to diagnosis of cancer (See Figure 2). Pain occurs due to actual or potential tissue damage and is comprised of both sensory and emotional components (International Association for the Study of Pain, 2009). Pain is shaped by the contribution of personal and social characteristics (American Pain Society, 2005) and is highly subjective, being "...whatever the experiencing person says it is, existing whenever he/she says it does" (McCaffery & Beebe, 1989, p. 7).

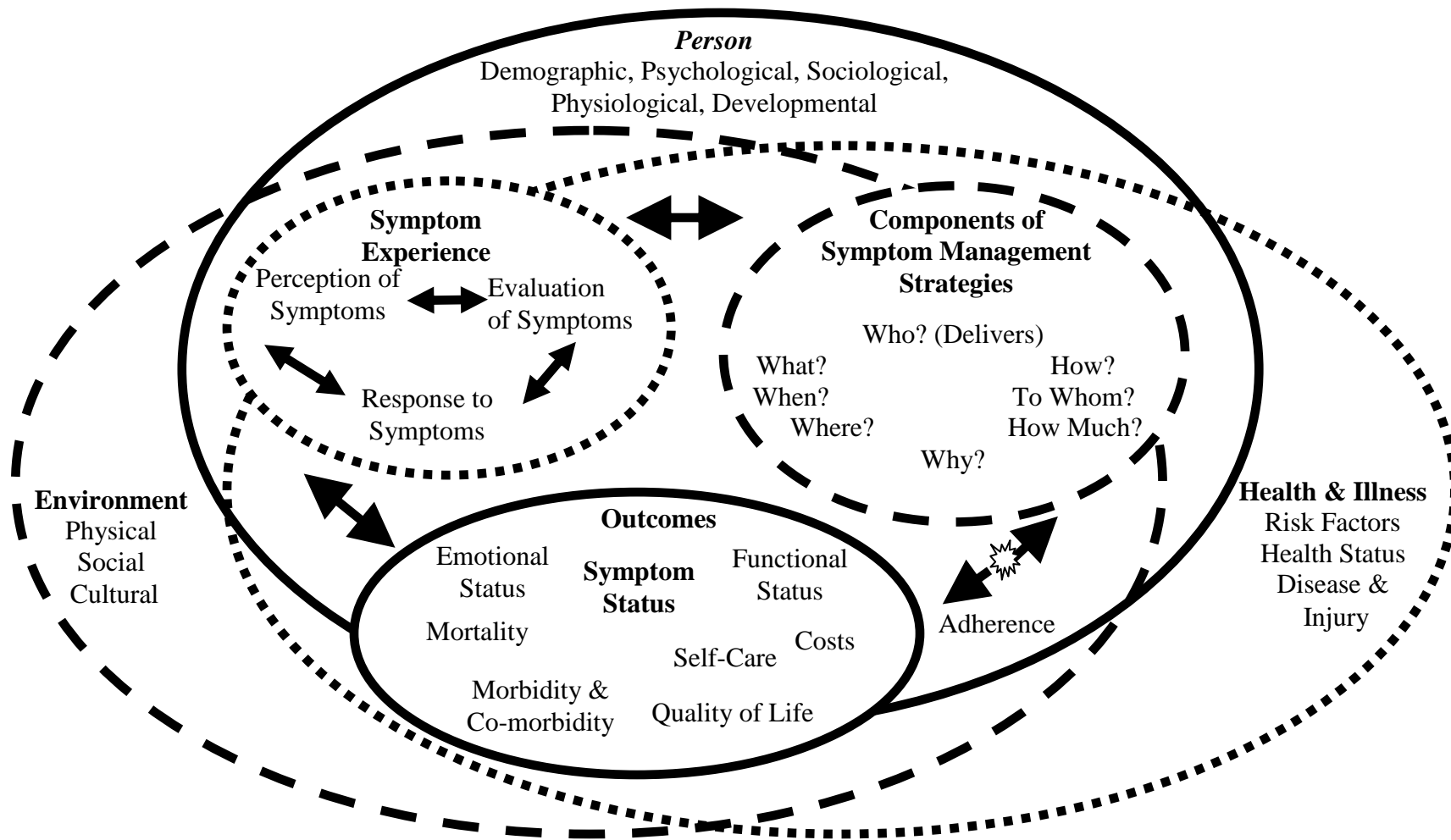


Figure 1. Symptom Management Theoretical Model. Reprinted from “Advancing the Science of Symptom Management” by M. Dodd, S.Janson, N. Facione, J.Faucett, E. S. Froelicher, J. Humphreys...D. Taylor, 2001, *Journal of Advanced Nursing*, 33, p.670. Reproduced with permission.

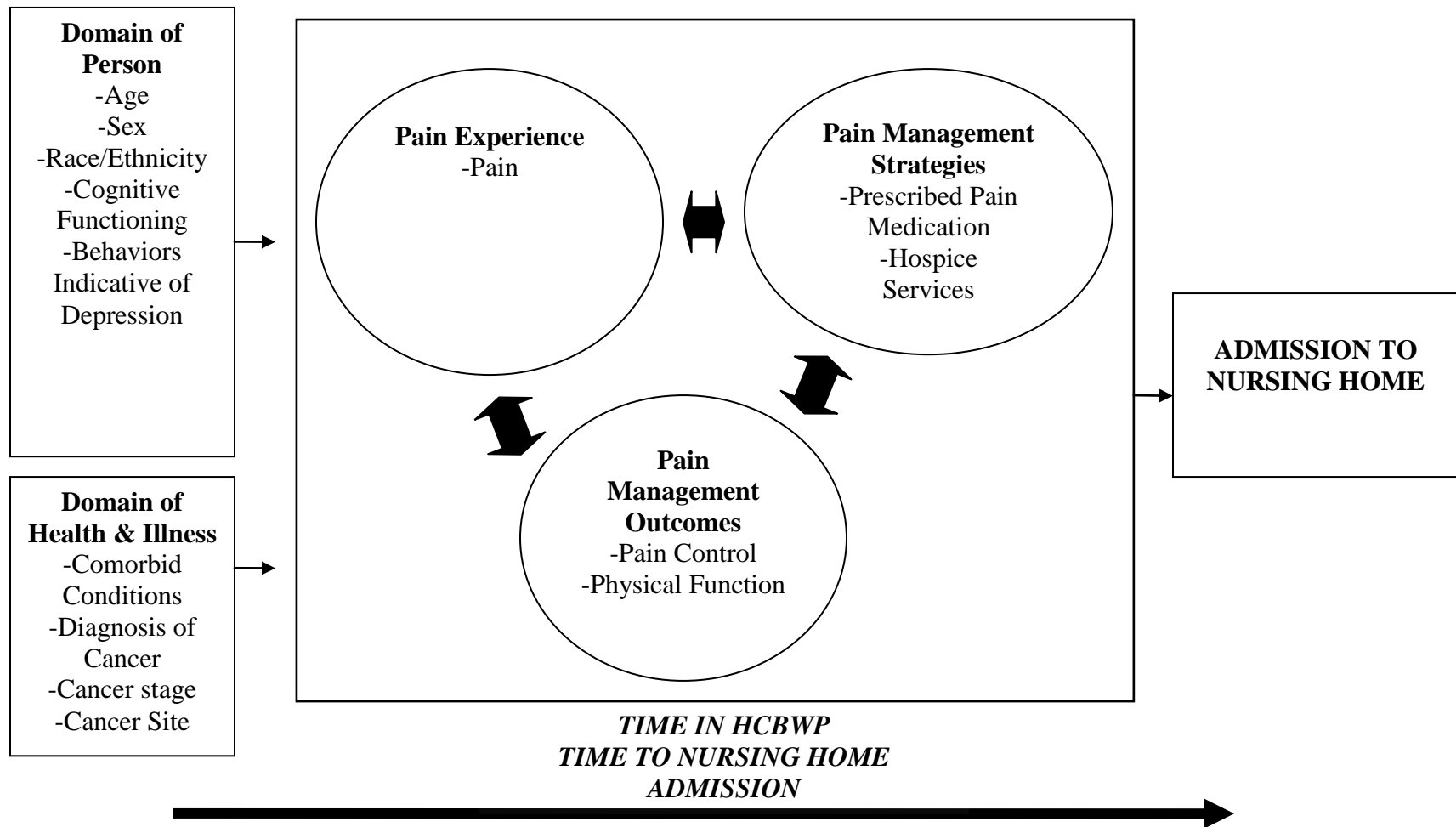


Figure 2. Conceptual Model for Study: Pain Management Among Older Adults within a Home and Community-Based Waiver Program *Note.* Adapted from “Advancing the Science of Symptom Management” by M. Dodd, S.Janson, N. Facione, J.Faucett, E. S. Froelicher, J. Humphreys...D. Taylor, 2001 , *Journal of Advanced Nursing*, 33, p.670.

Not all older adult HCBWP participants however, are able to make verbal reports of pain. Dodd and colleagues (2001) then allows for interpretation of the patient's pain experience by those who care for the patient for the purpose of intervening. Within the study, proxy reports of the pain experience, as provided by either healthcare providers or family members, were recorded if the HCBWP participant was unable to make verbal reports of pain. The American Geriatric Panel on Persistent Pain in Older Persons recommends the inclusion of information regarding an older adult's pain from caregivers and family members in the pain assessment (2002). The pain experience, pain management strategies, pain management outcomes of pain control and physical functioning of HCBWP participants, and admission of older adult HCBWP participants to a nursing home, as affected by the domains of person, health and illness, are depicted within the conceptual model for this study (See Figure 2). The following sections of this chapter will describe the conceptual model for this study and define concepts, beginning with the domain of person.

Domain of Person

Pain is subjective and shaped by person-related characteristics (American Pain Society, 2005). As depicted in Figure 2, the domain of person includes factors that may affect the manner in which the HCBWP participant views and responds to the pain experience, pain management strategies and pain management outcomes. For this study, the domain of person is conceptualized as including the age, sex, race/ethnicity, behaviors indicative of depression and cognitive functioning of the HCBWP participant.

Age. Age is conceptualized as having an effect on the pain experience, pain management and pain management outcomes of older adult HCBWP participants despite inconclusive results from previous research examining associations between pain and age. While some researchers

have noted that pain is more prevalent as one ages (Jakobsson, et al., 2003; Tsang et al., 2008), others have found a negative association between pain prevalence and age (Sawyer, Lillis, Bodner, & Allman, 2006; Thomas, et al., 2004) or even no association between age and pain (Reyes-Gibby, Aday, et al., 2007). Differences in these findings regarding the association between age and pain may be attributed to differences in pain measures used as well differences in the time period where pain was measured (i.e. daily, weekly etc.).

For this study, age was conceptually defined as one's chronological age at the time of assessment and all subjects will be 65 years and older. The age of 65 is generally used in older-adult related research to define older adult samples as the federal government has previously used the age of 65 as a marker for full social security (Social Security, 2009) and Medicare benefits (Centers for Medicare & Medicaid Services, 2008), as well as reporting statistics describing older adult populations (Administration on Aging, 2007).

Sex. Sex was conceptually defined as the distinction between male and female and is conceptualized as impacting the pain experience, pain management strategies and pain management outcomes of older adult HCBWP participants. Among older adults, females more significantly likely to have pain reported than males in NH (Reyes-Gibby, Aday, et al., 2007; Sawyer, et al., 2006).

Race/Ethnicity. Race/ethnicity is conceptually defined as the racial or ethnic group the HCBWP participant perceives him or herself as belonging to. Edwards, Fillingim and Keefe (2001) noted that "race distinguishes major groups of people according to their ancestry and more or less distinctive combinations of physical characteristics" (p. 134). In comparison, ethnicity was described as a social concept, providing a group designation, such as a shared nationality, tribal affiliation, religious faith, shared language or cultural and traditional origins

and background (Ezenwa, Ameringer, Ward, & Serlin, 2006; Huff & Kline, 1999; J. L. Riley et al., 2002). The National Institutes of Health (NIH) provides ethnic categories of “Hispanic of Latino” and “not Hispanic or Latino” separate from race. For the purposes of the study, the variable defining race/ethnicity will combine aspects of both race and ethnicity and describe whether the HCBWP participant is Caucasian, Black, American Indian, Other (includes Asian and Pacific Islander), Unknown and Hispanic by self or proxy report.

Past research among older adult populations has suggested that differences exist in the pain experience between racial and ethnic groups among older adults (Im et al., 2007; Reyes-Gibby, Aday, et al., 2007; Sawyer, et al., 2006; Teno, et al., 2004). Race and ethnicity influences pain management as well. African American and Hispanic persons are more likely to have their pain underestimated and undertreated and less likely to receive opioid pain medications when compared to whites (Cintron & Morrison, 2006; Sengupta, et al., 2010). If pain is under treated, then poor pain management outcomes may occur (American Geriatrics Society Panel on Persistent Pain in Older Persons, 2002).

Behaviors Indicative of Depression. Behaviors Indicative of Depression is conceptualized as the HCBWP participant exhibiting feelings of sadness, persistent anger, repetitive anxious complaints, sad facial expressions, recurrent crying and withdrawal from activities of interest, as per the Depression Rating Scale (Burrows, Morris, Simon, Hirdes, & Phillips, 2000). Additional information regarding the Depression Rating Scale (Burrows, et al., 2000) will be presented in Chapter 4. Pain is associated with depression among older adults, such that the presence of one increases the likelihood of the occurrence and worsening the prognosis of the other (Geerlings, et al., 2002; L. Li & Conwell, 2007). For this study, depression will be

conceptualized as influencing the pain experience, pain management strategies and pain management outcomes and will not be measured as an outcome of pain management.

Cognitive Functioning. Cognitive functioning is conceptualized as the overall mental performance of an individual regarding memory, decision making capability, awareness, and communication abilities, as per the Cognitive Performance Scale (Morris et al., 1994). The Cognitive Performance Scale examines one's short term memory, decision making capability, communication abilities and self-performance in eating (Morris, et al., 1994). Additional information regarding the Cognitive Performance Scale (Morris, et al., 1994) will be presented in Chapter 4.

Cognitive functioning is conceptualized as influencing the ability of the older adult HCBWP participant to convey their pain experience (Cohen-Mansfield, 2004; Fisher et al., 2002; Procter & Hirdes, 2001). Pain management strategies based on a poorly conveyed pain report by older adults with cognitive impairment may fail to truly meet the pain management strategy needs of the patient, as previous research has suggested that cognitively impaired older adult nursing home residents receive less pain medications than cognitively intact older adult nursing home residents (Reynolds, et al., 2008).

In summary, the domain of person includes age, sex, race, behaviors indicative of depression and cognitive functioning and is conceptualized (See Figure 2) as including factors which influence the way an individual views and responds to the pain experience, pain management strategies and pain management outcomes.

Domain of Health and Illness

The domain of health and illness is comprised of variables unique to the individuals health and illness state (Dodd, et al., 2001; Humphreys & et al., 2008) and will include variables

defining the diagnosis of cancer and comorbidity. Comparisons regarding the pain experience, pain management strategies, pain management outcomes of (pain control, pain medication costs and physical function) and the admission of HCBWP participants with and without a diagnosis of cancer to a nursing home are a purpose of this study.

Diagnosis of cancer, cancer site and cancer stage. Diagnosis of cancer is conceptualized as the identification of the presence of a malignant cells or neoplasm within the body and the resulting phases of health care that occur after the identification of malignant cells. Over the course of time while participating the HCBWP, participants with a diagnosis of cancer moved through the phases of cancer care as defined by Yabroff and colleagues (Yabroff, Warren, Knopf, Davis, & Brown, 2005; Yabroff et al., 2009): The initial phase, continuation phase and terminal phase. These phases are in relation to the time between diagnosis of cancer and death.

In this research, cancer diagnosis was represented as no diagnosis of cancer, initial phase, continuation phase and terminal phase. The development of the measure of diagnosis of cancer will be described in detail in Chapter 4. Older adults with cancer are more likely to experience pain when compared to older adults without a history of cancer in both community and nursing home settings (Buchanan, et al., 2005; Reyes-Gibby, Aday, et al., 2007; Rodin, 2008). Diagnosis of cancer was conceptualized as impacting the pain experience, pain management strategies, pain management outcomes of older adult HCBWP participants and admission of older adult HCBWP participants to a nursing home.

Diagnosis of cancer can be further characterized by cancer site and stage. *Cancer site* is conceptualized as the anatomical location or locations within the body where the cancer is present and will be described in terms of the primary or initial anatomical location of the cancer. *Cancer stage* is conceptualized as the method of defining how progressed or metastasized the

cancer is. Cancer stage will be presented in line with Surveillance, Epidemiology and End Results (SEER) summary stage: in situ, local, regional, distant, un-staged and invasive but site unknown.

Comorbid conditions. Comorbid conditions are conceptualized as the “...the co-occurrence of health conditions or diseases in reference to an index disease” (Yancik et al., 2007, p. 276) and as impacting the pain experience, pain management strategies and pain management outcomes. For this study, cancer is the index disease as comparisons will be made between older adults in regards to diagnosis of cancer.

Comorbid conditions such as arthritis, diabetes, peripheral vascular disease occur at higher rates in older adults populations and are conceptualized as affecting the pain experience, as a higher number of comorbidities is associated with an increased presence of pain (Mao, et al., 2007; Reyes-Gibby, Aday, et al., 2007). The presence of comorbid conditions may influence pain management strategies used by healthcare providers, as there may be concerns about drug interactions between pain medications and medications used to treat comorbid conditions (Duncan, et al., 2008; Goldstein & Morrison, 2005; McNeill, et al., 2007). Pain management strategies that are inappropriate for the patient’s pain experience may be utilized, thereby negatively influencing outcomes. Comorbid conditions were represented by a weighted index score which reflected both the summed number of comorbidities and the association between each comorbid condition and pain experienced by older adult HCBWP participants. Additional information describing the procedure for the development of the measure of comorbid conditions will be presented in Chapter 4.

In summary, variables defining diagnosis of cancer and comorbid conditions are conceptualized within the domain of health and illness. The domain of health and illness

contributes to the unique pain experience, pain management strategies and pain management outcomes (Buchanan, et al., 2005; Duncan, et al., 2008; Mao, et al., 2007; Reyes-Gibby, Aday, et al., 2007; Rodin, 2008).

The Pain Experience

The pain experience is the complex process of perceiving, evaluating, and responding to a sensory input (Dodd, et al., 2001; Humphreys & et al., 2008; Kandle, Schwartz, & Jessell, 2000; Turk & Okifuji, 1999) and for the purposes of the study, the pain experience is the verbal report of or behavioral responses to pain defining both pain frequency and pain intensity which will be examined over the time of participation in the HCBWP.

The Pain Experience is conceptualized as being affected by the domains of person and health and illness. For example, aging and disease processes may alter nerve function, predisposing one to pain production (Backonja, 2003; Gibson & Helme, 2001; Pasero, 2004; Zheng, et al., 2000). The pain experience is initiated with sensory inputs, which are sensed by nociceptors and transmitted to the dorsal horn in the spinal cord and to the brain where the sensory inputs are then interpreted as painful or not painful (Basbaum, Bushnell, & Devor, 2005; Kandle, et al., 2000). Once a sensory input is interpreted, the painful stimulus is evaluated by the patient and factors such as intensity, location, temporal nature, frequency and the affective impact of pain are used by the patient to appraise and characterize the pain (Dodd, et al., 2001; Humphreys & et al., 2008). Whether or not a stimulus is perceived as pain depends not only on the nature of the stimulus, but also on the context within which the stimulus was experienced, as well as memories and emotions in relation to pain (Basbaum, et al., 2005).

The patient's evaluation of pain is influenced by pain-related beliefs developed over one's lifetime (Turk & Okifuji, 2002). Once a patient has evaluated and characterized the pain,

the patient responds to the pain. Response to pain may include behaviors that communicate pain to others such as verbal reports, posturing, grimacing, moaning or crying out when moved (Goldstein & Morrison, 2005; NANDA, 2005; Turk & Okifuji, 1999). Because the sample for the study include older adult HCBWP participants who are cognitively impaired and therefore, not able to provide verbal reports of pain, pain behaviors such as posturing, grimacing, moaning or crying out when moved are used by assessors to define pain frequency and pain intensity.

Pain. For this study, *pain* is both the frequency and the intensity of the pain experienced by the HCBWP participant, as measured by the MDS Pain Scale (Fries, Simon, Morris, Flodstrom, & Bookstein, 2001). *Pain frequency* is the varying time dimension which characterizes a temporal aspect of pain: the frequency with which pain occurs in a certain period of time (Jensen, 2003; Lenz, Pugh, Milligan, Gift, & Suppe, 1997). *Pain intensity* is associated with the sensory dimension of pain and is the level of severity, strength or overall magnitude of the pain (C. S. Cleeland & Ryan, 1994; R. H. Dworkin et al., 2005; Jensen, 2003; Lenz, et al., 1997). Pain frequency and intensity are both assessed via patient or proxy report. Pain frequency and intensity are capable of changing over time in response to person and health and illness characteristics as well as pain management interventions (Harris et al., 2005; Henly, et al., 2003; Humphreys & et al., 2008).

In summary, the dimension of pain experience addresses the patient perceiving, evaluating and responding to pain. The pain experience dimension includes the concept of pain to characterize the patient's pain experience. *Pain* will be measured over time, to examine pain frequency and pain intensity over the course of care within the HCBWP. Within the conceptual model (See Figure 2), the pain experience dimension is depicted as influencing and being

influenced by the pain management strategies dimension (Bruckenthal & D'Arcy, 2007; Dodd, et al., 2001; Humphreys & et al., 2008).

Pain Management Strategies

The pain management strategies dimension included what is done for and by the older adult HCBWP participant to manage pain (Dodd, et al., 2001; Humphreys & et al., 2008). Pain management strategies are based on the assessment of the older adult HCBWP participant's pain experience (Bruckenthal & D'Arcy, 2007; Dodd, et al., 2001). Pain management strategies can be pharmacological and non-pharmacological (Deane & Smith, 2008; JCAHO, 2000) and within this study, pain management strategies were conceptualized as including prescribed pain medication and the provision of hospice services.

Prescribed Pain Medications. Prescribed pain medications are conceptually defined as medications that are prescribed by health care providers for pain management. In this study, pain medications were characterized as to whether they are non-opioid, opioid or adjuvant as per the World Health Organization Analgesic Ladder (NCI, 2006; WHO, 1996). Whether opioid, non-opioid or adjuvant pain medications were prescribed depends on the assessment of the pain experience (Humphreys & et al., 2008; NCCN, 2010; NCI, 2010b; WHO, 1996). For example, for mild pain, acetaminophen alone may have been prescribed, whereas for severe pain, an opioid such as morphine may have been prescribed (Humphreys & et al., 2008; NCCN, 2010; NCI, 2010b; WHO, 1996).

In addition to being directed by the pain assessment, prescribed pain medications were conceptualized as being influenced by patient and health and illness characteristics. For example, non-steroidal anti-inflammatory medications should be used with caution in older adults with renal impairment (Hanlon, Guay, & Ives, 2005) and older adults are at greater risk

for opioid side effects such as sedation, nausea, vomiting , respiratory depression and constipation (Weiner & Hanlon, 2001). Thus, providers may be concerned about medication side effects among older adults and may therefore limit what they do prescribe based on person and health and illness-related factors (Duncan, et al., 2008; Goldstein & Morrison, 2005; McNeill, et al., 2007).

Hospice Services. Hospice services were conceptually defined as the provision of palliative care including medical, emotional and spiritual care for terminally ill patients (life expectancy of less than 6 months) and their families (Hospice Association of America, 2006). Hospice care serves to identify goals for care, provide effective prevention and management of end of life symptoms such as pain and dyspnea and provide attention to psychosocial and spiritual issues and prevention of suffering, and assist with completion of developmental tasks related to the dying process and successful negotiation of the grief and bereavement processes (Ersek & Wilson, 2003). The provision of hospice services can take place in the home, nursing homes, hospitals or hospice centers (Hospice Association of America).

In summary, for this study, the pain management strategies dimension focused on prescribed pain medications and hospice services. Among older adults, pain management strategies were conceptualized as being influenced by the pain experience and person and health and illness characteristics (Bruckenthal & D'Arcy, 2007; Dodd, et al., 2001; Duncan, et al., 2008; Hanlon, et al., 2005; Humphreys & et al., 2008; Weiner & Hanlon, 2001). In this study, relationships between prescribed pain medications and hospice services, the pain experience, and the domains of person and health and illness were assessed over time. In addition to being influenced by the pain experience dimension, the pain management strategies dimension affects the pain management outcomes dimension.

Pain Management Outcomes

Outcomes are the end results of care (Patrick, 1997). The pain management outcomes dimension, as depicted in Figure 2, includes the end results of pain management strategies, is influenced by pain management strategies and has an effect on the pain experience (Dodd, et al., 2001; Humphreys & et al., 2008). For this study, pain management outcomes included pain control and physical function and were examined over the period of time that the older adult participates in the HCBWP. The outcomes of pain control and physical function are described in further detail in the following sections.

Pain Control. Past definitions of pain control are aligned with its role as an outcome of pain management strategies. Pain control is the result of pain assessment and analgesic treatments (Allard, Maunsell, Labbe, & Dorval, 2001; Shvartzman, et al., 2003). Pain control was conceptually defined as an outcome of pain management whereby pain is perceived by the patient or proxy as limited or decreased from a previous pain level and is an indicator of the effectiveness of pain management strategies (Allard, et al., 2001; Christine Miaskowski, et al., 2002; Oliver, et al., 2001; Shvartzman, et al., 2003). Pain control is therefore associated with perceived medication effectiveness.

For this study, pain control was represented by the HCBWP participant's or proxy's response to the statement "pain controlled by medication". The representation of pain control by the HCBWP participant's or proxy's response to the statement "pain controlled by medication" is a limitation of this study, as pain control was limited to medication only. The researcher acknowledges that pain control is an outcome of any pain management strategy, including pain medications, non-pharmacological strategies such as heat, cold, massage etc, or procedures such as nerve injection.

As a pain management outcome, pain control was influenced by pain management strategies and impacts the pain experience. For example, pain management strategies are implemented and reassessment of the pain experience takes place after pain management (NCCN, 2006). If pain management does not result in pain control, then pain management strategies should be altered and the pain experience reevaluated to determine if pain control has occurred (NCCN, 2006). This inter-relationship between the pain experience, pain management strategies and pain management outcomes is depicted in Figure 2.

Physical Function. Physical function is an outcome of pain and pain management strategies as previous research has shown that pain has a significant, negative effect on physical function (Onder, et al., 2006; Reyes-Gibby, et al., 2002; Soldato, et al., 2007). The concept of physical function has been noted to be within the overarching concept of *functional status* (Ferrans, Zerwic, Wilbur, & Larson, 2005) as depicted in the Symptom Management Theory conceptual model (See Figure 1) (Dodd, et al., 2001; Humphreys & et al., 2008).

Physical functioning has been noted to be “...a broad concept that includes physical abilities that range from simple mobility to engagement in complex activities that require adaptation to an environment” (Bennett, et al., 2006, p. 41). The Initiative on Methods, Measurement and Pain Assessment in Clinical Trials (IMMPACT) supports the use of activities of daily living as a fundamental measure of physical functioning to determine the effect of pain and pain management strategies on physical function (R. H. Dworkin, et al., 2005; Turk, et al., 2003). For this study, physical functioning was conceptualized as the dependency of the older adult HCBWP participant in activities of daily living (ADL).

This study examined predictors of the admission of older adult, HCBWP participants to a nursing home. Dependencies in ADL are a significant predictor of nursing home admission

(Gaugler, Duval, Anderson, & Kane, 2007). Therefore, physical function was conceptualized in Figure 2 as affecting the admission of HCBWP participants to a nursing home. Physical function is influenced by the pain experience and pain management strategies. Physical functioning was represented by a count of the following ADLs that the HCBWP participant is dependent in: dressing, personal hygiene, toilet use, bathing and eating. Additional information describing the summed ADL dependency scale will be presented in Chapter 4.

In summary, the pain management outcomes dimension includes the end results of pain management and consists of pain control and physical function. This study examined relationships among the pain experience, pain management strategies, pain management outcomes and completed an exploration of the associations among pain experience, pain management strategies, pain management outcomes and admission to the nursing home.

Admission to a Nursing Home

For this study, the domains of person and health and illness, the pain experience, pain management strategies and pain management outcomes were conceptualized as impacting the admission of older adult HCBWP participants to a nursing home.

Admission to a Nursing Home. Admission to a Nursing Home, as conceptualized in Figure 2, is conceptually defined as the movement of older adult, HCBWP participants to a nursing home facility, without returning to the HCBWP. Admission to a Nursing Home is part of the healthcare services continuum of older adults, where older adults move from community to institutionalization (L. Li & Zullo, 2003; Williams, 2001). A goal of the HCBWP is to prevent or delay admission to a nursing home (Fries, et al., 2002).

The concept of time was not included in the original SMT (Dodd, et al., 2001; Humphreys & et al., 2008) but is addressed in the developed conceptual model (Figure 2). Time

was included in the adapted model to account for the temporal aspects of pain, pain management and pain management outcomes as well as to conceptualize the long-term care continuum that exists for older adults (L. Li & Zullo, 2003; Williams, 2001) . Within the conceptual model depicted in Figure 2, there are two time-related variables: *Time in the HCBWP* and *Time to Nursing Home Admission*. These two time-related concepts are clarified in the following paragraphs.

Time in HCBWP. Time in the HCBWP is conceptually defined as the period of time in months that the older adult is a HCBWP participant among the pain experience, pain management strategies, pain management outcomes which are influenced by the domains of person and health and illness (Dodd, et al., 2001; Humphreys & et al., 2008). Even though Time in the HCBWP is not specifically included in the research questions as a study variable, it will be included in the analysis as a covariate in order to account for differences between subjects in time spent in the HCBWP. The statistical reason for the inclusion of Time in the HCBWP as a covariate will be described in more detail in Chapter 4.

Time to Nursing Home Admission. The timeline in the conceptual model also depicts time for *Time to Nursing Home Admission*, which is conceptualized as the time in months that a HCBWP participant spends in the HCBWP prior to admission to a nursing home, without returning to the HCBWP. As the goal of the HCBWP is to prevent or delay admission to a nursing home (Fries, et al., 2002), the concept of time to nursing home admission is included in the model to account for the influence of the pain experience, pain management strategies and pain management outcomes has on the above goal of the HCBWP.

In summary, the concept of time was included in the adapted model (Figure2) to conceptualize the longitudinal design of this study in order to examine the relationships between

dimensions and domains and predictors of time before admission of older adult HCBWP participants to a nursing home within the long-term care continuum.

Conclusion of Chapter 2

The conceptual model for this study accounts for the interactive nature of the pain experience, pain management strategies, pain management outcomes dimensions and admission to a nursing home along with the domains of person, and health and illness among older adult HCBWP participants. In this study, relationships between variables in the pain experience, pain management strategies, pain management outcomes dimensions and the concept of admission to a nursing home will be examined over time while accounting for differences among HCBWP participants according to variables with the domains of person and health and illness.

Chapter 3 will provide a literature review as to what is known regarding the issue pain, pain management and pain management outcomes among older adults as well as the need for and significance of research addressing the pain management needs of older adult HCBWP participants.

Chapter 3

The purpose of Chapter 3 was to provide an overview and synthesis of the literature regarding the Medicaid Home and Community Based Waiver Program (HCBWP) and the pain experience, pain management strategies, pain management outcomes and admission to a nursing home of older adult HCBWP participants. The developed conceptual model (See Figure 2) serves as a guide for the following literature review. The model domains (Person and Health and Illness), dimensions (Pain Experience, Pain Management Strategies, and Pain Management Outcomes) and admission will serve as section headings. Because the model was conceptualized to be within the HCBWP, a review of the literature regarding the HCBWP will be provided first. The review of the literature describing the HCBWP will present the overall history of the HCBWP as well as describe HCBWP policies, HCBWP admission criteria and HCBWP client characteristics.

The Home and Community Based Waiver Program

The Medicaid Home and Community Based Waiver Program (HCBWP) was established by the Omnibus Budget Reconciliation Act of 1981 (OBRA-81) and was incorporated into the Social Security Act at Section 1915(c) (Duckett & Guy, 2000). Medicaid is a joint federal and state program that provides health insurance coverage to provide services for certain categories of low-income individuals, including children, pregnant women, parents of eligible children, persons with disabilities and older adults (Centers for Medicare & Medicaid Services, 2005). Prior to the OBRA -81, Medicaid coverage of home and community-based services was limited and favored institutional-based care for long-term care needs (Duckett & Guy, 2000; Marek et al., 2005). The OBRA-81 supported the expansion of Medicaid coverage of home care benefits

provided by individual states via “Medicaid waivers” (L. Li & Zullo, 2003; Shugarman, et al., 1999).

Medicaid waivers “waive” certain regulatory requirements regarding individual state’s Medicaid plans thereby easing the expansion of Medicaid-covered home and community-based services (Kitchener & Harrington, 2003; Kitchener, Ng, & Harrington, 2004; Shugarman, et al., 1999). HCBWP services may be provided to individuals who are elderly and disabled, physically disabled, developmentally disabled, mentally retarded, mentally ill or suffer from chronic debilitating diseases, such as Acquired Immune Deficiency Syndrome caused by the Human Immunodeficiency Virus (Duckett & Guy, 2000; N. A. Miller, Elder, Kitchener, Kang, & Harrington, 2008). Services covered under the HCBWP includes homemaker services, respite care, adult day care, home modifications, transportation, medical supplies, personal emergency response system, private duty nurse, counseling, home delivered meals, physical and occupational therapy, and personal care supervision (Kitchener, et al., 2004; Shugarman, et al., 1999). Services can be provided in the participant’s home or in residential-care or assisted living facilities (Kitchener, Hernandez, Ng, & Harrington, 2006). The overall purpose of the HCBWP is to provide Medicaid covered home care services to those 18 and older who are at risk for nursing home placement because of the need for assistance with activities of daily living or medical services, in order to delay or avoid the high costs of institutional long-term care (D'Souza, James, Szafara, & Fries, 2009; Sands et al., 2008; Shugarman, et al., 1999)

HCBWP costs are controlled by individual states through the use of four mechanisms, which allow the states a great deal of flexibility in the designs of HCBWPs. Variations in the use of these four cost-containment mechanisms exist at both the inter and intra-state level (Kitchener, et al., 2004; Kitchener, Ng, & Harrington, 2007). First, states must demonstrate

HCBWP participant Medicaid costs are no greater than the Medicaid costs of comparable nursing home level care (Kitchener, Carrillo, & Harrington, 2003; Kitchener, et al., 2007). Second, states may limit the number of available HCBWP participant slots in order to limit total costs (Kitchener, et al., 2007). Third, states at their discretion, may set HCBWP participant medical and financial eligibility criteria and spending caps on provided services (Kitchener, et al., 2007). Fourth, states may limit waiver programs to specific geographical areas (i.e. a county with high need for long-term care services) and population groups (i.e. the elderly, persons with HIV/AIDS, persons with mental illness) (Duckett & Guy, 2000; Kitchener, et al., 2007; N. A. Miller, et al., 2008). Therefore, states have at their disposal methods to keep HCBWP costs under control. However, concerns have been raised regarding the effect of cost-containment mechanisms on access to HCBWP services and other HCBWP participant outcomes (Tonner & Harrington, 2003).

HCBWP cost-containment mechanisms may restrict individual choice of healthcare services and result in unnecessary institutionalization. Kitchener et al. (2004) performed a nationwide survey of cost-containment strategies utilized by 229 different waiver programs. There are inter and intra-state variations in financial eligibility criteria, which varied from between 300% of Supplemental Security Income (SSI) to 100% of SSI as well as other financial eligibility criteria based on other poverty indicators (Kitchener, et al., 2004). Kitchener et al. noted that 33% of the states were using more stringent financial criteria for their HCBWPs than for nursing home eligibility, a policy which would clearly favor nursing home admissions. D'Souza et al. (2009) explored variation in HCBWP participant outcomes in response to major state-level budget restrictions in Medicaid funding as well as policies which increased medical-eligibility threshold for HCBWP admission. D'Souza et al. examined 112,182 HCBWP

assessment records collected over a four-year time period. During time periods of worsening state budgets, HCBWP participants experienced decreases in the amount of care hours provided with resulting increases in emergency room use by HCBWP participants and increased caregiver burden when compared to time periods with the least state-level budget restrictions (D'Souza, et al., 2009). In summary, HCBWPs must strive to work within budgetary constraints while also meeting participant needs, as HCBWP participant outcomes appear to suffer with worsening budget situations (D'Souza, et al., 2009).

Despite difficulties with meeting both budget restrictions and participant needs, the use of HCBWP services results in improved participant outcomes compared to populations not receiving HCBWP services. Medicaid-eligible older adults with disabilities in activities of daily living (ADL) receiving home care services experienced a significantly reduced risk of death when compared to Medicaid-eligible older adults with disabilities in ADL not receiving home care services (Albert, Simone, Brassard, Stern, & Mayeux, 2005). Marek et al. (2005) compared clinical outcomes (cognitive decline, functional status decline, depression, pressure ulcers and incontinence) of HCBWP participants aged 50 and older to nursing home residents of a similar case mix over a 2 year time period. HCBWP participants had significantly better outcomes of functional status, cognition, depression and incontinence over time when compared to the matched nursing home residents (Marek, et al.). In summary, HCBWP services benefit HCBWP participants when compared to persons not receiving HCBWP services.

Although there are known benefits from receiving HCBWP services among older adults, little is known about any benefits of pain management and pain management outcomes experienced by older adult HCBWP participants with and without a diagnosis of cancer. Pain is reported by 53%-75% of HCBWP participants (Fries, James, & Aliaga, 2004; L. Li & Conwell,

2007; Spoelstra, Given, von Eye, & Given, 2010). Cancer prevalence rates among older adult HCBWP participants range from 13% (Spoelstra, et al., 2010) to 15% (L. Li, 2005) and this rate is slightly higher than the reported 11% of nursing home residents who have a diagnosis of cancer at admission (Buchanan, et al., 2005; Rodin, 2008). Therefore, over half of older adult HCBWP participants experience pain and cancer occurs at a higher rate than among older adult nursing home residents.

HCBWP participants must meet financial eligibility below 300% of the federal poverty level (L. Li & Zullo, 2003) and are therefore considered impoverished. Poverty is associated with increased pain and poor pain management and pain management outcomes. Fuentes, Hart-Johnson and Green (2007) found that as neighborhood socioeconomic status decreased (became poorer), pain and disability increased among older black and white older adults. Medicaid and Medicare recipients are at risk for poor pain management due to healthcare providers not prioritizing pain management as well as restrictive drug coverage benefits (Jost, 2000). Therefore, older adult HCBWP participants are at higher risk for pain and poor pain management and pain management outcomes when compared to wealthier older adults (Fuentes, et al., 2007; Jost, 2000).

In summary, the HCBWP was developed to provide Medicaid covered home care services to those 18 and older who are at risk for nursing home placement due to the need for medical care or assistance in activities of daily living in order to delay or avoid the high costs of institutional long-term care (D'Souza, et al., 2009; Shugarman, et al., 1999). Home and Community-Based Waiver Programs utilize various strategies to control the costs of health care services which result in decreased access to health care services and poor health outcomes (D'Souza, et al., 2009; Dodd, et al., 2001; Kitchener, et al., 2004; Tonner & Harrington, 2003).

Healthcare services directed toward pain and pain management among older adults are both frequent and costly occurrences in the healthcare system. Pain is the most common reason individuals seek medical attention (JCAHO, 2000) and older adults who experience pain utilize more healthcare services than older adults without pain (Mossey & Gallagher, 2004). The financial costs to the health care system related to pain management have been reported to exceed \$4000.00 per year for persons with chronic pain (Turk, 2002) and average \$891.00 per month for persons diagnosed with cancer (Fortner et al., 2003). While cost-containment is a key HCBWP strategy, very little is known regarding pain, pain management and pain management outcomes in HCBWP. Because of the high costs of pain and pain management, research is needed to describe differences in the pain experience, pain management and pain management outcomes of HCBWP participants with and without a diagnosis of cancer.

Domains of Person and Health and Illness

Within this research, participant characteristics are represented by the domain of person and domain of health and illness (Figure 2). The domain of person includes variables defining age, sex, race/ethnicity, participant cognitive function, depression. The domain of health and illness is represented by variables defining comorbid conditions and cancer. These variables are frequently associated with pain in research examining the pain experience, pain management and pain management outcomes among older adults. The following section of the literature review will examine each variable listed above as it relates to the pain experience, pain management and pain management outcomes among older adults in general.

Domain of Person. Variables within the domain of person comprise personal factors that may affect the manner in which the HCBWP participant views and responds to the pain experience, pain management strategies, pain management outcomes (Dodd, et al., 2001;

Humphreys & et al., 2008). Differences among persons in response to the pain experience, pain management strategies and pain management outcomes occur at the genetic level, causing differences in pain processing as well as drug metabolizing enzyme production (Webster, 2008) and opioid efficacy (Reyes-Gibby et al., 2007). For this study, variables within the domain of person included age, sex, race/ethnicity, cognitive functioning and depression. These variables are frequently examined in research examining the pain experience, pain management and pain management outcomes among older adults.

Age. The following review of the association of age to the pain experience, pain management and pain management outcomes presents a synthesis of findings from research examining the pain experience, pain management strategies and pain management outcomes among community dwelling older adults and older adult nursing home residents. The age of older adult HCBWP participants tends to be younger than older adult nursing home residents with 24% of HCBWP participants under 65, vs. 11% of nursing home residents, 36% of HCBWP participants are aged 65-79% vs. 27% of nursing home residents and 40% of HCBWP participants are aged 80 and older, compared to 62% of nursing home residents (Fries, James, & Aliaga, 2004). The present research focuses on HCBWP participants 65 and older. Research examining the association of age and the pain experience, pain management strategies and pain management outcomes among older adults has compared older adults to younger adults as well as developed group comparisons among older adults (i.e. comparing 65-74 year olds to 85 and older).

Aging contributes to widespread changes in the cellular and neuro-chemical substrates of the nociceptive system (Gibson & Farrell, 2004; Helme & Gibson, 2001). In a normally functioning central nervous system, pain stimuli causes the release of endogenous opioids,

which then attach to opioid receptors in the periaqueductal grey and dorsal horn and modulate pain transmission, decreasing pain perception (Basbaum, et al., 2005; Heinricher, 2005). Aging leads to diminished endogenous opioid mechanisms and differences in modulation to painful cold stimuli in healthy adults aged 51 and older (n=48) when compared to populations aged 18-25 (n=45) (R. R. Edwards, et al., 2003). Older adults aged 73 and above (n=10) experienced slower resolution of post-injury pain and tenderness from a capsaicin patch than younger adults aged 23-36 (n=10) due to age-related changes in the central nervous system (Zheng, et al., 2000). In a review of human and animal research examining associations between aging and pain, Gagliese and Farrell (2005) noted that although data from the reviewed research was inconsistent and not robust, older adults experience impairment of nerve restoration after nerve injury and that older adults are at greater risk of persistent pain following injury or disease. In summary, aging leads to physiological changes in the nervous system that influence the perception and production of pain such that older adults experience an increased and prolonged response to injury and pain stimuli (Basbaum, et al., 2005; R. R. Edwards, et al., 2003; Gagliese & Farrell, 2005; Gibson & Farrell, 2004; Heinricher, 2005; Helme & Gibson, 2001; Zheng, et al., 2000), thereby placing older adults at risk of pain that persists or in need of extended pain management.

The results of research examining the association between pain prevalence and age have been inconclusive, with some researchers finding that pain is more prevalent as one ages (Jakobsson, et al., 2003; Tsang, et al., 2008), while others have noted a negative association between pain prevalence and age (Sawyer, et al., 2006; Soldato, et al., 2007) or no association between age and presence of pain (C. Given, Given, Azzouz, Kozachik, & Stommel, 2001). Jakobsson et al. examined the prevalence of pain among 4, 093 community dwelling and institutionalized older adults aged 75 and older and compared those who reported pain (n=1,654)

with those who did not report pain (n=2,439). The prevalence of pain was significantly higher within the older age groups. Among 75-79 year olds, 34.1% reported pain, while in the 90 and older group, 50.1% reported pain (Jakobsson, et al., 2003). Tsang and colleagues (2008) examined associations between age and prevalence of pain among 42,249 adults from 17 different countries. Tsang et al. did not clarify if any of the participants were community dwelling or institutionalized. Mean age varied from 35 to 51. The prevalence of pain was positively associated with age, with 21%-35% of participants aged 18-35 reporting pain while 47%-73% of participants aged 66 and older reported pain, after controlling for comorbid conditions (Tsang, et al.).

As noted in the previous paragraph, Given et al. (2001) noted no association between age and presence of pain while Sawyer et al. (2006) and Soldato et al. (2007) each reported a negative association between pain prevalence and age. Given et al. examined predictors of pain and fatigue among 841 patients aged 65 and older who had been diagnosed with breast, colon, lung or prostate cancer. There was no significant association between age and presence of pain. Sawyer et al. reported that lower odds of substantial daily pain were associated with older age among 27,628 nursing home residents aged 65 and above. Soldato et al. utilized a longitudinal analysis of data from 1, 520 randomly selected elderly European home care patients to assess associations between pain and disability over a one year time period and found that subjects with daily pain were significantly more likely to be younger (2007). While Thomas, Peat, Harris, Wilkie and Croft (2004) also noted a negative association between pain prevalence and age, the authors did report a positive association between age and pain interference with daily activities among . Utilizing cross-sectional data from 11, 230 adults aged 50 and older, Thomas et al. found a significant increase in pain interference in activities of daily living with increased age.

Research results reporting the association between pain severity and age are consistent. Zyczkowska et al. explored pain among 193,158 institutionalized and community-dwelling older adults (age 65 and older). Based on 5-year age groups beginning at age 65, the mean reported pain severity score was lower with each age increment in age for both men and women (Zyczkowska, et al.). Likewise, Baker and Green (2005) presented findings noting a significant difference in pain severity between Black and White American adults less than 50 vs. Black and White American adults 50 and older who were seeking care for pain at a pain management clinic. Overall, research examining associations between pain and age among both community dwelling and institutionalized older adults found that while it is not clear whether pain prevalence increases or decreases with age (Jakobsson, et al., 2003; Sawyer, et al., 2006; Soldato, et al., 2007; Tsang, et al., 2008), interference from pain may increase and pain severity diminish as one ages (Thomas, et al., 2004).

In addition to being associated with pain prevalence, pain severity and pain interference, age is also associated with pain management. Among community-dwelling older adults with dementia, insufficient analgesia was three times more likely for each additional year of age (Shega, et al., 2006). Won et al. (2004) noted that older adult nursing home residents 85 and older were significantly less likely to have received analgesics when compared to younger older adult groups. Among community-living older adults, Landi and colleagues (2001) found that older adults 85 and older were significantly less likely than younger older adults to receive pain medication. Zyczkowska (2007) reported that among older adults who were receiving home care or nursing home care and reporting severe pain, older age groups were less likely than younger older adults (aged 65-69) to receive stronger opioid pain medications (codeine, morphine) as odds ratios for receiving opioid pain medications dropped from 0.76 for older adults aged 70-74

to 0.42 for older adults aged 100-115 (Zyczkowska, et al., 2007). In summary, older adults are at increased risk of not receiving adequate pain management when compared to younger adults (Landi, et al., 2001; Shega, et al., 2006; Won, et al., 2004; Zyczkowska, et al., 2007).

In summary, research that has examined the associations between age, the pain experience and pain management has taken place among community-dwelling older adults and older adult, nursing home residents. Aging may cause physiological changes in one's perception and resolution of pain (Basbaum, et al., 2005; Gagliese & Farrell, 2005; Gibson & Farrell, 2004; Heinricher, 2005; Helme & Gibson, 2001). Age is positively associated with pain interference and negatively associated with pain severity (Baker & Green, 2005; Thomas, et al., 2004; Zyczkowska, et al., 2007). Results describing associations between age and pain prevalence are inconsistent (B. Given, et al., 2001; Jakobsson, et al., 2003; Sawyer, et al., 2006; Soldato, et al., 2007; Tsang, et al., 2008).

Sex. The following review of the association of sex to the pain experience, pain management and pain management outcomes will present findings from research examining the pain experience, pain management and pain management outcomes among community-dwelling older adults and older adult nursing home residents. Differences between sexes must be considered research examining pain, pain management and pain management outcomes.

Females experience an overall higher prevalence of pain (Chou & Chi, 2007; C. Given, et al., 2001; Jakobsson, et al., 2003; Reyes-Gibby, Aday, et al., 2007; Soldato, et al., 2007), more frequent pain (Soldato, et al., 2007), more severe pain (Reyes-Gibby, Aday, et al., 2007; Zyczkowska, et al., 2007) and worsening pain over time (Rosso, et al., 2008) when compared to males. Female, community-dwelling and nursing home resident older adults consistently report a

higher prevalence of pain as well as experience more frequent and severe pain when compared to male, community-dwelling and nursing home resident older adults.

Research results regarding differences in pain management between older adult males and females, however, are inconsistent. Won et al. (2004) presented results of lower use of opioid pain medications by men (32% vs. 40%) when compared among older adult nursing home residents with and without persistent pain (n=21,380). These results seem logical after considering that female older adults report a higher prevalence of pain and more severe pain, as noted in the previous section. However, Soldato et al. (2007) found no difference in pain medication use between community-dwelling male and female older adults who reported daily pain. More evidence regarding the association between sex and pain management among older adults is needed. In summary, it is unclear from previous research if differences in prescribed pain medications exist between male and female older adult nursing home residents and community-dwelling older adults.

There is limited research examining the association between sex and pain management outcomes among older adults. In regards to physical function, Soldato et al.(2007) noted that the association between daily pain and disability was stronger among female community-dwelling older adults when compared to male community-dwelling older adults. Deimling, Bowman and Wagner (2007) reported sex as a significant predictor of the effects of pain and fatigue on physical functioning among long-term (5 years) cancer survivors aged 60 and older, after controlling for other personal, age-related and cancer-related characteristics as well as weakness, pain, and fatigue. Results indicate that being female increases difficulty with physical functioning, after controlling for other personal, age-related and cancer-related characteristics as well as weakness, pain, and fatigue. In summary, limited research results find that among

community-dwelling older adults, females are more likely to experience pain-related diminished physical functioning.

Differences between the sexes in regards to pain, pain management and pain management outcomes have been explained by the increased likelihood of females to experience diseases which result in chronic pain as well as psychosocial differences between males and females (Greenspan et al., 2007; Wiesenfeld-Hallin, 2005). Chronic exposure to pain results in central sensitization, where neurons in the central nervous system (CNS) become hyper-excitabile (Samad, 2004). Prolonged central sensitization leads to permanent structural changes in the CNS that includes death of inhibitory neurons, replacement with new excitatory neurons, and creation of aberrant excitatory synaptic connections (Samad, 2004). These changes collectively lead to a state of fixed sensitization that is resistant to most analgesic medications (Samad, 2004). In addition, central sensitization increases the size of the field in which dorsal field neurons respond to stimuli, thereby extending pain sensitivity well past the site of injury (Miaskowski, 2004). Psychosocial factors specific to women may account for their increased pain sensitivity: hyper-vigilance toward threatening situations, greater bodily monitoring and greater prevalence of anxiety and depression when compared to men (Rollman, Abdel-Shaheed, Gillespie, & Jones, 2004). Pain is a stressful experience and differences between the sexes in stress responses, including the inflammatory response due to stressors, contribute to sex differences in pain (Greenspan, et al., 2007).

In summary, while older adult females report more prevalent, severe and worsening pain over time than older adult males (C. Given, et al., 2001; Jakobsson, et al., 2003; Reyes-Gibby, Aday, et al., 2007; Rosso, et al., 2008; Zyczkowska, et al., 2007), there are inconsistent results regarding differences between community dwelling and nursing home resident older adult males

and females regarding pain management (Soldato, et al., 2007; Won, et al., 2004) and the association between sex and pain on physical functioning (Deimling, et al., 2007; Soldato, et al., 2007). Biological and psychosocial differences between males and females account for differences in the pain experience, pain management and pain management outcomes of older adult HCBWP participants.

Race/Ethnicity. Race/ethnicity was utilized as a variable which allowed for comparison between racial/ethnic groups in terms of the pain experience, pain management and pain management outcomes. Racial breakdown of HCBWP participants has been noted to be predominantly “white” (77%), with 23% “black” and 1% “other” (Fries, James, & Aliaga, 2004). The following is a review of the association between race/ethnicity and the pain experience, pain management and pain management outcomes among older adults residing in the community or nursing homes. As noted by Ezenwa, Ameringer, Ward and Serlin (2006) there is misuse and confusion regarding the use of race and ethnicity throughout research literature. The use of the terms of race and ethnicity, as well as group-names in the review of literature in the following review is as the original authors reported.

Regarding association between the pain experience and race, while Horgas, Yoon, Nichols and Marsiske (2008) found no difference in pain presence, intensity, locations and durations between black and white older, community dwelling older adults, Teno, Kabumoto, Wetle, Roy and Mor (2004) reported that African American nursing home residents were less likely to experience daily, excruciating pain than white nursing home residents. Won et al. (2004) as well noted that among elderly nursing home residents (n=21,380) African Americans experienced a much lower rate (36%) of persistent pain than whites (49.6). Additionally, Sawyer et al. (2006) also noted that white nursing home residents were more likely to experience pain

than African American nursing home residents (n=27, 628). In comparison, Reyes-Gibby, Aday and Cleeland (2002) found that among community-dwelling older adults, more Hispanics than Whites, Blacks and American Indians were often bothered by pain although these results diminished when education and insurance status were controlled for. Results of a literature review found that African Americans perceived greater pain intensity than whites (Cleeland, Palmer, & Venzke, 2005). Among community-dwelling older adults aged 51 and older, Reyes-Gibby et al. (2007) noted that Non-Hispanic blacks and Hispanics had a higher risk of severe pain compared with Non-Hispanic whites. Variation exists in the pain experience in older adults residing in the community or nursing homes among racial and ethnic groups.

Research addressing differences between racial/ethnic groups and pain management and pain management outcomes among older adults is limited. The body of literature examining racial/ethnic differences in pain management and pain management outcomes is primarily focused on a general adult population, without developing a specific focus on older adults. Overall, white adults younger than 65 are significantly more likely to receive appropriate pain management than adults from other racial groups and Hispanics with similar pain levels (Cintron & Morrison, 2006; J. A. Cleeland, Palmer, & Venzke, 2005; Green, et al., 2003; Rodin, 2008). Specific to older adults residing in nursing homes, Won et al. (2004) found a lower use of opioid pain medications by African American nursing home residents when compared to white nursing home residents. Regarding the association between race and ethnicity and pain management outcomes, Cleeland and colleagues reported that there is a clear trend that adult African Americans experience higher pain-related disability compared to white adults. In summary, these results from research primarily conducted with a general adult population found that compared to

white adults, minority adults are less likely to receive appropriate pain management and African Americans are more likely to experience disability from pain.

In summary, Fries et al. (2004) reported that a HCBWP sample was 77% white, still leaving a significant portion of that HCBWP sample to be counted as from a minority group. There is significant variation in the pain experience of older adults residing in the community or nursing homes among racial and ethnic groups. Research examining differences in pain and pain management outcomes by race or ethnicity in general adult populations indicate that compared to white adults, minority adults are less likely to receive appropriate pain management (Cintron & Morrison, 2006; J. A. Cleeland, et al., 2005; Green, et al., 2003; Rodin, 2008; Won, et al., 2004) and African Americans are more likely to experience disability from pain (J. A. Cleeland, et al.). There is limited research specific to older adults examining differences in pain management and pain management outcomes by race and/or ethnicity. Additional research is needed to clarify the effect of race/ethnicity on the pain experience, pain management and pain management outcomes in older adults as well as older adult HCBWP participants.

Cognitive functioning. Cognitive functioning is vitally important to address in any pain-related research among older adult populations. Poor cognitive functioning, or cognitive impairment occurs in 37% to 41% of HCBWP participants, compared to 80% of nursing home residents (Fries, James, & Aliaga, 2004; L. Li & Conwell, 2007). Impaired cognitive functioning may influence the older adult's ability to report pain as well as the health care providers' ability to assess the patient's pain (Delgado-Guay & Bruera, 2008; Goldstein & Morrison, 2005). It is through pain-related behaviors (i.e. verbal reports of pain, grimacing, guarding etc) that the pain experience is conveyed by the patient to a health care provider (Sawyer, et al., 2006). The subjective report of pain is the gold standard for pain assessment, as pain is a subjective

experience and is best conveyed by the one who is experiencing the pain (American Pain Society, 2005; Dodd, et al., 2001; McCaffery, 1972). If changes in cognitive functioning alter the ability of the older adult to convey pain, then the older adult's pain experience may not be accurately conveyed. If the pain experience is not accurately conveyed, pain management (which is based on the pain experience) may be inadequate, thereby resulting in poor pain management outcomes.

Older adults with poor cognitive function consistently report less pain than cognitively intact older adults such that as the level of cognitive performance deteriorates pain prevalence decreases (Chu, Schnelle, & Osterwell, 2004; Duncan, et al., 2008; Procter & Hirdes, 2001; Sawyer, et al., 2006; Zyczkowska, et al., 2007) and this effect was noted in both nursing home and community-dwelling older adult populations. Reynolds, Hanson, DeVellis, Henderson and Steinhauser (2008) utilized a cross-sectional method to examine disparities in pain management between cognitively intact and cognitively impaired nursing home residents (n=551). Cognitively impaired older adults were more likely than cognitively intact nursing home residents to have their pain recognized as occurring less than daily and of mild severity. Reynolds et al. also noted that among nursing home residents, as the degree of cognitive impairment increased, the less likely the nursing home resident was to receive treatment for pain. Eighty-percent of cognitively intact nursing home residents received pain medications, while only 56% of those with cognitive impairment received pain medications (Reynolds, et al.).

In summary, about 37% to 41% of HCBWP participants have some degree of cognitive impairment (Fries, James, & Aliaga, 2004; L. Li & Conwell, 2007). For this study, cognitive functioning was treated as a covariate in analytic models in order to account for the negative effects of poor cognitive functioning on the pain experience, pain management and pain

management outcomes among older adult HCBWP participants. Cognitively impaired community dwelling older adults and older adults who are nursing home residents have their pain consistently assessed as less prevalent and severe as well as receive less analgesic medication than cognitively intact older adults (Chu, et al., 2004; Duncan, et al., 2008; Procter & Hirdes, 2001; Reynolds, et al., 2008; Sawyer, et al., 2006; Zyczkowska, et al., 2007).

Behaviors indicative of depression. Depressive symptoms are commonly associated with pain in research literature. Depressive symptoms and pain are associated with one another such that an increased number of depressive symptoms has been shown to predict worsening levels of pain among community dwelling older adults (n=241) (Rosso, et al., 2008). Sawyer et al. (2006) found that a presence of a sad/depressed mood was a significant predictor of substantial daily pain among nursing home residents, after controlling for other personal and facility-related factors. Community-dwelling older adults with reported pain are more likely to have depressive symptoms (Jakobsson, et al., 2003; L. Li & Conwell, 2007; Reyes-Gibby, et al., 2002), have a higher rate of developing a new onset of depressive symptoms, and have a slower resolution of depressive symptoms than older adults without pain (n=652) (Geerlings, et al., 2002). Therefore, pain is associated with depressive symptoms among older adults, with the presence of one increasing the likelihood of occurrence and worsening the prognosis of the other (Geerlings, et al., 2002; L. Li & Conwell, 2007; Reyes-Gibby, et al., 2002). Compared to older adult nursing home residents, HCBWP participants are half as likely to report “feelings of sadness or being depressed” (20% vs. 42%) (Fries, James, & Aliaga, 2004).

Researchers have struggled to determine the direction of the relationship between pain and depression. Chou and Chi (2007) completed a longitudinal study over one year to examine the relationship between depressive symptoms and pain among 457 elderly Chinese primary care

patients living in the community. Participants who reported pain at baseline were significantly more likely to report depressive symptoms one year later. However, the presence of depressive symptoms at baseline did not predict pain one year later (Chou & Chi, 2007), supporting that the direction of the relationship is from pain to depressive symptoms and not depressive symptoms to pain. In another longitudinal study, Geerlings and colleagues (2002) noted that the prognosis of comorbid pain and depressive symptoms was much worse than having depressive symptoms alone over a three year period among community-based older adults aged 55-85. The percentage of subjects developing depressive symptoms was more than three-times higher in those with pain at baseline when compared to subjects without pain at baseline (Geerlings, et al.). Additionally, Geerlings et al. found that pain and depressive symptoms had a reciprocal association where one predicted the other over the three year time span of the study.

In summary, pain and depressive symptoms are strongly associated with each other among older adults in both community and nursing home settings. Depressive symptoms are positively associated with worsening pain (Rosso, et al., 2008). The presence of pain increases the risk of developing depressive symptoms and of experiencing a slower resolution of depressive symptoms than older adults without pain (Geerlings, et al., 2002). Additional longitudinal research is needed to clarify the direction of the relationship between pain and depressive symptoms. HCBWP participants are half as likely to report feeling of sadness or depressed mood when compared to nursing home residents (Fries, James, & Aliaga, 2004). Although this result seems to potentially indicate less of a problem of depressive symptoms among HCBWP, the association between depressive symptoms and the pain experience, pain management and pain management outcomes of older adult, HCBWP participants has not been examined. Research is needed to examine behaviors indicative of depression among HCBWP

participants and its association with the pain experience, pain management and pain management outcomes.

Domain of Health and Illness. The domain of health and illness was comprised of variables unique to the HCBWP participant's state of health (Dodd, et al., 2001) and included variables defining comorbidity and cancer. These variables are frequently examined in research examining the pain experience, pain management and pain management outcomes among older adults in community and nursing home settings. The following is a review of the association between comorbidities and the pain experience, pain management and pain management outcomes among older adults residing in the community and in nursing homes. A review of the association between cancer and the pain experience, pain management and pain management outcomes among older adults residing in the community or in nursing homes will follow.

Comorbid conditions. Pain is known primarily as a symptom of injury or disease (Reyes-Gibby, Aday, et al., 2007). While the researcher acknowledges that chronic pain (pain lasting greater than six months) (Basbaum, et al., 2005; Greener, 2009) can be considered a chronic condition and therefore capable of occurring along with other conditions (i.e. comorbid), (Staud, Price, Robinson, Mauderli, & Vierck, 2004) this research did not distinguish between chronic and acute pain. Therefore, for the purposes of this research pain was conceptualized as a symptom influenced by the factor of comorbid conditions.

Comorbid conditions are noted to be the co-occurrence of conditions in relation to an index disease (Yancik, et al., 2007). For this research, cancer was conceptualized as the index disease. The researcher acknowledges that cancer may not in fact be the actual index disease experience by each subject and therefore the effect of the diagnosis of cancer may be influenced or superseded by the effect of an alternative index condition. The researcher also acknowledges

that the comorbid conditions may resolve over time and therefore, the effect of each comorbid condition on the pain experience, pain management strategies and pain management outcomes would change.

Older adult populations are at increased risk of experiencing conditions that are commonly associated with pain such as arthritis, diabetes and peripheral vascular disease (Bruckenthal & D'Arcy, 2007; Davis & Srivastava, 2003; Freedman, 2002; Yancik, et al., 2007). Prevalence rates of hip fracture, osteoporosis and diabetes among older adult HCBWP participants is 5%, 22% and 38% respectively (Fries, James, & Aliaga, 2004). The burden placed on the body from multiple, co-occurring conditions is referred to as pathologic load, which is an overriding factor contributing to the increased pain complaint among older adults (Helme & Gibson, 2001; Reyes-Gibby, Aday, et al., 2007). Among older adults, the risk and behavior of cancer is strongly associated with the presence of comorbid conditions and their related treatment (Extermann, 2007). Therefore, associations between comorbid conditions and the pain experience, pain management and pain management outcomes must be considered when examining pain among older adult populations.

Research results have confirmed the effect of pathological load on pain, concluding that increases in the number of comorbid conditions has an effect on pain prevalence, pain severity and pain interference among older adults. In research examining pain, frailty and comorbidity among 1705 community dwelling older men (age 70 and older), Blythe et al (2008) noted that having greater than one comorbid condition significantly and incrementally increased the risk of pain interference. The risk of presence of pain and pain severity is positively associated with the presence of comorbid conditions among community-dwelling and institutionalized older adults (Soldato, et al., 2007; Zyczkowska, et al., 2007). In summary, the presence of comorbid

conditions increases the risk of older adults experiencing pain, pain severity and pain interference (Blyth, et al., 2008; Soldato, et al., 2007; Zyzkowska, et al., 2007).

Specific comorbid conditions have been noted to cause more pain than others. Proctor and Hirdes (2001) utilized descriptive research to examine relationships among pain and cognitive status among Canadian nursing home residents. Among cognitively intact nursing home residents, those with arthritis, osteoporosis and pressure ulcers were more likely to experience pain than those with other conditions (Procter & Hirdes). In comparison, Reyes-Gibby et al. (2002) noted a higher prevalence of pain among community dwelling older adults with lung disease, heart disease and stroke. Sawyer et al. (2006) found that among older adult nursing home residents the presence of musculoskeletal disease, anemia and cancer were associated with a significantly greater likelihood of substantial daily pain. In summary, specific conditions have been found to be more highly associated with pain among older adults than other conditions: lung and heart disease, musculoskeletal disease, anemia, stroke and cancer (Procter & Hirdes, 2001; Reyes-Gibby, et al., 2002; Sawyer, et al., 2006).

The presence of comorbid conditions influences the provision of pain management among older adult HCBWP participants. For example, certain conditions, such as liver or kidney disease warrant caution in prescribing pain medications as these conditions affect drug metabolism (Goldstein & Morrison, 2005). Older adults often have complex clinical patient presentations, as they may have multiple, co-occurring chronic diseases (Duncan, et al., 2008; Goldstein & Morrison, 2005; McNeill, et al., 2007). As a result, health care providers may have concerns about drug interactions with other medications prescribed for chronic diseases which may affect pain management by limiting pain medication prescribing patterns (Duncan, et al., 2008; Goldstein & Morrison, 2005; McNeill, et al., 2007). Providers may be concerned about

opioid side effects with older adults and may therefore not prescribe opioid pain medications to older adults (Duncan, et al., 2008; Goldstein & Morrison, 2005; McNeill, et al., 2007).

In summary, older adults from community and nursing home settings are at increased risk of developing comorbid conditions and comorbid conditions increase the likelihood of older adults experiencing pain (Bruckenthal & D'Arcy, 2007; Davis & Srivastava, 2003; Freedman, 2002; Yancik, et al., 2007). The presence of comorbid conditions may act as a barrier to pain management, as clinicians may be more cautious in prescribing pain management due to side effects of medications and interactions with medications prescribed for comorbid conditions (Duncan, et al., 2008; Goldstein & Morrison, 2005; McNeill, et al., 2007).

Diagnosis of cancer. More than 60% of cancers diagnosed and 70% of cancer-related deaths occur in older adults (Yancik & Ries, 2000). Older adults are more likely to have pain at the time of diagnosis (Freedman, 2002; McNeill, et al., 2007). Pain has been noted to be one of the most distressing symptoms in patients with cancer (Laird, et al., 2008; Valeberg, et al., 2008). With cancer, pain may occur due to the cancer itself or to its treatment (Chang, et al., 2006). Older adults with cancer are more likely to experience pain when compared to older adults without a history of cancer in both community and nursing home settings (Buchanan, et al., 2005; Reyes-Gibby, Aday, et al., 2007; Rodin, 2008). Therefore, the presence of cancer may further increase the risk of pain in older adult HCBWP participants.

Past research has noted that 11% of nursing home residents have a diagnosis of cancer at admission and residents with a diagnosis of cancer were more likely to have pain when compared to residents without cancer at admission (Buchanan, et al., 2005; Rodin, 2008). Fries et al. (2004) noted that 11% of older adult HCBWP participants reported having been diagnosed with cancer (other than skin cancer) in comparison to 7% of nursing home residents. Other

research found that 20% of nursing home residents who reported daily, excruciating pain also have a diagnosis of cancer (Teno, et al., 2004). Because of the high prevalence of pain among older adult nursing home residents with cancer, Buchanan et al. emphasized the need for research examining the pain management needs of older adults with cancer and developing research comparing pain, pain management and pain management outcomes between older adult nursing home residents with and without cancer.

A diagnosis of cancer has an impact on the outcomes of physical function and pain control. Buchanan et al. (2005), in an analysis of nursing home residents with and without cancer (n=61,980) noted that a larger proportion of those with cancer were totally dependent and required extensive assistance with activities of daily living when compared to nursing home residents without cancer. Therefore, older adult nursing home residents with cancer have more physical function impairments than their cancer-free counterparts (Buchanan, et al., 2005). Regarding pain control, older adults with cancer who are community-dwelling or residing in a nursing home experience higher pain prevalence as well as higher pain severity than their cancer-free counterparts (Buchanan, et al., 2005; Duncan, et al., 2008; Reyes-Gibby, Aday, et al., 2007; Rodin, 2008). More frequent and severe pain may require more aggressive pain management than less frequent or milder pain. In summary, based on the above results among community-dwelling and nursing home-dwelling older adults, HCBWP participants with cancer may be more at risk for pain-related physical function impairment as well as potentially having more difficulty controlling pain.

In summary, older adults are more likely to be diagnosed with cancer when compared to younger populations. Older adults living in the community or in nursing homes and diagnosed with cancer report more pain than older adults without a diagnosis of cancer. Therefore, older

adults with cancer are at risk for experiencing pain above and beyond older adults without cancer. Older adult diagnosed with cancer and experiencing pain are more likely to experience physical function impairments as well as potentially needing more aggressive pain management. Additional research is needed to examine differences in the pain experience, pain management strategies and pain management outcomes of older adult HCBWP participants with and without cancer.

Summary

The above review of research presents the overall impact that age, sex, race/ethnicity, depression, cognitive functioning, comorbidities and cancer have on the pain experience, pain management strategies and pain management outcomes among older adults. The above review also presents the limitations in research that has examined associations among person and health and illness-related factors and pain, pain management and pain management outcomes. The results of this study will expand what is known regarding associations among age, sex, race/ethnicity, depression, cognitive functioning, comorbidities, cancer, the pain experience, pain management strategies and pain management outcomes among older adults. Most importantly, however, this study will add to the science by examining associations among person and health and illness-related factors and pain, pain management and pain management outcomes in an infrequently studied vulnerable population who is at risk for both pain and cancer (Green, et al., 2003; Ward, et al., 2004b).

The Pain Experience

Research Question 1 of this research determined what differences exist in the pain experience of older adult HCBWP participants over time in regards to diagnosis of cancer, while

controlling for age, sex, race/ethnicity, cognitive functioning, depression and comorbid conditions.

Pain is an unpleasant sensory and emotional experience (International Association for the Study of Pain, 2009) that is influenced by one's social history, cultural expectations, as well as individual differences in physiological, developmental and psychological makeup (Dodd, et al., 2001; Hollenack, Cranmer, Zarowitz, & O'Shea, 2006). The very foundation of physiological differences among persons, genetic makeup, is associated with differences in nerve functioning and sensitivity to painful stimuli (Diatchenko et al., 2006; Diatchenko et al., 2005; C. Miaskowski, 2009). The pain experience is the culmination of perceiving, evaluating and responding to pain (Dodd, et al., 2001). The human pain experience involves complex interactions of sensory, cognitive and behavioral factors which aging may influence (American Geriatrics Society Panel on Persistent Pain in Older Persons, 2002; Hollenack, et al., 2006). It is logical, therefore, to surmise that age-related changes in sensation and cognition would influence the perception of pain as well as the ability to evaluate and respond to pain and thereby impact the pain experience of older adult, HCBWP participants.

Age-related changes in sensation were reviewed and presented earlier in Chapter 3. To summarize: aging may lead to physiological changes in the nervous system that influence the perception and production of pain such that older adults may experience an increased and prolonged response to injury and pain stimuli, thereby placing older adults at risk of pain that persists or in need of extended pain management (Basbaum, et al., 2005; R. R. Edwards, et al., 2003; Gagliese & Farrell, 2005; Gibson & Farrell, 2004; Heinricher, 2005; Helme & Gibson, 2001; Zheng, et al., 2000). In addition to age-related changes in sensation, the presence of comorbidities such as cancer, cancer and arthritis can alter the sensation of painful stimuli

(Backonja, 2003; Chang, et al., 2006; Pasero, 2004; SAS System for Windows (Version 9.3.1)," 2002). Age-related increases in diseases associated with pain such as diabetes, cancer and arthritis are more likely to occur in older adults than in younger populations and place older adults at risk for pain (Bruckenthal & D'Arcy, 2007; Davis & Srivastava, 2003; Freedman, 2002).

Diabetes and chemotherapeutic treatments for cancer may both alter nerve function, leading to increased nerve sensitivity as well as ectopic and spontaneous nerve discharges (Backonja, 2003; R. Dworkin et al., 2003; Pasero, 2004). Cancer-related tumors can press on nerves or internal organs, causing pain. The added burden of cancer increases pain among older adults as nursing home residents with a diagnosis of cancer at admission were more likely to have pain when compared to residents without cancer at admission (Buchanan, et al., 2005; Rodin, 2008). In nursing homes, 20% residents who reported daily, excruciating pain also had a diagnosis of cancer (Teno, et al., 2004).

Arthritis is a common, chronic condition among older adults, affecting about 50% of community-dwelling older adults (Blyth, et al., 2008; Zyczkowska, et al., 2007). Chronic exposure to pain may lead to central sensitization where changes occur in the dorsal horn in the spinal cord that cause the threshold for nerve activation to be lowered, the response to stimuli increased, the size of the receptive field expanded (Beydoun & Backjona, 2003; Pasero, 2004), and inhibitory pathways are lost or suppressed (Pasero, 2004). Therefore, central sensitization leads to less stimuli being needed to produce pain as well as an alteration of the central nervous system's ability to inhibit incoming painful stimuli. In summary, age-related and disease and treatment-related changes in the nervous system may alter the production of and sensation of painful stimuli and therefore, the pain experience of older adults.

Based on the above evidence that older adults are at increased risk of experiencing pain due to age-related physiological changes and disease-related effects on the nervous system, one would expect that older adults would experience a greater prevalence of pain and more severe pain than younger adults. A higher pain prevalence and more severe pain is not clearly shown in research examining pain in older adults, as research findings of comparisons of pain prevalence between older and younger adults have been inconsistent (C. Given, et al., 2001; Jakobsson, et al., 2003; Sawyer, et al., 2006; Soldato, et al., 2007; Tsang, et al., 2008) and older adults have reported less severe pain than younger adults (Baker & Green, 2005; Zyczkowska, et al., 2007). This discrepancy between older adults being more at risk for pain than younger adults yet not having a consistent higher prevalence of pain or more severe pain than younger adults may be explained by characteristics of older adults that influence the evaluation and reporting of pain.

A clinician's awareness of a patient experiencing pain is dependent on the response to pain via the verbal report or through pain behaviors, which is preceded by the patient evaluating the pain (Dodd, et al., 2001; Humphreys & et al., 2008). Pain is evaluated by the patient in relation to its location, frequency as well as by its sensory and affective dimensions (Dodd, et al., 2001). Pain is multidimensional, having both a sensory dimension (level of severity, strength or overall magnitude of the pain) (C. S. Cleeland & Ryan, 1994; R. H. Dworkin, et al., 2005; Jensen, 2003) and an affective dimension (the extent to which pain affects or impacts day-to-day functioning) (C. S. Cleeland & Ryan, 1994; Jensen, 2003; Thomas, et al., 2004). Once pain is evaluated by the patient, the patient then responds by either ignoring the pain or reporting the pain via a verbal report and/or pain-related behaviors.

The resulting verbal report and/or pain behaviors can then be assessed. For this study the pain experience was assessed through the Pain Scale, a measure of both pain frequency and pain

intensity (Fries, et al., 2001). Pain is multidimensional, including sensory, affective and temporal dimensions (C. S. Cleeland & Ryan, 1994; Jensen, 2003). Therefore, the pain experience can be assessed by using measures of the different dimensions of pain. For example, pain intensity (sensory dimension) can be measured through the use of the numeric rating scale, the visual rating scale (C. S. Cleeland & Ryan, 1994; Jensen, 2003). The affective dimension of pain can be measured through a pain interference scale, which assesses how pain interferes with activities (C. S. Cleeland & Ryan, 1994; Jensen, 2003). Temporal aspects of pain can be measured by pain frequency or how often pain occurs i.e. daily, less than daily (Jensen, 2003).

In addition to the pain experience, pain control is assessed in the present research. Cancer pain guidelines (American Pain Society, 2005; National Comprehensive Cancer Network, 2006; WHO, 1996) recommend assessing changes in pain levels, impairments and frequency to determine the effectiveness of pain interventions. Allard, Maunsell, Labbe, and Dorval (2001) defined pain control as a result of “...routine assessment of pain characteristics and intensity, and analgesic treatment based on the regular intake of agonist opioids combined with additional doses of relief of breakthrough pain” (p. 192) and equated pain control with changes in pain levels. Shvartzman (2003) assessed cancer pain control with appropriateness of pain medication, as based on worst pain intensity levels, and whether or not pain levels were affected by medications and noted that pain control is related to adequate and correct treatment of pain. Miaskowski and colleagues (2002) used significant differences in pain intensity scores between around-the-clock pain medication dosing and as needed dosing to determine better pain control. Overall, cancer pain control was shown to be an outcome and equated with a decrease in or better values of pain levels, impairments and frequency due to pain interventions. Farrar, Berlin and Strom (Farrar, Portenoy, Berlin, Kinman, & Strom, 2000) noted that a decrease in pain

intensity scores of 33% overtime was equated with clinically significant difference in pain pre and post intervention. Due to data limitations, the researcher did not have knowledge as to the timing of the assessment of the pain experience in relation to the provision of pain management strategies. Additionally, because pain was assessed with the Pain Scale and not a numeric scale the researcher could not determine if changes in the pain experience were clinically significant.

Response to pain is shaped by the contribution of personal and social characteristics and is therefore, individualistic (American Pain Society, 2005). Awareness of these characteristics and their effect on response to pain assists in explaining "...discrepancies between expected pain, pain behaviors, and patient's self reports of pain" (American Pain Society, 2005, p. 22). Older adults may expect pain to be part of aging and disease processes and therefore, may underreport or be reluctant to report their pain (Delgado-Guay & Bruera, 2008; Goldstein & Morrison, 2005; Yong, Gibson, de L. Horne, & Helme, 2001). Among older adults, the ability to evaluate and to report pain may be compromised by the presence of cognitive impairment (Bruckenthal, 2008; Helme & Gibson, 2001). Cognitively impaired older adults consistently report less pain than cognitively intact older adults such that as the level of cognitive performance deteriorates pain prevalence decreases and this effect was noted in both nursing home and community-dwelling older adult populations. (Chu, et al., 2004; Duncan, et al., 2008; Procter & Hirdes, 2001; Sawyer, et al., 2006; Zyczkowska, et al., 2007). Proctor and Hirdes found that there was no difference between cognitively intact and impaired nursing home residents in the prevalence of diseases likely to cause pain, but the cognitively impaired nursing home residents had a significantly lower prevalence of pain than the cognitively intact nursing home residents. Cognitively impaired older adults report less pain not because they experience less pain-causing diseases than cognitively intact older adults, but because they are not able to

convey an accurate, understandable verbal report of pain (Chu, et al., 2004; Duncan, et al., 2008; Procter & Hirdes, 2001; Sawyer, et al., 2006; Zyczkowska, et al., 2007).

Because of the difficulties with pain assessment among cognitively impaired older adults, some researchers examining pain among older adults have chosen to exclude subjects with cognitive impairment (Soldato, et al., 2007). This however, would reduce generalizability of research results to older adults, as cognitive impairment may occur in 29% -82% of nursing home residents (Levin et al., 2007; Procter & Hirdes, 2001) and 37% to 41% in older adult, HCBWP participants (Fries, James, & Aliaga, 2004; L. Li & Conwell, 2007). Therefore, older adults with cognitive impairment represent a significant portion of nursing home residents and HCBWP participants and they should be included in research examining pain among older adults.

Summary. In summary, this research examined if differences exist in the pain experience of older adult HCBWP participants with and without a diagnosis of cancer over time. Despite being at high risk for developing diseases that are associated with pain as well as experiencing age-related changes in the nervous system, research results have not confirmed that older adults have a higher prevalence of pain compared to younger adults. This discrepancy may be explained in part by reluctance of older adults in reporting pain and the detrimental effect cognitive impairment has on the patient self-report of pain.

Even though the prevalence of pain among older adults is not higher than younger adults, pain remains prevalent among older adult populations. Pain prevalence among HCBWP participants has been reported to be 53-69% (Fries, James, & Aliaga, 2004; L. Li & Conwell, 2007). The prevalence of pain has been reported to be between 28% and 72% in community-dwelling older adults (Landi, et al., 2001; Reyes-Gibby, Aday, et al., 2007; Thomas, et al., 2004).

In comparison, pain prevalence has been estimated to be between 41% to 80% for older adult residing in nursing homes (American Geriatrics Society Panel on Persistent Pain in Older Persons, 2002; Teno, Weitzen, Wetle, & Mor, 2001; Won, et al., 2004). Pain is a prevalent problem among older adults. The study will fill a vital gap in the knowledge of the pain experience of older adult HCBWP participants.

The pain experience and the reporting of the pain experience is what pain management is based on. Accurate assessment of the pain experience is a necessary precursor to pain management as pain management would be difficult and dangerous to in the absence of basic knowledge of the patient's pain experience (Deane & Smith, 2008). In the following section, literature examining pain management strategies among older adults will be presented.

Pain Management Strategies

The first part of Research Question 2 of the study examined how the pain experience of older adult, HCBWP participants related to pain management strategies and how did this relationship differ in regards to diagnosis of cancer, while controlling for age, sex, race/ethnicity, cognitive functioning, depression and comorbid conditions. For the purposes of this research, pain management strategies will include both prescribed pain medications and the provision of hospice services.

Prescribed pain medications are categorized as non-opioid, opioid and adjuvant pain medications. Non-opioid medications include acetaminophen and non-steroidal anti-inflammatory (NSAID) medications such as ibuprofen or naproxen sodium and are useful for mild to moderate pain and in conjunction with opioid medications for more intense pain (American Pain Society, 2005). The mechanism of action for acetaminophen is still unknown, but it is postulated that it has a central nervous system mechanism, because of its pain and fever

reducing effects (Schug, 2005). In comparison, the mechanism of action of NSAIDs is well known. NSAIDs inhibit cyclooxygenase, an enzyme that catalyzes the production of prostaglandins, which are key instigators of the inflammatory process (American Pain Society, 2005). Because of this mechanism, NSAIDs are especially useful in treating inflammatory pain, as they prevent the very process that causes it (Samad, 2004).

Opioid pain medications are the medications most frequently used for moderate to severe pain because of their effectiveness, ease of titration, and favorable risk-to-benefit ratio (American Pain Society, 2005). Opioid medications include morphine, hydromorphone, methadone, codeine, oxycodone, hydrocodone, levorphanol, and fentanyl (American Pain Society, 2005). Opioid pain medications may be a combination of narcotic pain medications and acetaminophen or non-steroidal anti-inflammatory medications. Opioid medications act on opioid receptors which are found both peripherally and centrally in nerve tissue, in gastrointestinal, respiratory, and cardiovascular organs, and the bladder (Lipman & Gautier, 1997). One particularly opioid receptor-rich area in the central nervous system is the periaqueductal gray, which is a key area in the modulation or control of pain (Heinricher, 2005). When an opioid binds to the opioid receptor, an excitatory or inhibitory response occurs, which inhibits the transmission of pain impulses in the brain and spinal cord (Sweeney & Bruera, 2003).

The term adjuvant analgesics describes "...non-opioid medications that have pain-relieving effects in certain conditions, but whose primary or initial indication was not for the treatment of pain" (American Pain Society, 2005, p. 73). Medications that have been used as adjuvant pain medications include anticonvulsants and antidepressants (American Pain Society, 2005). Adjuvant medications diminish pain by altering nerve function. Anticonvulsants, such as

phenytoin and carbamazepine work by blockading the sodium channels and stabilizing the nerve membrane (Kalso, 2005). Antidepressants, such as amitriptyline increase the availability of neurotransmitters, block sodium channels, and block receptors (Kalso, 2005). If sodium channels are blocked, then nerve depolarization and stimulation will be affected, and nerve hyper-excitability is diminished (Kalso, 2005).

The type of pain medication prescribed (i.e. non-opioid, opioid, adjuvant) is an important indicator of pain management quality as pain management guidelines recommend specific types of medication in response to different reports of pain (American Pain Society, 2005; NCCN, 2006; NCI, 2006; WHO, 1996). While the researcher acknowledges that the management of pain can take place via medications and non-pharmacological or procedural interventions this study was limited to the use of prescribed pain medication data in Medicaid paid claim files. Since the purpose of the study is to examine differences in the pain experience, pain management and pain management outcomes among older adult HCBWP participants between those with and without a diagnosis of cancer the provision of hospice services for palliative care will be examined as well.

Literature describing and examining the issue of pain management among older adults is primarily framed by a discussion of barriers to pain management among older adults. The majority of older adult pain management literature is in clinical guideline format. Pain management barriers are described in terms of where the barrier originates: patient, provider or health care system (American Pain Society, 2005; NCI, 2006). Pain management barriers to the treatment of pain among older adults have been noted to take place at both during the pain assessment phase as well as during the provision of prescribed pain medication. The overarching goal of pain assessment in older adults is to provide successful pain management. Therefore,

pain management must be preceded by a successful and comprehensive pain assessment (Bruckenthal, 2008). This study was limited to a measure of the pain experience (pain frequency and pain intensity) taken approximately every three months and the data did not include information detailing when the assessment occurred in relation to the reception of pain management strategies. In the following section, literature describing pain management among community-dwelling and nursing home-residing older adults will be presented and discussed in accordance with where the barrier originates.

Patient Barriers to Pain Management among Older Adults. Patient-related barriers to pain management among older adults are primarily focused on older-adult factors that may prevent a valid pain assessment from taking place. An inadequate assessment would impact any resulting pain management. Older adults may expect pain to be part of aging and disease processes and therefore, may underreport their pain (Delgado-Guay & Bruera, 2008; Goldstein & Morrison, 2005). Older adults may fear being a nuisance to health care providers by reporting pain or may be concerned about the financial costs of extensive testing to determine the cause and treatment of pain (American Geriatrics Society Panel on Persistent Pain in Older Persons, 2002; Bruckenthal & D'Arcy, 2007). As noted earlier in this chapter, older adult nursing home residents who are cognitively impaired are less likely than a cognitively intact older adult to receive treatment for pain (Reynolds, et al., 2008). Reynolds et al. noted that 88% of cognitively intact nursing home residents received pain medications, while only 56% of those with cognitive impairment received pain medications.

Other patient-related barriers to pain management are not necessarily isolated to just older adults but may be common to all persons with pain and include issues of race/ethnicity and fears of addiction. White adults are significantly more likely to receive appropriate pain

management than adults from other racial groups and Hispanics with similar pain levels (Cintron & Morrison, 2006; Cleland, et al., 2005; Green, et al., 2003; Rodin, 2008; Won, et al., 2004).

Fears of addiction are a well known barrier to the use of opioid pain medications by persons with pain (American Pain Society, 2005; NCI, 2006).

In summary, patient-related barriers to pain management among older adults may include cognitive impairment, reluctance to report pain, race/ethnicity, and fears of addiction. These barriers inhibit a valid pain assessment from taking place and from the patient receiving adequate pain management strategies.

Provider-Related Barriers to Pain Management Among Older Adults. Professional barriers are behaviors that include inadequate knowledge of opioid medications and proper assessment and management of pain and concerns about controlled substance regulation and patient addiction (APS, 2005; Chang, Hwang, & Kasimis, 2002; JCAHO, 2000; Lin & Mathew, 2005; Sun et al., 2007). Healthcare providers assessing pain among older adults with cognitive impairment may be unfamiliar with assessing pain behaviors such as grimacing, moaning and agitation (Barkin, Barkin, & Barkin, 2005). Pain may be challenging for healthcare providers to accurately assess in older adults with cognitive changes or communication difficulties if pain-related behaviors must be assessed instead of verbal self-reports of pain (Delgado-Guay & Bruera, 2008; Goldstein & Morrison, 2005). However, pain behaviors may be a reliable indicator of response to pain management. In results from a pilot study, Elliot and Horgas (2009) noted that among community-dwelling older adults with dementia, pain behaviors decreased in frequency in response to scheduled acetaminophen dosing. For the purposes of the current study, the pain item is based on two pain measures which use patient verbal report of pain and verbal report by a proxy that the patient frequently complains of pain or shows evidence of pain via

pain behaviors and that the pain is unusually intense. The pain item therefore relies not only on the patient verbal report, but on the interpretation and report of patient behaviors by the proxy. The pain measure used in the study was the Pain Scale (Fries, et al., 2001) which is based on measures of pain frequency and intensity and is described in more detail in Chapter 4.

Health professionals may be hesitant to treat pain aggressively in older adults due to concerns about opioid side-effects, complex clinical presentations, as well as drug interactions with other medications prescribed for comorbid conditions (Duncan, et al., 2008; Goldstein & Morrison, 2005; McNeill, et al., 2007). Health professions may have inadequate knowledge of the treatment of pain in older adults with comorbid conditions and the best pain medication choices for those with organ impairment (Bruckenthal & D'Arcy, 2007). Older adults may experience pain that is persistent or chronic in nature due to the lingering conditions they are at increased risk for experiencing, such as osteoarthritis and diabetes. Chronic pain, unfortunately, is often negatively associated with psychiatric problems, drug seeking and futility in treatment by healthcare providers and may prevent the health care provider from treating an older adult's pain aggressively (American Geriatrics Society Panel on Persistent Pain in Older Persons, 2002).

In summary, provider-related pain management barriers among older adults include inappropriate pain assessment skills of pain in older adults, lack of knowledge of pain management among older adults and fears of addiction. These barriers act to prevent the older adult from receiving adequate pain management.

System-Related Barriers to Pain Management. Older adults may receive health care services in a number of settings. In the community they may receive pain management via home care and/or primary care in clinics; they may reside in nursing homes and receive pain

management there; and finally, in relation to the study, receive pain management services, including hospice services, while participating in the HCBWP.

The healthcare system has an obligation to provide comfort and pain management for older patients (American Geriatrics Society Panel on Persistent Pain in Older Persons, 2002). Both JCAHO (2001) and the American Pain Society (2005) have noted that there may be poor reimbursement of the most appropriate pain treatments and therefore, these effective treatments may be too costly for patients. The provision of pain management and hospice services is of key importance in the population of interest for the study, as the HCBWP provides services for poor older adults who are dual eligible for Medicaid and Medicare services and pain management coverage and hospice services may be limited.

In addition to limited insurance coverage, older adults may receive poor pain management due to where they receive pain management services. Pain experienced by older adult nursing home residents is poorly assessed and under treated (Fisher, et al., 2002; Reynolds, et al., 2008; Sawyer, et al., 2006; Won, et al., 2004). Weissman, Griffie, Muchla and Matson (2001) noted that the organization of nursing home care presents an obstacle to effective pain management. Nursing home-related obstacles to effective pain management include that physicians are rarely on site, that nursing assistants are the primary care providers and are untrained in pain assessment and there is a reluctance to use narcotic pain medications due to fear of scrutiny by state and federal surveyors (Weissman, et al.). Older adults receiving home care services at home are also at risk of poor pain management due to patient, provider and system-related barriers to pain management (Delgado-Guay & Bruera, 2008; Goldstein & Morrison, 2005; Lin & Mathew, 2005; Sun, et al., 2007). Soldato et al. (2007) noted that among 1520 older adult home care recipients 46% had daily pain, but only 38% were taking pain

medications. In summary, older adults are at risk for poor pain management in both home care and nursing home health care settings.

In addition to prescribed pain medication, the study examined the use of hospice services as a pain management strategy. Hospice, as a health care service provider, provides palliative rather than curative care and coordinates the provision of medical, emotional and spiritual care for terminally ill patients (life expectancy of less than 6 months) and their families (Hospice Association of America, 2006). While hospice services are primarily equated with care of persons with cancer, patients with a terminal prognosis due to other diseases may receive hospice services as well such as heart failure, chronic obstructive pulmonary disease (COPD) and dementia and Alzheimer's disease (Locher, et al., 2006; Rodin, 2008). Ersek and Wilson (2003) noted that as the U.S. population continues to age, end of life and hospice services will become an increasingly important issue to address.

Palliative and hospice care serves to identify goals for care, provide effective prevention and management of end of life symptoms such as dyspnea and pain, provide attention to psychosocial and spiritual issues and prevention of suffering, and assist with completion of developmental tasks related to the dying process and successful negotiation of the grief and bereavement processes (Ersek & Wilson). The provision of hospice services can take place in the home, nursing homes, hospitals or hospice centers (Hospice Association of America). The provision of hospice services in nursing homes has been examined and found to be lacking. Among older adult nursing home residents with cancer (n=61, 890), 67% had a terminal diagnosis, but only 19% were receiving hospice services (Buchanan, et al., 2005). Similarly, Duncan, Bott, Thompson and Gajewski (2009) found that among nursing home residents with cancer, 30% had clinically deteriorated within three months of admission and needed improved

symptom management (pain, dyspnea and weight loss). However, only 11.9% were receiving hospice services (Duncan, et al.).

Despite its limited use in nursing homes, hospice services has been shown to provide high quality end of life care and result in positive outcomes, such as reduced hospitalizations and improved pain management (Stevenson & Bramson, 2009). As HCBWP are an alternative to nursing home care, knowledge is needed regarding the use of hospice services among older adults and to make comparisons regarding hospice use between HCBWP participants with and without cancer.

Summary. In summary, pain management among other older adults is often inadequate, as patient, provider and health care system-related barriers prevent adequate pain management from taking place (Duncan, et al., 2008; Goldstein & Morrison, 2005; McNeill, et al., 2007). In the study, pain management strategies will include prescribed pain medications and the provision of hospice services. Hospice services are not only be provided for those with cancer, but also older adults with other chronic, terminal illnesses such as heart failure, COPD, dementia and Alzheimer's (Locher, et al., 2006; Rodin, 2008). In nursing homes, hospice services are not provided as frequently as they perhaps should be, based on reported symptoms and terminal prognosis (Buchanan, et al., 2005; Duncan, et al., 2009). Because HCBWP are designed to be an alternative to nursing home care, knowledge is needed regarding the use of hospice services in HCBWPs. Associations between the pain experience and pain management strategies and pain management outcomes can then be examined.

Pain Management Outcomes

Outcomes are the end results of care (Patrick, 1997). In the Symptom Management Theory (Figure 1), outcomes are conceptualized as including symptom status, functional status,

emotional status, self-care, costs, quality of life, morbidity/co-morbidity and mortality (Dodd, et al., 2001; Humphreys & et al., 2008). While the researcher acknowledges the importance of all of the above outcomes pain management outcomes were limited to physical functioning and pain control for the present research. Physical functioning and participant ratings of improvement and/or satisfaction with treatment have been noted to be core outcomes for pain clinical trials (R. H. Dworkin, et al., 2005). Pain control is conceptually defined as an outcome of pain management whereby pain is perceived by the patient or proxy as limited or decreased from a previous pain level and is an indicator of the effectiveness of pain management strategies (Allard, et al., 2001; Christine Miaskowski, et al., 2002; Oliver, et al., 2001; Shvartzman, et al., 2003). For this study, pain control was represented by the HCBWP participant's or proxy's response to the statement "pain controlled by medication". The Initiative on Methods, Measurement and Pain Assessment in Clinical Trials (IMMPACT) supports the use of activities of daily living as a fundamental measure of physical functioning to determine the effect of pain and pain management strategies on physical function (R. H. Dworkin, et al., 2005; Turk, et al., 2003). For this study, physical functioning was conceptualized as the dependency of the older adult waiver participant in activities of daily living (ADL). The second part of Research Question 2 of the study examined how the pain experience of older adult, HCBWP participants related to pain management strategies and pain management outcomes of physical functioning and pain control and how these relationships differed in regards to diagnosis of cancer, while controlling for age, sex, race/ethnicity, cognitive functioning, behaviors indicative of depression and comorbid conditions.

Physical Functioning. Decreased physical functioning has been noted to be a serious consequence of pain as it fosters learned helplessness, social isolation and greater healthcare

costs because of more dependencies in activities of daily living and therefore, more nursing care needs (Weiner & Hanlon, 2001). Associations between pain and physical functioning have been found to occur among both community-dwelling older adults as well as older adult nursing home residents (Jakobsson, et al., 2003; Soldato, et al., 2007; Teno, et al., 2004). Soldato and colleagues (2007) assessed the association between pain and risk of developing a need for assistance with the following activities of daily living (ADL): eating among 1,520 older adults receiving home care services: dressing, transferring, mobility in bed, personal hygiene or bathing. When compared to older adults with no pain, older adults with daily pain had a increased hazard of developing new onset disability even after controlling for age, gender, flare-up of comorbid conditions, number of comorbid conditions and level of physical activity (Odds Ratio=1.36, CI=1.05-1.78) (Soldato, et al.). Compared to older adults with no painful sites, older adults with multiple pain sites had an increased hazard of developing a need for assistance with ADLs (Odds Ratio=1.56, CI=1.13-2.15) (Soldato, et al.).

Jakobsson, Klevsgard, Westergren and Hallburg (2003) identified variables associated with pain prevalence among 4, 093 older adults aged 75 and older residing in nursing homes and in the community. Jakobsson and colleagues utilized a measure called *functional health status* which was comprised of items which assessed walking, mobility and activities of daily living including personal hygiene, food intake and dressing. Pain was reported by 40.4% of subjects. When compared to older adults without pain, older adults with pain were significantly more likely to experience walking problems, mobility problems, as well as require assistance with activities of daily living (Jakobsson, et al., 2003). Teno, Kabumoto, Wetle, Roy and Mor (2004) completed a cross-sectional analysis of data from 2,138,442 assessments of nursing home residents to examine associations between excruciating daily pain outcomes among nursing

home residents and demographic characteristics, functioning (cognitive functioning, activities of daily living and change in self-sufficiency) and measures of disease burden. Activities of daily living was measured by a *Activities of Daily Living Score* which ranged from 0=minimal oversight for ADL to 5=high dependence. When compared to older adults who did not have daily, excruciating pain older adults with daily, excruciating pain were more likely to require greater than or equal to extensive assistance with ADLs (69% vs. 62%). In summary, pain is associated with physical functioning among older adults in both community and nursing home settings.

Pain Control. Pain control is a key outcome in pain management as the goal of pain management is to reduce or control pain. Allard, Maunsell, Labbe, and Dorval (2001) describe pain control as a result of “ ...routine assessment of pain characteristics and intensity, and analgesic treatment ...” (p. 192). Among younger adults and in pain management guidelines pain control is equated with decreased or diminished pain level, impairments or frequency in response to a pain management intervention (American Pain Society, 2005; Carpenter, Hastie, Morris, Fries, & Ankri, 2006; Christine Miaskowski, et al., 2002; NCCN, 2006; NCI, 2006; Oliver, et al., 2001; Shvartzman, et al., 2003). For the purposes of the present study, pain control was conceptually defined as an outcome of pain management whereby pain is perceived by the patient or proxy as limited or decreased from a previous pain level and is an indicator of the effectiveness of pain management strategies (Allard, et al., 2001; Christine Miaskowski, et al., 2002; Oliver, et al., 2001; Shvartzman, et al., 2003).

Research examining pain and pain management in older adults in either nursing homes or community settings has been primarily cross-sectional (Reynolds, et al., 2008; Won, et al., 2004) and not longitudinal, where response to pain management strategies could be measured overtime.

Elliott and Horgas (2009) measured both frequency and duration of pain behavior in a longitudinal pilot study, noting a decline in pain frequency and duration in response to scheduled acetaminophen dosing among community-dwelling older adults with Alzheimer's disease. The present study used longitudinal methods to assess pain control over time among HCBWP participants in response to pain management strategies. Pain control was operationalized as a yes or no response via patient or proxy to the question "Pain controlled by medication?"

Conclusion of Pain Management Outcomes. In conclusion, physical functioning is associated with pain among older adults residing in nursing homes and in the community (Jakobsson, et al., 2003; Rosso, et al., 2008; Soldato, et al., 2007; Teno, et al., 2004). The outcome of pain control determines if the patient or a proxy noted a limited or decreased pain level through the use of pain management strategies and is an indicator of the effectiveness of pain management strategies (Allard, et al., 2001; Christine Miaskowski, et al., 2002; Oliver, et al., 2001; Shvartzman, et al., 2003).

Time and Pain

This research examined differences in pain, pain management strategies and pain management outcomes among those with and without cancer over time in the HCBWP. Pain, pain management strategies and pain management outcomes have strong temporal (time-related) components and occur as a series of events (Henly, et al., 2003). Temporal aspects of pain consist of variation of pain over time, how frequently pain occurs, as well as the duration of pain (Jensen, 2003). The perception, evaluation and response to pain, as presented in the Symptom Management Theory (Humphreys & et al., 2008) not only occur over time, but are affected by the past events over time. For an older adult, the perception, evaluation and response to pain are influenced by a lifetime of personal, environmental and health and illness events. For example,

one's perception, evaluation and response to pain are affected by beliefs and culture (Cleland, Palmer, & Venzke, 2005). Chronic exposure to pain leads to permanent structural changes in the CNS that includes death of inhibitory neurons, replacement with new excitatory neurons, and creation of aberrant excitatory synaptic connections (Samad, 2004). These changes result in an increased area which dorsal field neurons respond to, thereby extending pain sensitivity well past the site of injury (Miaskowski, 2004). Patients can experience pain that is persistent (greater than 12 hours per day) and or transient exacerbations of significant or severe pain or "breakthrough" pain (Mishra, Bhatnagar, Chaudhary, Pratap, & Rana, 2009).

Pain management strategies are associated with time through the scheduling or timing of pain management strategies and pharmacokinetics. Pharmacokinetics is activity of drugs in the body over a period of time, including the processes by which drugs are absorbed, distributed in the body, localized in the tissues, and excreted (NCI, 2010a). Pain medications can include either short or long-acting pain medications, treating pain that may be either sporadic (as needed) or continuous (scheduled) across time (American Pain Society, 2005; NCI, 2010b).

Pain management outcomes are the end results of care (Patrick, 1997) and should be assessed after the provision of pain management interventions (Humphreys & et al., 2008). The assessment of pain management outcomes should be timed to occur after an intervention has had an effect. For example, pain management guidelines recommend that the level of pain is reassessed after a dose of pain medication has had time to act, based on pharmacokinetics (American Pain Society, 2005; NCCN, 2010; NCI, 2010b). A limitation in this research was that the timing of pain management strategies and assessment of outcomes was not known from the study data. Instead, the pain management outcomes of physical function and pain control and the pain management strategy of hospice services were assessed approximately every 90 days,

with the measure of prescribed pain medications including all prescribed pain medications in the 30 days prior to assessment (described in more detail in Chapter 4).

In summary, pain, pain management and pain management outcomes occur over time and therefore, longitudinal research may be a better choice than cross-sectional research to examine relationships among pain, pain management and pain management outcomes over time among older adults with and without a diagnosis of cancer. Optimally, pain management outcomes should be assessed within specific time periods after the provision of pain management strategies. This research was limited by the lack of information regarding the timing of pain management strategies and assessment of outcomes in the study data, i.e. it could not be known how much time transpired between the taking of pain medications or reception of hospice services and the assessment of pain management outcomes.

Admission of HCBWP Participants to Nursing Homes

The overall purpose of the HCBWP is to provide Medicaid covered home care services to those 18 and older who are at risk for nursing home placement because of the need for assistance with activities of daily living or medical services, in order to delay or avoid the high costs of institutional long-term care (D'Souza, et al., 2009; Sands, et al., 2008; Shugarman, et al., 1999). As the goal of the HCBWP is to prevent or delay nursing home admission (Fries, et al., 2002), knowledge gained about the impact of the pain experience, pain management strategies and pain management outcomes on admission of HCBWP participants to nursing homes and differences between HCBWP participants with and without a diagnosis of cancer would be beneficial for guiding the development of care strategies for assisting older adults in staying in the community and avoiding institutionalization. Research Question 3 of the study guides an examination of the effect of the pain experience, pain management strategies and pain management outcomes on the

admission of HCBWP participants to nursing homes. The review that follows will examine predictors of admission of older adults to nursing homes. Research examining predictors of nursing home placement among older adults addresses two populations: a general older adult placement and older adults with dementia and/or diagnosis of Alzheimer's disease.

Predictors of Nursing Home Admission among a General Older Adult Population.

In a meta-analysis of 77 reports that included community-based samples and longitudinal designs Gaugler, Duval, Anderson and Kane (2007) noted that the strongest predictors of nursing home admission were three or more activities of daily living (ADL) dependencies, cognitive impairment and prior nursing home use. In a 14-year longitudinal study of 2,805 Australian elders there was a 9% nursing home rate (McCallum, Simons, Simons, & Friedlander, 2005). Forty-four percent of these placements were due to dementia, with dementia being listed as a secondary diagnosis on admission in an additional 20% of the admissions. Urinary incontinence, impaired peak flow, physical disability and depression were other significant predictors of nursing home admission in this sample (McCallum, et al.).

In summary, the strongest predictors of nursing home placement among a general population of community-dwelling older adults were ADL/physical deficiencies, cognitive impairment, prior nursing home use, urinary incontinence, depression and impaired peak flow.

Predictors of Nursing Home Admission Among Older Adults with Dementia.

Separate research has examined predictors of admission of older adults with cognitive impairment or dementia to nursing homes. Results of a systematic review of 80 studies by Gaugler et al. (2009) noted that among older adults with dementia the most consistent predictors of a nursing home admission were severity of cognitive impairment, diagnosis of Alzheimer's disease, basic activities of daily living (ADL) dependencies, behavioral symptoms and

depression. Caregiver characteristics that predicted nursing home admission included indication of greater emotional distress, desire to institutionalize the care recipient and feelings of being “trapped” in care responsibilities (Gaugler, et al., 2009).

Yaffe et al. (2002) performed an analysis of data from the Medicare Alzheimer’s Disease Demonstration and Evaluation study to develop and validate a predictive model of predictors of nursing home placement of 5, 788 community-living persons with advanced dementia. Patient characteristics that were predictive of nursing home placement were black race or Hispanic ethnicity, living alone, one or more ADL dependencies, high cognitive impairment and one or more difficult behaviors. Caregiver characteristics predictive of care recipient admission to a nursing home included caregiver age of 65 or older and high care giver burden (2002). Gaugler et al. (2000) noted that caregivers of cognitively impaired older adults who received assistance from family members in overnight monitoring and ADL performance were significantly less likely to admit the care recipient to a nursing home than care givers who did not receive assistance.

In summary, the predictors of older adults with dementia being institutionalized were similar to older adults from a general population and included level of cognitive impairment, physical impairment and behavior issues. Caregiver characteristics that predicted institutionalization of older adults with dementia included older age, high care giver burden and not receiving assistance in ADL and night supervision.

Of interest in this study is the association of the pain experience, pain management strategies and pain management outcomes to the admission of older adults to a nursing home. Pain is highly associated with impairment in physical function and depression and impaired ADL performance or physical functioning and depression is associated with admission to a nursing

home. Therefore, the pain experience, pain management strategies and pain management outcomes may have a role in the admission of HCBWP participants to a nursing home.

Time to Admission to Nursing Home. For Research Question 3, which examines predictors of nursing home admission, time to admission will also be explored. Because a goal of the HCBWP is to prevent or delay nursing home admission (Fries, et al., 2002), the amount of time spent in the HCBWP program prior to admission to a nursing home is important consideration. If the pain experienced, pain management strategies received and assessed pain management outcomes are predictive of time to nursing home admission then information gained from this study can guide the development of pain assessment and pain management strategies for HCBWP participants. Additionally, if there are differences in predictors of admission to a nursing home and time to admission between older adult HCBWP participants with and without a diagnosis of cancer, focused pain assessment and pain management strategies can be developed for older adult HCBWP participants at higher risk for nursing home admission. These associations will be examined via the third research question of the study.

Conclusion of Chapter 3

The primary purpose of this study was to examine longitudinal differences in the pain experience, pain management strategies and pain management outcomes among older HCBWP participants with respect to diagnosis of cancer while participating in the HCBWP. The secondary purpose of this study was to determine what differences exist in how the pain experience, pain management strategies and pain management outcomes among older adult, HCBWP participants associates with the admission of older adult HCBWP participants to a nursing home, with respect to diagnosis of cancer, over the course of time while participating in the HCBWP.

The above literature review presented findings from research examining the pain experience, pain management and pain management outcomes of community-dwelling older adults and older adult nursing home residents and predictors of nursing home admission. Community-dwelling older adults and nursing home residents are at high risk for pain, poor pain management and poor pain management outcomes and which older adults with cancer are more likely to experience pain than older adults without cancer.

This study addressed a vital gap in the literature addressing the needs of frail, poor, older adults, as there is no known research examining differences in the pain experience, pain management strategies, pain management outcomes or admission to a nursing home between older adult, HCBWP participants with and without a diagnosis of cancer overtime. Chapter 4 follows and will present a thorough description of the research design and methods which were utilized to address the research questions of the study.

Chapter 4

The purpose of Chapter 4 is to present design and methodology of the study. First, the design, sample and setting of the study are introduced. Next, instruments, operational definitions and measurement of experimental variables are presented. Last, the proposed data analysis plan, data management and protection of human subjects are described.

The study is a secondary analysis of a large dataset comprised of data from Michigan Medicaid paid claims files and eligibility data; the Minimum Data Set Home Care (MDS-HC); and Michigan Cancer Registry and death certificate information from the Michigan Division for Vital Records and Health Statistics. The study is a longitudinal, descriptive design that utilized data obtained over the time period that subjects participated in the state of Michigan Home and Community-Based Waiver Program (HCBWP), known as MIChoice.

Purpose and Research Questions

The primary purpose of this study is to examine longitudinal differences in the pain experience, pain management strategies and pain management outcomes among older HCBWP participants with respect to diagnosis of cancer while participating in the HCBWP. The secondary purpose of this study is to determine what differences exist in how the pain experience, pain management strategies and pain management outcomes among older adult, HCBWP participants associates with the admission of adult HCBWP participants 65 and older to a nursing home, with respect to diagnosis of cancer, over the course of time while participating in the HCBWP. The study answered the following research questions:

Among HCBWP participants 65 and older and with a minimum of five Minimum Data Set-Home Care assessments:

- 1) How does the pain experience differ between older adult HCBWP participants in regards to diagnosis of cancer over time? How is the relationship between the pain experience and diagnosis of cancer affected by sex, age, race, comorbid conditions, behaviors indicative of depression and cognitive functioning over time?
- 2) How does the pain experience of older adult, HCBWP participants relate to pain management strategies and pain management outcomes and how does this relationship differ in regards to diagnosis of cancer over time? How is the relationship between the pain experience, pain management strategies, pain management outcomes and diagnosis of cancer affected by sex, age, race, comorbid conditions, behaviors indicative of depression and cognitive functioning over time?
- 3) How do the pain experience, pain management strategies and pain management outcomes of older adult, HCBWP participants predict the admission and time to admission of older adult HCBWP participants to a nursing home over time and how does this relationship differ in regards to diagnosis of cancer while accounting for sex, age, race, comorbid conditions, behaviors indicative of depression and cognitive functioning?

The above research questions follow a natural progression from the assessment and management of pain in a HCBWP to whether pain, pain management or pain management outcomes among HCBWP participants act as predictors of admission to a nursing home from a HCBWP in regards to diagnosis of cancer.

Sample

The target sample for the study were older adults aged 65 and above who participated in the Michigan Medicaid HCBWP, known as MICHoice and who had a minimum of five

assessments. Assessments were completed using the Minimum Data Set Home Care assessment tool on admission and quarterly thereafter. The Minimum Data Set Home Care (MDS-HC) will be described in detail later in this chapter.

The sample consists of older adults aged 65 and above who were continuously Medicaid-eligible between 1/1/2002-12/31/2005 and who were enrolled in the MIChoice HCBWP between 1/1/2003-12/31/2005 (See Figure 1 for Sample Selection Flow Chart). Continuous Medicaid eligibility was required as Medicaid eligibility can vary month to month depending on assets and thus, data from subjects who lose eligibility, are discharged from the HCBWP and then re-enter at a later date could be sporadic. Requiring continuous Medicaid eligibility ensures multiple assessment measures over time for each subject in order to complete longitudinal analysis.

The date restrictions were selected because Medicare Plan D, which provides prescription drug coverage for Medicare beneficiaries, began 1/1/2006. Older adult HCBWP participants aged 65 and older may be eligible for both Medicare and Medicaid coverage. The proposed data set does not include Medicare data, as the researcher did not have access to Medicare paid claim files. The study did however have access to Medicaid paid claim files. In order for Medicaid to be the sole payer for pain medications so that prescribed pain medications could be ascertained, the dataset was restricted to the time period before Medicare Part D began.

Additional inclusion criteria required a minimum of five MDS-HC assessments and that the five MDS-HC assessments were completed by 12/31/2005. As the MDS-HC is completed at admission and quarterly, a minimum of five assessments would allow for a minimum of approximately one year's worth of data for analysis. Analysis of data will begin at the second assessment in order to allow for 30 days prior to the second assessment to examine the Medicaid

paid claim files for the billing of pain medications. The second assessment will be referred to as “Time 1” beginning in Chapter 5.

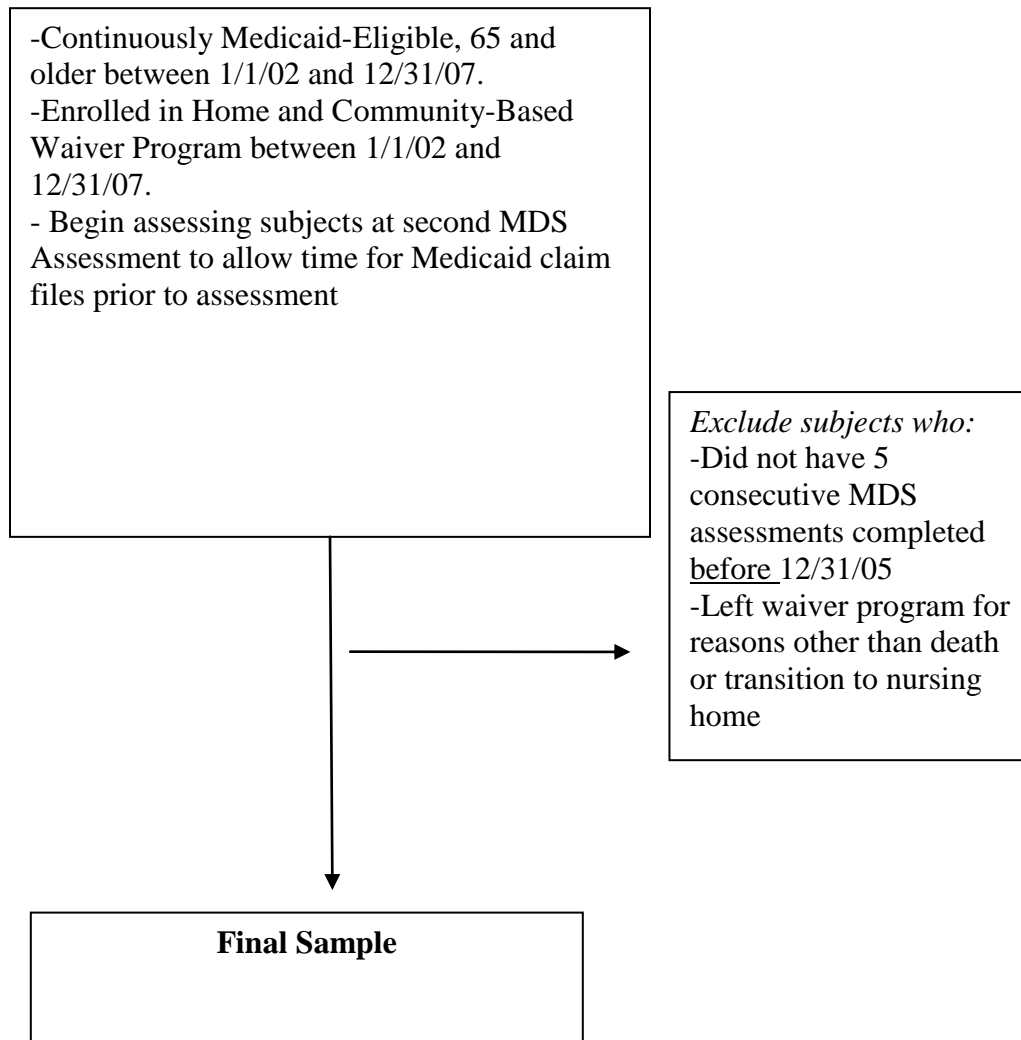


Figure3. Proposed Sample Selection Flow Chart

Setting

The data for the study were collected from MIChoice participants in private homes, assisted living and group homes and nursing homes throughout the state of Michigan as part of

the assessment of participants in the MIChoice program. A brief history and description of the HCBWP and MIChoice follows.

The Medicaid Home and Community Based Waiver Program (HCBWP) was established by the Omnibus Budget Reconciliation Act of 1981 (OBRA-81) and was incorporated into the Social Security Act at Section 1915(c) (Duckett & Guy, 2000). Medicaid is a joint federal and state program that provides health insurance coverage to certain categories of low-income individuals, including children, pregnant women, parents of eligible children, persons with disabilities and older adults (Centers for Medicare & Medicaid Services, 2005). Prior to the OBRA -81, Medicaid coverage of home and community-based services was limited and favored institutional-based care for long-term care needs (Duckett & Guy, 2000; Marek, et al., 2005).

The OBRA-81 supported the expansion of Medicaid coverage of home care benefits provided by individual states via “Medicaid waivers” (Shugarman, et al., 1999). Medicaid waivers “waive” certain regulatory requirements regarding individual state’s Medicaid plans thereby easing the expansion of Medicaid-covered home and community-based services (Kitchener & Harrington, 2003; Kitchener, et al., 2004; Shugarman, et al., 1999). The overall purpose of the waiver program is to provide Medicaid-covered home care services to those 18 and older who are at risk for nursing home placement in order to delay or avoid more expensive institutional long-term care (Shugarman, et al., 1999). Services covered under waiver programs may include homemaker services, respite care, adult day care, environmental modifications, transportation, medical supplies, personal emergency response system, private duty nurse, counseling, home delivered meals, physical and occupational therapy and personal care supervision (Shugarman, et al., 1999).

The state of Michigan's HCBWP was initiated in 1992 and expanded statewide in 1998 and became part of MIChoice (L. Li & Zullo, 2003; Shugarman, et al., 1999). The MIChoice waiver program is managed by the Michigan Department of Community Health, which contracts with home health agencies, Area Agencies on Aging, community mental health boards and private nonprofit organizations across the state to provide the program at a regional level (L. Li & Zullo, 2003; Tilly & Kasten, 2001). MIChoice waiver participants must meet financial and medical eligibility criteria for Medicaid-funded nursing home care in order to receive waiver services (Fries, James, Hammer, Shugarman, & Morris, 2004; Shugarman, et al., 1999). Financially eligible persons include those currently receiving supplemental social security income or those with income at or below 300% of the SSI level (Fries, et al., 2002). Medical eligibility is determined via a two-step process. First, the potential participant who desires home and community based services or a representative calls a waiver agent program for a 15-20 minute telephone-screening by the waiver agent (Fries, James, Hammer, et al., 2004). The screening process determines level of care (nursing home, home care, intermittent personal care, homemaker services and information and referral with no formal services) needed by the potential participant based on care needs (Fries, James, Hammer, et al., 2004).

MIChoice participants designated by the telephone screening as requiring nursing home level of care are then prioritized by the waiver agency to receive a second, more thorough in-person assessment by team of a registered nurse and social worker to determine if the potential participant meets criteria for nursing home care (Fries, James, Hammer, et al., 2004; Fries, et al., 2002; L. Li & Zullo, 2003). Criteria for nursing home level of care is defined as having functional limitations in activities of daily living, complex and unstable medical needs, failing social supports, a recent history of hospitalization, and/or requiring care by a trained aid (Fries,

James, Hammer, et al., 2004; Shugarman, et al., 1999). If the individual is determined to need nursing-home level care, they are admitted to the MiChoice waiver program.

At or shortly after admission to the MiChoice waiver program and quarterly thereafter, an assessment takes place in the participant's home, nursing home or hospital room utilizing the Minimum Data Set Home Care (MDS-HC) instrument. The MDS-HC is a comprehensive, standardized questionnaire for evaluating the care needs, strengths and preferences of clients of home care agencies (Landi et al., 2000) and has been validated for use in United States and international populations (Kwan, Chi, Lam, & Chou, 2000; Landi, et al., 2000; Morris, Fries, Steel, et al., 1997). The MDS-HC is comprised of 223 items that assess home care clients' sociodemographic characteristics, functional and cognitive status, social support, psychosocial well-being, clinical diagnoses and nursing needs relevant to care planning (Landi et al., 2005; Morris, Fries, Steel, et al., 1997; Shugarman, et al., 1999). Additional information regarding the MDS-HC will be presented in the section in this chapter detailing Instruments and Measures.

Instructions detailing the process of administering the MDS-HC are presented in the MDS-HC instruction manual (Morris, Fries, Bernabei, et al., 1997) for the version of the MDS-HC used by MiChoice during the inclusion dates for the proposed research. The MDS-HC items consists of questions which are primarily asked of the waiver participant if possible or the caregiver or family member of the waiver participant if the waiver participant is not capable of responding (Morris, Fries, Bernabei, et al., 1997). Observations of the waiver participant are also to be made by the assessor (Morris, Fries, Bernabei, et al., 1997). The potential for information for key study variables by proxy is included in the operational definitions and measures.

Data Sources

Data for this study were obtained for the time period when subjects were participating in the MIChoice HCBWP. Sources of data include Michigan Medicaid paid claims files, the Michigan Cancer Registry Data and death certificate data from the Michigan Division for Vital Records and Health Statistics and the Minimum Data Set Home Care. However, the primary source of data for the study is the Minimum Data Set Home Care (MDS-HC), version 1 instrument (Morris, Fries, Steel, et al., 1997). Development of and access to this combined dataset was overseen by the Institute of Health Care Studies (IHCS) at MSU. Additional information regarding the creation of the dataset will be presented in the Procedures section. Each data source will be described in more detail in the following.

Michigan Medicaid Paid Claim Files. Medicaid is a health insurance program for persons with low incomes and resources that is jointly funded by the federal and state governments (Centers for Medicare & Medicaid Services, 2009b). Medicaid recipients may include low income children, pregnant women, the blind, aged and disabled and persons who are eligible to receive federal income assistance (Bradley et al., 2007; Centers for Medicare & Medicaid Services, 2009b). Medicaid paid claim files contain claims for inpatient, outpatient and health care provider services and nursing home services and prior to 1/1/2006, pharmacy claims (Bradley, et al., 2007). The use of Medicaid pharmacy claims for estimating medication use has been found to be accurate. McKenzie, Semradek, McFarland, Mullooly and McCamant (2000) compared Medicaid pharmacy claims to nursing home resident chart information and found an 85% agreement. For this study, the researcher examined pharmacy Medicaid paid claim files data to determine which pain medications were billed to Medicaid as billed medications will

indicate medications that were ordered by a clinician and received at a pharmacy for the MIChoice participant.

Michigan Cancer Registry and Death Certificate Data. The Michigan Cancer Registry and death certificate data are collected by the Michigan Division for Vital Records and Health Statistics through reporting of diagnoses of cancer and deaths by physicians. The Michigan Division for Vital Records and Health Statistics is supervised by the Michigan Department of Community Health for the purpose of monitoring the health of Michigan citizens (Michigan Department of Community Health, 2009). The Michigan Cancer Registry contains data, reported by physicians, regarding patient's date of diagnosis, cancer site, histology, cell behavior, summary stage and related morphological descriptors. Death certificates must be filed for every known death. Death certificate data includes: data defining date of death, underlying and related causes of death and categorical place of death code.

Minimum Data Set Home Care. The Minimum Data Set Home Care (MDS-HC) (Morris, Fries, Steel, et al., 1997) is completed around the time of admission to the MIChoice waiver program by a nurse or social worker case manager trained in using the MDS-HC. Additional MDS-HC assessments are then performed quarterly or sooner if a major change occurs in the waiver participant's health or a major event, such as a fall. This study utilized MDS-HC data from multiple points in time over the course of participation in the MIChoice waiver program.

The MDS-HC was developed from the Minimum Data Set (MDS) (Morris, Hawes, & Fries, 1990). The MDS is used in Medicaid and Medicare certified nursing homes as part of the federally mandated process for clinical assessment of all residents (Centers for Medicare & Medicaid Services, 2009a). The MDS-HC is a comprehensive, standardized questionnaire for

evaluating the care needs, strengths and preferences of clients of home care agencies (Landi, et al., 2000) and has been validated for use in United States and international community-based populations (Kwan, et al., 2000; Landi, et al., 2000; Morris, Fries, Steel, et al., 1997) with the weighted kappa score for the MDS-HC averaging 0.72 (Morris, Fries, Steel, et al., 1997).

The MDS-HC is comprised of 223 items that assess home care clients' sociodemographic characteristics, functional and cognitive status, social support, psychosocial well-being, clinical diagnoses and nursing needs relevant to care planning (Landi, et al., 2005; Morris, Fries, Steel, et al., 1997; Shugarman, et al., 1999). While the MDS-HC contains many items directly from the MDS, home care-specific items were also developed and included in the MDS-HC to address areas unique to the home environment, such as role of informal supports and indicators of abuse (Morris, Fries, Steel, et al., 1997).

MDS items within specific domains were combined to create internal scales that include the Cognitive Performance Scale (CPS) (Morris, et al., 1994), the MDS Depression Rating Scale (DRS) (Burrows, et al., 2000) and the MDS Activities of Daily Living scale (ADLS) (Morris, Fries, & Morris, 1999). While these internal scales were originally developed from MDS items, researchers have since altered the scales to incorporate items from the MDS-HC, as some MDS-HC items differ from their MDS item counterparts in order to better assess the home-care client instead of the nursing home client (Morris, Fries, Steel, et al., 1997). The proposed research will use the CPS, the DRS and the ADLS. These scales will be further described in following Operational Definitions and Measures section.

Operational Definitions & Measures

Operational definitions and measurement of the key study variables are described below and are organized according to their function within the proposed analyses: as dependent

variables, covariates, as both independent variables and covariates and as both independent and dependent variables. Cancer, cancer site and cancer stage will serve as both independent variables and covariates, depending on the research question. Variables defining pain experience, pain management strategies and pain management outcomes will serve as both independent and dependent variables within the proposed research, depending on the research question. At the completion of this section, Table 2 is presented as a summary of study variables and includes place in the conceptual model, data source, item information, coding and variable type.

Dependent Variables

Admission to a Nursing Home. Admission to a Nursing Home is the movement of a HCBWP participant from the HCBWP to a nursing home as detected by a change in the Medicaid paid claim files level of care coding from “22” (MIChoice) to “2” (nursing home). The measure of transition described if during over the period of four MDS-HC assessments and prior to 12/31/2005, the subject is admitted to a nursing home. Admission to a Nursing Home was rated as “remains in MIChoice”=0 vs. “to nursing home”=1. Admission to a Nursing Home was used as a dichotomous variable.

Time to Nursing Home Admission. Time to Nursing Home Admission is the number of months from admission to the HCBWP until the admission of HCBWP participant to a nursing home. Time to nursing home admission was measured by a variable developed from Medicaid paid claim files and will indicate the time, in total number of months from HCBWP admission to admission to nursing home. The admission of a HCBWP participant to a nursing home was detected in the Medicaid paid claim files by a change in the level of care coding from a “22” (MIChoice) to “2” (nursing home). Subjects who stayed in the HCBWP prior to 12/31/2005

were censored, i.e. their time to nursing home admission will be from the date of HCBWP admission to 12/31/2005. Time to nursing home admission was treated as a continuous variable.

Covariates

Covariates for the proposed analyses were comprised of variables defining the domains of person and health and illness and included age, sex, race/ethnicity, cognitive functioning, depression, comorbidities and time in HCBWP.

Age. Age is the chronological age of the HCBWP participant, as measured in years and is determined from the HCBWP participant or proxy reported date of birth of the HCBWP participant as recorded on the MDS-HC face sheet. Age was used as a continuous variable in the analytic models (Appendix A).

Sex. Sex is the sex - male or female of the HCBWP participant, as reported by the participant or proxy and recorded on the MDS-HC face sheet. Sex was treated as a dichotomous variable in analytical models (Appendix A).

Race/Ethnicity. Race/Ethnicity is the race and/or ethnicity of the HCBWP participant, as identified and reported by the participant or proxy and recorded on the MDS-HC face sheet: Caucasian, Black, American Indian, Other (includes Asian and Pacific Islander), Unknown and Hispanic. Race/ethnicity was a categorical variable (Appendix A).

Cognitive functioning. Cognitive functioning is represented by the dichotomized hierarchical scale score of the Cognitive Performance Scale (CPS) (Morris, et al., 1994), adapted for use with items from the MDS-HC (Fries, James, & Aliaga, 2004). The original CPS is a measure of cognitive impairment and has been validated against (Morris, et al., 1994; Paquay et al., 2007) and correlated ($r=-0.65$) with the Mini-Mental Health Examination

(Gruber-Baldini, Zimmerman, Mortimore, & Magaziner, 2000). The adapted CPS has been correlated against the Mini-Mental Health Examination ($r=0.81$) (Landi, et al., 2000). While the adapted CPS has been used in research examining home care populations, additional validity and reliability measures of the adapted CPS were not reported (L. Li & Conwell, 2007; Soldato, et al., 2007).

The adapted CPS is comprised of four MDS-HC items which includes the HCBWP participant's memory recall after 5 minutes, ability to make decisions, make self understood and eating dependency (Fries, James, & Aliaga, 2004; Morris, et al., 1994). The nurse or social work assessor asks the items of the caregiver and/or family member to determine cognitive performance. A scoring algorithm was then completed using the categorical responses to each of the four CPS items to develop the hierarchical scaled CPS score (Appendices A & B). Scoring of the CPS was as follows: 0=cognitively intact, 1=borderline intact, 2=mild impairment, 3=moderate impairment, 4=moderately severe impairment, 5=severe impairment, 6= very severe cognitive impairment, with "2" or greater indicative of cognitive impairment (Morris, et al., 1994). For the analyses the CPS score was dichotomized: 0=cognitively intact (score 0-1) and 1=cognitively impaired (≥ 2). Instead of using the full CPS scale (0-5) the CPS score was dichotomized to clearly distinguish which subjects was cognitively intact versus cognitively impaired.

Behaviors indicative of depression. Behaviors indicative of depression is represented by the score of the Depression Rating Scale (DRS) (Burrows, et al., 2000), adapted for use with seven MDS-HC items. The original DRS scale was comprised of seven items from the MDS that document behaviors that are indicative of depression (Table 1). During development, the original

DRS was validated against Hamilton Depression Rating Scale and Cornell Scale for Depression (Burrows, et al., 2000) and has demonstrated adequate internal consistency reliability (Cronbach's alpha 0.71-0.74) (Burrows, et al., 2000; Martin et al., 2008). Additional validity testing of the DRS in older adult populations has been recommended (Anderson, Buckwalter, Buchanan, Maas, & Imhof, 2003; Burrows, et al., 2000). The six items in the adapted DRS (See Table 1) differ from the original DRS as items indicative of depression in the MDS-HC (Fries, James, & Aliaga, 2004) differ from the MDS. Li and Conwell (L. Li & Conwell, 2007) adapted the DRS for use with MDS-HC items while examining the mental health status of community-dwelling Michigan older adults with demonstrated reliability (Cronbach's alpha 0.74).

The adapted DRS was the HCBWP participant or proxy observation of the HCBWP participant exhibiting in the 30 days prior to assessment feelings of sadness, persistent anger, repetitive anxious complaints, sad facial expressions, recurrent crying and withdrawal from activities of interest (Burrows, et al., 2000; L. Li & Conwell, 2007). Response coding for the adapted DRS included 0=indicator not exhibited in last 30 days; 1=indicator of this type exhibited daily or almost daily up to 5 days a week; 2=indicator of this type exhibited daily or almost daily (6-7 days a week). Responses were then summed to create a possible score of 0-12, with "0" meaning no behaviors indicative of depression over the previous 30 days and "12" meaning feelings of sadness, persistent anger, repetitive anxious complaints, sad facial expressions, recurrent crying and withdrawal from activities all exhibited daily or almost daily up to 5 days a week. A DRS score of 3 or above was indicative of depression (Burrows, et al., 2000; L. Li & Conwell, 2007). For the study, the adapted DRS score was used as a continuous variable.

Table 1.

Items from the Adapted and Original Depression Rating Scale

Adapted MDS-HC Depression Rating Scale Indicators (Li & Conwell, 2007)	Original MDS-NH Depression Rating Scale Indicators (Burrows et al., 2000)
<ul style="list-style-type: none"> • A feeling of sadness or being depressed, that life is not worth living, that nothing matters and he or she is of no use to anyone or would rather be dead • Persistent anger with self or others (easily annoyed, anger at care received) • Repetitive anxious complaints, concerns • Sad, pained, worried facial expressions • Recurrent crying, tearfulness • Withdrawal from activities of interest 	<ul style="list-style-type: none"> • Resident made negative statements • Persistent anger and irritability with self and others • Expressions of what appear to be unrealistic fears • Repetitive health complaints • Repetitive anxious complaints/concerns (non-health-related) • Sad, pained, worried facial expressions • Crying, tearfulness • N/A

Comorbid conditions. Comorbid conditions was represented by a comorbidities measure indicating the summed, weighted effect of the presence of multiple diseases other than cancer (diabetes, chronic pulmonary disease, congestive heart failure, cerebrovascular disease, peripheral vascular disease, paralysis, acute myocardial infarction, old myocardial infarction, moderate/severe renal disease, diabetes with complications, ulcer disease, rheumatologic disease and mild liver disease) on the pain experience, pain management strategies, pain management outcomes and admission to a nursing home of HCBWP participants. The measure

of comorbid conditions was developed from MDS-HC data utilizing the same statistical methods used by Klabunde, Potosky, Legier and Warren (2000) while adapting the Charlson comorbidity index (CCI) (Charlson, Pompei, Ales, & MacKenzie, 1987) to determine non-cancer related mortality.

Klabunde and colleagues' (2000) adaptation of the CCI was selected to develop the comorbidity index for the proposed research for the following reasons. First, Klabunde and colleagues developed the adaptation of the CCI with outpatient ICD-9 coding which is more similar to the MDS-HC data than inpatient hospital ICD-9 codes used in older CCI adaptations (Deyo, Cherkin, & Ciol, 1992; Romano, Roos, & Jollis, 1993). Second, Klabunde and colleagues corrected statistical errors (Harrel, 1996; Romano, et al., 1993) used in the original CCI and other adaptations. Lastly, Klabunde and colleagues' method had greater ease of use and equal predictive power compared to Elixhauser and colleagues' comorbidity measure with 30 comorbid conditions (Baldwin, Klabunde, Green, Barlow, & Wright, 2006). The development of the comorbidity index measure is described in the following sections.

Data to develop the comorbid conditions measure came from the MDS-HC Section I, questions 7 and 9 and utilized data from the admission, or first assessment of the waiver participant. Section I in the MDS-HC collects data detailing physicians, hospitalizations and presence of endocrine, circulatory, cardiovascular, musculoskeletal, neurological, psychiatric, pulmonary and sensory conditions. Question 7 assesses for presence of specific diseases, with possible responses as 0=not present, 1= present, not subject to focused treatment, 2=present, monitored or treated by home care nurse. MDS-HC Section I, question 9 allows for the assessor to enter in specific ICD-9 codes not addressed or addressed fully in Question 7. The MDS-HC data was then searched for the presence of the following 13 comorbid conditions: diabetes,

chronic pulmonary disease, congestive heart failure, cerebrovascular disease, peripheral vascular disease, paralysis, acute myocardial infarction, old myocardial infarction, moderate/severe renal disease, diabetes with complications, ulcer disease, rheumatologic disease and mild liver disease. Comorbid conditions were indicated as not present=0, present=1 based on their presence in the MDS-HC section I, questions 7 or 9.

The dichotomized individual comorbidities were then used in multinomial logistic regression models which were fitted using the Pain Scale score (Fries, et al., 2001) as the dependent variable. Comorbidity data from the first MDS-HC assessment was used to predict the Pain Scale score from the first MDS-HC assessment. Using the method described in Klabunde et al. (2000), the estimated coefficients from the multinomial logistic regression models for each comorbidity were multiplied by its dichotomous indicator (not present, present) and then summed over all conditions to create the comorbidity index score for each subject, with a higher score indicating higher comorbidity. The resulting summed comorbidities index score was used as a continuous variable.

The measure of comorbid conditions used in this research had several weaknesses. First, the comorbid condition measure may have underestimated the presence of comorbid conditions in each subject. Other researchers who have developed comorbid measures have used Medicaid and Medicare claim files data and chart data to determine the presence of comorbid conditions (Charlson, et al., 1987; Deyo, et al., 1992; Klabunde, et al., 2000; Romano, et al., 1993). The present research used data from the MDS-HC, as the researcher did not have access to Medicare paid claim files and in older adults 65 and older have Medicare as the primary health care service payor. Although the researcher had access to Medicaid paid claim files, health care providers may not have billed Medicaid (the secondary payor) for services after Medicare paid and

therefore, there would be no ICD-9 coding for conditions related to treatment located in the Medicaid paid claim files. Second, information regarding the presence of comorbid conditions was at a single moment in time at each assessment. Whereas researchers utilizing Medicare and Medicaid data could search the data for specific time periods before or after an event, the MDS-HC data was at one moment in time. This may have led to an underestimation of the presence of comorbid conditions. Third, the data did not allow the researcher to determine if conditions that were present were severe or mild and therefore, the researcher was not able to weight conditions according to severity.

Time in HCBWP. Time in the HCBWP is the number of months from the date of admission to the date of each of the assessments for each subject. Time in HCBWP was measured by a variable developed from Medicaid paid claim files and the MDS-HC. The date that each subject began the HCBWP is noted in the Medicaid paid claim files, while the date of each assessment for each subject is recorded in the MDS-HC. The date of beginning the program will be subtracted from each assessment to provide the number of days, at the time of assessment, from the date the subject began the HCBWP.

The incorporation of the Time in HCBWP variable as a covariate is necessary as the study data is unbalanced- meaning each subject may have data from different points in time from his or her admission to the HCBWP (Fitzmaurice, Laird, & Ware, 2004). Even though the goal is to assess each patient quarterly, some assessment may be closer or further apart. Therefore, time in the HCBWP was included as a covariate (Fitzmaurice, et al., 2004). Time in HCBWP was a continuous variable.

Independent Variables/Covariates

Diagnosis of cancer, cancer site and stage are variables within the domain of health and illness that were used as both independent variables and covariates in analytic models in order to make comparisons between HCBWP participants with and without a diagnosis of cancer.

Diagnosis of cancer. Diagnosis of cancer was categorically defined using “phases of care” definitions based on the date of death in relation to the date of cancer diagnosis (Brown, Riley, Potosky, & Etzioni, 1999; G. F. Riley, Potosky, Lubitz, & Kessler, 1995; Yabroff, et al., 2005; Yabroff, et al., 2009). “Phases of care” definitions were originally developed in accordance with the use of healthcare services within specific time periods after a diagnosis of cancer and before death (Brown, et al., 1999; G. F. Riley, et al., 1995; Yabroff, et al., 2005; Yabroff, et al., 2009). Data from the Michigan Cancer Surveillance Data by the Michigan Division for Vital Records Coding were utilized. Coding was as follows: 0=no cancer, 1=initial phase, 2=continuing phase, 3=terminal phase.

The measure of diagnosis of cancer was determined from cancer registry data. Subjects who do not have a diagnosis of cancer recorded in the cancer registry data were placed in the “no diagnosis of cancer” level of the diagnosis of cancer measure. For subjects who survived at least 24 months after diagnosis of cancer, the *initial phase* level of the diagnosis of cancer measure was defined as the first 12 months after diagnosis. The *terminal phase* of the diagnosis of cancer measure was defined as the final 12 months preceding death and the *continuing phase* as all months between the initial and terminal phases. For subjects surviving less than 24 months, the final 12 months was the terminal phase and all other months were part of the initial phase. There were no continuing phase for these subjects (Yabroff, et al., 2005; Yabroff, et al., 2009). Subjects with cancer were further described according to cancer stage and cancer site.

Cancer stage. Cancer stage was classified categorically based on the Surveillance, Epidemiology and End Results (SEER) summary stage from categorical data from the Michigan Cancer Surveillance Data by the Michigan Division for Vital Records and Health Statistics: 1=in situ, 2=local, 3=regional, 4=distant, 05=un-staged, 09=invasive unknown.

Cancer site. Cancer site was classified categorically in terms of the primary or initial anatomical location of the cancer from the Michigan Cancer Surveillance Data by the Michigan Division for Vital Records and Health Statistics. Preliminary analysis was completed to determine distribution and cancers were categorized and coded as follows: 1=Colon, 2=Lung, 3=Lymphoma/Leukemia, 4=Breast, 5=Female Reproductive, 6=Prostrate, 7=other.

Dependent/ Independent Variables

Pain. The variable *pain*, which defines the pain experience, is a hierarchal variable- The MDS Pain Scale- developed from two MDS-HC items which describe pain frequency and pain intensity (Chou & Chi, 2007; Fries, et al., 2001; L. Li & Conwell, 2007). The measure of pain experience was used as a dependent variable in question 1 and as an independent variable in question 2 and 3.

To develop the pain variable, MDS-HC Section J items were used. Section J of the MDS-HC was designated as the “*Health Conditions and Preventive Measures*” section. This section included items that inquired about preventative health (vaccinations, prostate check, mammogram, pap smear), pain, fall risk, changes in health status and hygiene and abuse screening. Two items in Section J, item 8a and b, were used for the MDS Pain Scale: **8a)** *Over the past 7 days, the HCBWP participant or proxy reported frequently complains or shows evidence of pain (no pain, pain less than daily, pain daily)* and **8b)** *HCBWP participant or proxy reported pain is unusually intense (0=no, 1=yes)* were used. The MDS-HC Pain Scale scoring is

as follows: “0”= no pain; “1”=mild pain (less than daily); “2”= moderate pain (daily, not unusually intense); 3= intense pain (daily, unusually intense). The hierarchical scoring is presented by diagram in Appendix D.

Pain management strategies. Variables defining the pain management strategies dimension include *prescribed pain medications* and *hospice services*. Prescribed pain medications and hospice services will be used as dependent variables for Question 2 analyses and independent variables in Question 3 analyses.

Prescribed pain medications. Prescribed pain medications is the type of pain medications prescribed by a health care provider for the HCBWP participant and billed to Medicaid in the 30 days period before each assessment. The measure of prescribed pain medication was developed from Medicaid paid claim files pharmacy data. Within the pharmacy data are three drug codes: Generic Therapeutic Class, Therapeutic Drug Class and Specific Therapeutic Drug Class. These three drug codes were used to find medications used to treat pain. The process of categorizing prescribed pain medication from the Medicaid pain claim files pharmacy data was a very time intensive process due to inconsistencies in the data and this process is described further in the following section.

Descriptive analyses was used initially examine the pharmacy paid claim files and Generic Therapeutic Drug Class (GTDC) was found to most stable and basic variable to begin the process of categorizing prescribed pain medications. The GTDC codes were then examined to determine which medications were clinically consistent with pain management in accordance with the literature and the researcher’s clinical experience. These included: 02=Analgesics, 03=Analgesics and Antihistamine combinations, 05=Anesthetics, 11=Anti-arthritis, 44=CNS Drugs and 80=Psychotherapeutic drugs.

The GTDC codes were then cross-tabulated with the Standard Therapeutic Drug Class (STDC) to determine which STDC codes existed within each GTDC. Within Analgesics, there was a STDC code for “emetics”, but on further examination with the 3rd code (HIC3 Specific Therapeutic Drug Class (HIC3)) these “emetics” were found to be aspirin, Tylenol, Oxycontin and Vicodin and not emetics. Furthermore, the GTDC code for anti-arthritic medications was the same as the STDC code for psycho-stimulants. On further examination, medications noted to be psycho-stimulants under the STDC coding had HIC3 codes for Vioxx, Motrin, which are not psycho-stimulants but COX-2 inhibitors, a type of non-steroidal anti-inflammatory medication.

Overall, by carefully using all three medication codes to carry out extensive cross-tabulation procedures among the three drug codes, the research was able to create a prescribed pain medication variable which was coded 0=no prescribed pain medications, 1=non-opioid prescribed pain medications, 2= opioid prescribed pain medications and 3=adjuvant prescribed pain medications. Non-opioid, opioid and adjuvant pain medications were described in Chapter 3. To briefly review, non-opioid pain medications include acetaminophen and non-steroidal anti-inflammatory medications. Opioid pain medications included medications that were either in part or fully narcotic. Adjuvant analgesics describes “...non-opioid medications that have pain-relieving effects in certain conditions, but whose primary or initial indication was not for the treatment of pain” (American Pain Society, 2005, p. 73). Medications that are used as adjuvant pain medications include anticonvulsants, antidepressants, and local anesthetics (American Pain Society, 2005). Adjuvant medications diminish pain by altering nerve function. There was unfortunately no measure within the data documenting medication administration or subject ingestion of medication. Prescribed pain medications were used as an independent variable in the analytic models examining the association between the pain experience, prescribed pain management strategies and pain management outcomes.

Hospice Services. Hospice services was the reporting of scheduling and adherence of hospice service utilization by the HCBWP participant per the MDS-HC. The measure of hospice services was developed from Section Q of the MDS-HC titled *Service Utilization*. Items in Section Q inquired about recent surgery, formal care that the participant is already receiving, treatments (for example, drug treatment, chemotherapy, cardiac rehabilitation), therapies (exercise, physical therapy), programs (day care, hospice care, clinic visit) and special procedures done in the home (EKG, skin treatment, special diet). For the measure of hospice services, Item 3y was used and worded as follows, *Special treatments, therapies, program received or schedules during the last 14 days (received in home or outpatient basis) and adherence to the required schedule*. Response to the item was 0=N/A, 1=scheduled, full adherence as prescribed, 2=scheduled partial adherence, 3=scheduled, not received. For this research, hospice was dichotomized as follows: 0=Hospice services not received (original code 0 and 3) 1=Hospice services received (original code 1 and 2).

Pain management outcomes. Variables defining the pain management outcomes dimension include pain control and physical function. Pain control and physical function are used as dependent variables for Question 2 analyses and independent variables in Question 3 analyses.

Pain control. Pain control is the waiver participant's or the HCBWP participant's or proxy's response to an MDS-HC item in Section "J" *Health Conditions and Preventative Health Measures*. Section "J" included items that inquired about preventative health (vaccinations, prostate check, mammogram, pap smear), pain, fall risk, changes in health status and hygiene and abuse screening. The measure of pain control was developed from a single item (J8e) asking "pain controlled by medication" with possible responses as 0=no pain, 1=medication offered, no control and 2=pain is partially or fully controlled by medication (Appendix E). Pain control was utilized as a

categorical variable.

Physical function. Physical function is represented by a count of the following activities of daily living (ADLs) that the HCBWP participant is dependent in: dressing, personal hygiene, toilet use, bathing and eating (Appendix E). Physical function score ranges from 0 to 5, with a higher score indicating more dependency with ADLs. As pain has been shown to have a significant, negative effect on physical functioning among older adults (Helme & Gibson, 2001; Onder, et al., 2006; Reyes-Gibby, et al., 2002; Soldato, et al., 2007), physical function, as measured by the number of ADLs the HCBWP participant is dependent in, is an outcome of pain management strategies.

The measure indicating physical function is comprised of the observed ability of the HCBWP participant in regards to dressing, personal hygiene, toilet use, bathing and eating over the previous 7 days as measured by MDS-HC items (Section P, Question 2) (C. Given, Spoelstra, You, Haque, & Given, 2010; Morris, et al., 1999). Responses to each item address the amount of assistance the MICHoice participant needs with mobility in bed, transferring, locomotion, dressing, eating, toilet use and personal hygiene over the previous 7 days: 0=independent, 1=supervision, 2=limited assistance, 3=extensive assistance and 4=total dependence 5=Activity did not occur, regardless of ability . For this study, item scores were then recoded to : 0 to 1=independent “0” and ≥ 2 =dependent “1”. Responses to each of the five items were then summed together for a total possible score ranging from 0-5, with a higher value indicating greater dependence with activities of daily living. The continuous variable defining physical function was used as both a dependent variable for Question 2 analyses and as a covariate for Question 3 analyses.

Table 2.

Study Variables by Place in Conceptual Model, Data Source, Item, Coding and Variable Type

Variable	Place in Conceptual Model	Data Source	Item Information/ Question	Coding	Variable Type
Age	Domain of Person	MDS-HC face sheet, #2	• Date of birth	• Continuous variable Number of years	• Continuous • Covariate Questions 1,2,3
Sex	Domain of Person	MDS-HC face sheet, #3	• Gender	• Male • Female	• Categorical • Covariate Questions 1, 2, 3
Race/ Ethnicity	Domain of Person	MDS-HC face sheet, #7	• Race	• Caucasian • Black • American Indian • Other (includes Asian and Pacific Islander • Unknown • Hispanic	• Categorical • Covariate Questions 1,2,3
Cognitive Functioning	Domain of Person	MDS-HC Sections E 1& 2 F 2 P 2e	• Will be assessed using the Cognitive Performance Scale (CPS), a subscale created from 4 items of the MDS-HC. The CPS scores will then be dichotomized to indicate whether a HCBWP participant is cognitively intact vs. cognitively impaired	• The CPS is a 7-point hierarchical summary scale that rates cognitive impairment from 0=intact to 6=very severe. The CPS is scored via a decision tree. • The CPS is then dichotomized: 0-1=cognitively intact ≥ 2=cognitively impaired	• Categorical • Covariate Questions 1,2,3

Table 2 (Continued)

Variable	Place in Conceptual Model	Data Source	Item Information/ Question	Coding	Variable Type
Behaviors Indicative of Depression	Domain of Person	MDS-HC Section G 2	<ul style="list-style-type: none"> Will be assessed using the Depression Rating Scale, a subscale created from 6 MDS-HC items. 	<ul style="list-style-type: none"> The DRS is a summary scale 0-12 possible with a higher score indicating more behaviors that are indicative of depression 	<ul style="list-style-type: none"> Continuous Covariate Questions 1,2,3
Diagnosis of Cancer	Domain of Health & Illness	Michigan Cancer Surveillance Registry	<ul style="list-style-type: none"> Diagnosis of Cancer 	<ul style="list-style-type: none"> No diagnosis of cancer Initial Phase Continuation Phase Terminal Phase 	<ul style="list-style-type: none"> Categorical Independent Questions 1,2, Covariate 3
Cancer site	Domain of Health & Illness	Michigan Cancer Surveillance Registry	<ul style="list-style-type: none"> Recorded via ICD-9 codes 	<ul style="list-style-type: none"> 1=Colon 2=Lung 3=Lymphoma or Leukemia 4=Breast 5=Female Reproductive 6=Prostate 7=Other 	<ul style="list-style-type: none"> Categorical Independent Question 1,2 Covariate 3
Cancer stage	Domain of Health & Illness	Michigan Cancer Surveillance Registry	<ul style="list-style-type: none"> Records stage according to Surveillance, Epidemiology and End Results (SEER) summary stage. 	<ul style="list-style-type: none"> 1=In situ 2=Local 3=Regional 4=Distant 5=Un-staged 9=Invasive, unknown 	<ul style="list-style-type: none"> Categorical Independent Questions 1,2 Covariate 3

Table 2 (Continued)

Variable	Place in Conceptual Model	Data Source	Item Information/ Question	Coding	Variable Type
Comorbid conditions	Domain of Health & Illness	MDS-HC Section I	<ul style="list-style-type: none"> • Disease/ infection that is indicated as present and affects client's status, requires treatments or requires symptom management. 	<p>Responses are categorized as:</p> <ul style="list-style-type: none"> • A summed, weighted index was developed utilizing Klabunde et al's method (Klabunde, Harlan, & Warren, 2006; Klabunde, et al., 2000). • Range for mortality as outcome: 0-27. <p><i>Note: For present research used pain as outcome.</i></p>	<ul style="list-style-type: none"> • Continuous • Covariate Questions 1,2, 3
Pain	Pain Experience Dimension	MDS-HC Section J8	<ul style="list-style-type: none"> • MDS Pain Scale -Frequently complains or shows evidence of pain in last 7 days? -Pain is unusually intense? 	<ul style="list-style-type: none"> • 0-3, with 0=no reported pain to 3=daily pain that is unusually intense 	<ul style="list-style-type: none"> • Categorical • Dependent Question 1 • Independent Questions 2 & 3

Table 2 (Continued)

Variable	Place in Conceptual Model	Data Source	Item Information/ Question	Coding	Variable Type
Prescribed pain medication	Pain Management Strategies Dimension	Medicaid paid claim files	<ul style="list-style-type: none"> Includes all pain medications billed to Medicaid for time period of 30 days prior to each assessment. 	<ul style="list-style-type: none"> Medications known to be specific for pain treatment will be categorized & coded as 0=no pain medications 1=non-opioid pain medication 2=opioid pain medication 3=adjuvant pain medication 	<ul style="list-style-type: none"> Categorical Dependent and Independent Question 2 Independent Question 3
Hospice Services	Pain Management Strategies Dimension	MDS-HC Section Q 3y	<ul style="list-style-type: none"> Special treatments, therapies, programs received or scheduled during the last 14 days (received in the home or on an outpatient basis) and adherence to the required schedule 	<ul style="list-style-type: none"> 0= Hospice services not received 1=Hospice services received 	<ul style="list-style-type: none"> Dependent Question 2 Independent Question 3

Table 2 (Continued)

Variable	Place in Conceptual Model	Data Source	Item Information/ Question	Coding	Variable Type
Physical Function	Pain Management Outcomes	MDS-HC Section P 2	<ul style="list-style-type: none"> • Will be assessed using a sum of the number of ADLs the participant is dependent in • Includes dressing, eating, toileting, personal hygiene, and bathing 	<ul style="list-style-type: none"> • Summary scale from 0-5, with a higher value indicating more ADL dependencies 	<ul style="list-style-type: none"> • Continuous • Dependent Question 2 • Independent Question 3
Pain control	Pain Management Outcomes	MDS-HC Section J 8e	<ul style="list-style-type: none"> • Pain controlled by medication? 	<ul style="list-style-type: none"> • 0=Medication offered no control, • 1=Pain is partially or fully controlled 	<ul style="list-style-type: none"> • Categorical • Dependent Question 2 • Independent Question 3
Admission to Nursing home	Admission to Nursing Home	Medicaid paid claims files	<ul style="list-style-type: none"> • Variable will describe if subject was admitted to a nursing home from the HCBWP prior to 12/31/05 	<ul style="list-style-type: none"> • 0=Remains in MIChoice (NO) • 1=To nursing home (YES) 	<ul style="list-style-type: none"> • Categorical • Dependent Question 3

Table 2 (Continued)

Variable	Place in Conceptual Model	Data Source	Item Information/ Question	Coding	Variable Type
Time to nursing home admission	Time to Nursing Home Admission	Medicaid paid claims files	<ul style="list-style-type: none"> • Time from HCBWP admission to admission to nursing home • Subjects who stay in the waiver program prior to 12/31/05 will be censored • Event= admission to nursing home 	<ul style="list-style-type: none"> • Total number of months from admission day to HCBWP until admission to a nursing home or end of measurement time. 	<ul style="list-style-type: none"> • Continuous • Dependent Question 3
Time in the HCBWP	Time in HCBWP	Medicaid Paid Claim Files & MDS-HC Section A2	<ul style="list-style-type: none"> • Time from HCBWP admission to each MDS-HC Assessment 	<ul style="list-style-type: none"> • Total number of months from HCBWP admission day to each MDS-HC assessment 	<ul style="list-style-type: none"> • Continuous • Covariate Questions 1 2 & 3

Data Preparation and Management

The study was a secondary analysis of a large dataset comprising data from Michigan Medicaid paid claims files; the home care version of the Minimum Data Set (MDS-HC); and cancer diagnosis, tumor staging, and death certificate information from the Michigan Cancer Surveillance Data by the Michigan Division for Vital Records and Health Statistics. The study

data set included multiple assessments of the waiver participant, services billed to Medicaid, diagnoses of cancer.

Development of and access to this combined dataset was overseen by the Institute of Health Care Studies (IHCS) at Michigan State University. The IHCS has been granted direct access to the data by the Michigan Department of Community Health (MDCH). IHCS staff first extracted Medicaid paid claim files from 6/1/2002 to 12/31/2005 and MDS-HC data from 1/1/2003 to 12/31/2005. The MDS-HC data was then matched to the Medicaid data through social security number, date of birth and first and last name. With this initial dataset constructed, IHCS staff consulted with the state registrar to obtain date of death, date of cancer diagnosis, staging and tumor description records from the Michigan Division for Vital Records. The state registrar matched death and cancer-related records to the Medicaid paid claim files and MDS-HC data by social security number, date of birth and first and last name. The completed dataset was then returned to the IHCS where staff removed all patient identification from the data. Subjects will not be identifiable, directly or through identifiers linked to the subjects in the final study dataset to which the applicant will have access.

The de-linked dataset was provided in its entirety to a statistician in the College of Nursing Research Center and is kept on a password protected computer to which only the statistician has access to. The researcher was not able to identify persons in the data set because it is de-linked. The researcher consulted with the statistician and obtained a copy of the de-linked dataset. All data was received in electronic form. The study data was kept on a password protected laptop computer that only the researcher has access to. A codebook was developed for the MDS-HC data. Coding guides were also available for the cancer diagnosis, tumor staging, and death certificate and Medicaid data. Both the MDS-HC and Medicaid data were broken

down into sections for ease of use. The statistician utilized both SAS and SPSS to complete the analyses for this study.

Analysis of Data

The primary purpose of this study was to examine longitudinal differences in the pain experience, pain management strategies and pain management outcomes among older HCBWP participants with and without a diagnosis of cancer over the course of time of participating in the HCBWP. The secondary purpose of this study was to determine differences in how the pain experience, pain management strategies and pain management outcomes among older adult, HCBWP participants with and without a diagnosis of cancer associates with the admission of older adult HCBWP participants to a nursing home over the course of time of participating in the HCBWP. Data were analyzed using SPSS and SAS. Tests had a 0.05 set level of significance.

Power. Power analysis was conducted using G*power software (Faul, Erdfelder, Lang, & Buchner, 2007) utilizing a z-test for the difference between two independent proportions. For the P1 and P2 proportion values the researcher used values for the prevalence of pain in HCBWP participants with a diagnosis of cancer after admission to the HCBWP and HCBWP participants with no diagnosis of cancer: 0.77 and 0.72, respectively. The last assessment for the presence of pain (no pain or less than daily vs. daily pain) was used. For the allocation ratio the researcher used the percentage of older adult HCBWP participants with a diagnosis of cancer over the percentage of HCBWP participants without a diagnosis of cancer for an allocation ratio of 5.67. A two-tailed test with 0.05 error probability and 0.90 power was computed. For an actual power of .90, the total sample size required was 6189 subjects: 928 in the group with a diagnosis of cancer and 5261 in the group without a diagnosis of cancer. Effect size was 0.11, indicating a small effect (Cohen, 1988).

For Medicaid-eligible adults, 65 and older and HCBWP participants from 1/1/03-12/31/05, the sample size for the proposed research would include approximately 12,750 individuals. With the proposed research being a secondary data analysis of such a large dataset, the sample adequacy to detect differences between groups should be assured by the large dataset size.

Analysis. Initial data analysis served to determine sample size and to assess distribution of data for each variable in order to make final decisions regarding categorical coding of variables. Descriptive statistical analysis was completed to profile the study sample in terms of demographic characteristics and other study variables. Continuous variables were summarized with the number of observations, mean, standard deviation, range and 95% CI for the mean. The relationships among the variables were examined.

Research questions and proposed plans for analysis of longitudinal data were as follows:

- 1) How does the pain experience differ between older adult HCBWP participants in regards to cancer over time? How is the relationship over time between the pain experience and diagnosis of cancer affected by sex, age, race, comorbid conditions, depression and cognitive functioning over time?
- Dependent variables: Pain.
 - For Research Question 1, the pain measure was dichotomized as follows Pain Scale 0-1="0", Pain Scale 2-3="1" to provide a dichotomous dependent variable for Generalized Estimated Equation Model.
 - Independent variable: Diagnosis of cancer as: no cancer, initial phase, continuation phase, terminal phase. This variable was named as "group" in the following statement and the rest of the analysis section.

- The following model addressed research question 1:

Pain= Diagnosis of cancer group + covariates

The main effect was the group (no cancer, initial phase, continuation phase, terminal phase). Covariates include age, sex, race/ethnicity, depression, cognitive functioning and comorbidities. Age, depression, comorbidities and Time in HCBWP are continuous variables while sex, race/ethnicity and cognitive functioning are categorical variables. Repeated measures analysis was used. SAS procedure GENMOD with Generalized Estimating Equations modeling (Lipsitz & Kim, 1994) was used for the categorical outcome of pain. To account for the relation of multiple measurements across time within a patient, auto regressive 1 (ar(1)) covariance was specified. Categorical outcomes with more than two levels were treated as ordinal response and the proportional odds model was used. If the proportional odds assumption (M. E. Miller, Davis, & Landis, 1993) did not stand, then the dependent variables were dichotomized as binaries based on their frequency.

2. How does the pain experience of older adult, HCBWP participants relate to pain management strategies and pain management outcomes and how does this relationship differ in regards to diagnosis of cancer over time? How is the relationship between the pain experience, pain management strategies, pain management outcomes and diagnosis of cancer affected by sex, age, race, comorbid conditions, depression and cognitive functioning over time?

Dependent variable: prescribed pain medications, hospice, pain control and physical function. Each dependent variable was used once in the model to create four separate GEE models. Prescribed pain medications was categorical 1=opioids, 2=adjuvants, 3=non-opioid, as defined by the World Health Organization analgesic ladder (World Health Organization, 2002)

as well as 0=no pain medication. For Research Question 2, dummy variables were created to provide a dichotomous dependent variable for GEE modeling. The dummy variables compared each prescribed pain medication level (1-3) against prescribed pain medication="0" no pain medication. Separate GEE models were then carried out for each dummy variable.

Independent variable: 1) Groups as diagnosis of cancer: no cancer, initial phase, continuation phase, terminal phase 2) Pain.

The following model addressed research question 2: dependant variable (prescribed pain medications, hospice, pain control, physical function) across time= group + covariates + Pain . The main effect was group and pain. Pain was represented by the full pain scale (Fries, et al., 2001), including values 0 to 3. Covariates include age, sex, race, comorbid conditions, depression, cognitive functioning and Time in HCBWP.

Repeated measures analyses were implemented. GENMOD with Generalized Estimating Equations modeling was used for binary, count and categorical outcomes (Lipsitz & Kim, 1994). For categorical outcomes, proportional odds methods was used. To account for the relation of multiple methods across time with patients, auto regressive 1 (ar(1)) covariance was specified.

3. How does the pain experience, pain management strategies and pain management outcomes of older adult, HCBWP participants predict the admission and time to admission of older adult HCBWP participants to a nursing home over time and how does this relationship differ in regards to diagnosis of cancer while accounting for sex, age, race, comorbid conditions, depression and cognitive functioning?

- For research question 3, an analysis was performed that included subjects who stayed in the HCBWP and those who were admitted to a nursing home in order to investigate whether variables defining the pain experience, pain management strategies and pain

outcomes related to this admission and time to admission. Subjects who had died or left the program for reasons other than admission to a nursing home were excluded from this analysis.

- Dependent variable:

- 1) Admission to nursing home: yes/no. Logistic regression was used for this analysis

- 2) Time to transition: Cox proportional survival analysis models were used. For those who transferred to the nursing home, the time in the waiver program was programmed as “event” and those who remained in the waiver program until 12/31/05 were censored. Proportional hazard ratio was tested to ensure that the assumption of analysis stood. If the proportional hazard ratio had not stood then time to nursing home admission would have been treated as a continuous variable and general linear modeling would have been used to carry out the analysis.

- Independent variable: Groups as diagnosis of cancer, pain, prescribed pain medications, hospice, pain control, physical function

- Covariates: include age, sex, race, comorbid conditions, depression, cognitive functioning and Time in HCBWP.

The following models were used to address research question 3:

- Admission to nursing home (yes versus no) = independent variables + covariates
- Time to admission to nursing home = group + independent variables + covariates
- The main effect in both models were pain, prescribed pain medications, hospice, pain control, physical function. Pain was represented by the full pain scale (levels 0-3).

Prescribed pain medications was represented by 0=no pain medications, 1=non-opioid pain medications, 2=opioid pain medications, 3=adjuvant pain medications. The covariates

included groups as diagnosis of cancer: no cancer, initial phase, continuation phase, terminal phase.

Study Limitations

This research was a secondary analysis of pre-existing data and therefore, data analyses was limited to what was already recorded. The study was limited to mostly categorical data and therefore information regarding pain measures was not as detailed as when numeric or visual pain measurement scales are used. The MDS-HC was collected by interviewing both the patient and informal caregivers. If the patient was unable to respond, the data would be limited to what the caregiver provided. Proxy reporting can be inaccurate and thus the pain assessment measures provided by the caregiver may not have truly reflected what the patient's pain experience was. Generalizability to older adults who are able to self-report measure of pain was therefore limited. The data does not include information regarding patient need of pain medication and whether a subject took pain medication, only that pain medication was prescribed and billed to Medicaid. This research was limited to four assessments, thereby limiting the sample to older adult HCBWP participants who were in the HCBWP for approximately 15 months. Therefore, older adult HCBWP participants who left the HCBWP in less than 15 months were excluded, creating a selection bias.

The researcher acknowledges that pain management strategies include more than prescribed pain medication and hospice services. Pain management strategies include both pharmacological and non-pharmacological strategies (JCAHO, 2000) such as cold and heat therapy, massage, acupuncture, for example. The consequences of poor pain management among older adults includes clinical symptoms of depression, anxiety, decreased social interaction, sleep disturbances, impaired physical function, agitation, delirium, decreased

appetite, delayed healing, lower quality of life and higher health care utilization and costs (American Geriatrics Society Panel on Persistent Pain in Older Persons, 2002). Although the researcher acknowledges the many negative outcomes of pain and poor pain management, this research was limited to examining the effects of pain and pain management on pain control, physical function and transfer to a nursing home. Additional outcomes such as the financial costs of pain management were not possible due to data limitations. Additional pain management outcomes will be examined in future research. Finally, the proposed research did not seek to determine if pain was acute, chronic or cancer-related, as this was outside of the scope of the project.

Study Strengths

The dataset of this study was very large, thereby allowing for more precision in estimation of population properties than a smaller dataset. The proposed research examined cancer, pain and pain management in older adult waiver program participants. An extensive literature search showed no previous research has addressed this issue. Therefore, this research examined an area that although significant, had not been previously addressed. The proposed research was longitudinal and allowed for multiple measures over time. This provided a clinical and management “picture” of each subject as they participated over time in MIChoice. The proposed research served to provide an initial descriptive assessment of pain in a HCBWP on which future research can build.

Protection of Human Participants

The study was granted exempt status by the Michigan Department of Community Health (MDCH) Institutional Review Board and the Michigan State University Institutional Review Board (IRB# X08-742), as the study was a secondary analysis of de-identified data. For the

study, the researcher applied for and received permission to access Medicaid paid claim files, Michigan Cancer Registry data, death certificate information from Vital Records, and MDS-HC data from the Michigan Department of Community Health (MDCH) Institutional Review Board. Data use and non-disclosure agreements were completed by the researcher as required by the MDCH. As the data are de-linked, there are minimal additional risks to the subject. All data were kept confidential. Although the subjects of the proposed research will not likely receive additional benefits from the proposed research, future older adult HCBWP participants may benefit from the findings of the research.

Data Security

All data for the study were stored on a password protected laptop computer that only the researcher had access to. All data had been de-linked and the researcher does not have access to the identification key. The researcher completed mandatory IRB training regarding protection of human subjects.

Women and Minority Inclusion in Clinical Research

The study was a secondary analysis of existing data and therefore, the inclusion of women and minorities in the proposed study was as they are already represented in the existing data set. From 2005 records, the Bureau of Medicaid Policy and Actuarial Services reported the breakdown by gender among MIChoice participants as 72% female (Bureau of Medicaid Policy and Actuarial Services of Michigan Department of Community Health, 2004, 2006). Also from the 2005 records, minorities comprised a small percentage of MIChoice participants: African Americans 20% and Hispanics 1%. The majority of persons in MIChoice in the 2005 records were Caucasian, 75% (Bureau of Medicaid Policy and Actuarial Services of Michigan Department of Community Health, 2004, 2006). A similar breakdown in sex and race in the

dataset for the proposed research was expected and descriptive statistics regarding sex and race are reported in Chapter 5.

Conclusion of Chapter 4

The purpose of this chapter was to present the design and methods that were used for this study as well as human subject protection and data safety. Chapter 5 will describe the results of the analyses. Chapter 6 will present contributions to science and implications for policy, clinical practice and research.

Chapter 5

The primary purpose of this study was to examine longitudinal differences in the pain experience, pain management strategies (prescribed pain medications and hospice services) and pain management outcomes (physical function and pain control) among older HCBWP participants with respect to diagnosis of cancer while participating in the HCBWP. The secondary purpose of this study was to determine what differences exist in how the pain experience, pain management strategies and pain management outcomes among older adult, HCBWP participants associates with the admission of older adult HCBWP participants to a nursing home, with respect to diagnosis of cancer while participating in the HCBWP. This study addressed the following research questions:

- 1) How does the pain experience differ between older adult HCBWP participants in regards to diagnosis of cancer over time? How is the relationship between the pain experience and diagnosis of cancer affected by sex, age, race, comorbid conditions, depression and cognitive functioning over time?
- 2) How does the pain experience of older adult, HCBWP participants relate to pain management strategies and pain management outcomes and how does this relationship differ in regards to diagnosis of cancer over time? How is the relationship between the pain experience, pain management strategies, pain management outcomes and diagnosis of cancer affected by sex, age, race, comorbid conditions, depression and cognitive functioning over time?
- 3) How do the pain experience, pain management strategies and pain management outcomes of older adult, HCBWP participants predict the admission and time to admission of older adult HCBWP participants to a nursing home over

time and how does this relationship differ in regards to diagnosis of cancer while accounting for sex, age, race, comorbid conditions, depression and cognitive functioning?

Generalized estimating equation (GEE) analyses (Liang & Zeger, 1986) were used to respond to Research Questions 1 and 2. GEE is an extension of generalized linear models that provides a semi-parametric approach to longitudinal data analysis with univariate outcomes for which the quasi-likelihood formulation is sensible, i.e. normal, Poisson, binomial and gamma response variables. This approach allows for the analyses of longitudinal data where there are multiple measures of a subject characteristic over time (Liu, Dixon, Qiu, Tian, & McCorkle, 2009; Molenberghs & Verbeke, 2005). When a subject has a characteristic assessed at multiple time points, the assumption of independence cannot be met as subject response at one time point is very likely to predict the subject's response at a future time point (Fitzmaurice, et al., 2004; Singer & Willett, 2003). GEE analysis takes the dependence among multiple measures of a subject characteristic over time into consideration and allows for examination of changes in the subject characteristic over time (Fitzmaurice, et al., 2004; Singer & Willett, 2003).

GEE analysis requires the specification of distribution (normal, Poisson, binomial and gamma response variables) and link functions which connects the expected value of the dependent variable to the linear combination of the independent variable and covariates (Liu, et al., 2009). SAS and SPSS can use the GEE approach for the longitudinal analysis of binomial or multinomial outcomes. Few examples in the literature were found to support the use of computer language other than SPSS or SAS to perform multinomial longitudinal analysis (Lee, Kang, Liu, & Seo, 2010). Thus, the technique of multinomial longitudinal data analysis is not

well established and for the current research the researcher chose to use the built in approach in SAS.

Based on the dependent variables of research questions 1 and 2, an ordinal multinomial GEE approach would have been preferred. However, this approach had two disadvantages. First, it required that the outcome had an ordinal distribution (i.e. the proportional odds assumption stands). Second, only an independence covariance matrix could be assumed. To test the ordinal distribution of the outcomes of pain and prescribed pain medications, the model at time point 1 with covariates was carried out by SAS logistic procedure. The proportional odds assumption was rejected (p value < 0.001 for both models). Therefore, the ordinal multinomial approach was not appropriate for the analyses for Research Question 1 and 2.

For the analyses, Research Question 1 was decomposed into 2 sub-questions: 1) How do the covariates affect the older adult HCBWP participant who experienced daily pain vs. those with no pain or less than daily pain and 2) How do the covariates affect the older adult HCBWP participant with daily unusually intense pain vs. those with daily not unusually intense pain. For Research Question 1, a binomial link function or distribution was specified. Pain was dichotomized “0”=Pain Scale 0-1 (no pain, less than daily pain) and 1= (daily pain, both not unusually intense and unusually intense). Because pain was dichotomized for GEE analyses for Research Question 1 the results were limited to examining the likelihood of older adult HCBWP participants with daily pain vs. older adult HCBWP participants with no pain or less than daily pain instead of the full pain scale (0-3).

The first section of Research Question 2 examined the association between the pain experience and pain management strategies. The dependent variable, prescribed pain medications, was originally a nominal variable. Because the GEE analyses were limited to either

dichotomous or count dependent variables, dichotomous dependent variables which compared no prescribed pain medications and non-opioid, opioid and adjuvant pain medications were developed. For the second part of Research Question 2, which addressed associations between the pain experience, pain management strategies and physical function among older adult HCBWP with and without cancer, a Poisson distribution was specified as the dependent variable was a count of the number of ADL dependencies. The Poisson distribution (also known as log-linear) is used for the analysis of counts of the number of times an event occurs in time or space (Fitzmaurice, et al., 2004; Liu, et al., 2009). For this research, physical function was represented by the count of activities of daily living that the subject was dependent in. The use of and results of the GEE analyses are described further in the Results section later in Chapter 5.

The following section will present sample characteristics followed by descriptive analyses of study variables. All descriptive analyses of study variables included examining for differences in regards to diagnosis of cancer. Diagnosis of cancer was represented using the “phases of care” definitions based on the date of death in relation to the date of cancer diagnosis ((Brown, et al., 1999; G. F. Riley, et al., 1995; Yabroff, et al., 2005; Yabroff, et al., 2009). Preliminary descriptive analyses of the diagnosis of cancer measure revealed that there were very few subjects in the “terminal” phase at each assessment, making longitudinal modeling difficult (Table 3). Therefore, subjects in the continuing phase and terminal phase were consolidated under a single category “continuing/terminal”. Descriptive statistics for the revised diagnosis of cancer at each assessment are presented in Table 4. Across four assessments, cancer diagnosis remained consistent over time with approximately 6-7% of subjects having a diagnosis of cancer at each assessment.

Table 3

Reported Diagnosis of Cancer at Each Assessment Time Point

	No Diagnosis of Cancer	Initial Phase N (%)	Continuing Phase N (%)	Terminal Phase N (%)	Total Response N
Time 1 (%)	3812 (94)	96 (2)	145 (4)	1 (0)	4054
Time 2 (%)	3797 (94)	92 (2)	160 (4)	5 (0.1)	4054
Time 3 (%)	3786 (93)	80 (2)	177 (4)	11 (0.3)	4054
Time 4 (%)	3774 (93)	68 (2)	193 (5)	19 (0.5)	4054

Table 4

Revised Measure of Reported Diagnosis of Cancer at Each Assessment Time Point

	No Cancer N (%)	Initial Phase N (%)	Continuing/Terminal Phase N (%)	Total Response N
Time 1 (%)	3812 (94)	96 (2)	146 (4)	4054
Time 2 (%)	3797 (94)	92 (2)	165 (4)	4054
Time 3 (%)	3786 (93)	80 (2)	188 (5)	4054
Time 4 (%)	3774 (93)	68 (2)	212 (5)	4054

Sample

A total of 4054 subjects met the inclusion criteria for this study. Exclusion criteria were used to ensure that subjects had completed five MDS assessments prior to 12/31/2005 which was the date that Medicaid ceased being the sole payer of prescription medications for dually eligible (Medicaid and Medicare) older adults. Additionally, in order to clearly specify diagnosis of cancer, cancer survivors (those who had a diagnosis of cancer five years prior to the MDS assessment) were excluded. Other exclusion criteria and the determination of the final sample size of 4054 subjects are depicted in Figure 4. Analyses were started at the second MDS assessment to allow for at least 30 days in the Medicaid paid claim files prior to each MDS assessment. The second assessment will be referred to as Time 1 from this point on.

Subject socio-demographic characteristics by diagnosis of cancer at Time 1 are presented in Table 5. Overall, the majority of subjects were female (80%, n=3238) and Caucasian (74% n=3010). Race level “other” was comprised of American Indian (n=5), Asian and Pacific Islanders (n=12), Unknown (n=74) and Hispanic (n=37). The overall mean subject age at Time 1 was 77 years (not in Tables). There was no significant association between diagnosis of cancer and age or race at Time 1 (Table 5) and there was no significant difference in mean age by diagnosis of cancer at Time 1 (Table 5).

Table 5

Significance of Differences in Diagnosis of Cancer by Sociodemographic Characteristics at Time 1 among Study Subjects (n=4054)

Variable	No Diagnosis of Cancer N (%)	Initial Phase of Cancer N (%)	Continuing /Terminal Phase of Cancer N (%)	Total Response N	Signif. Testing
<hr/>					
<u>Sex</u>					
(% of row)					
Male	760 (93)	23 (3)	33 (4)	816	Chi-Square p-value= 0.47
Female	3052 (94)	73 (2)	113 (4)	3238	
<u>Race/Ethnicity</u>					
Caucasian	2825 (94)	71 (2)	114 (4)	3010	Chi-Square p-value= 0.76
Black	866 (94)	23 (3)	27 (3)	916	
Other	121 (94)	2 (1)	5 (4)	128	
<hr/>					
<u>Mean Age at Time 1</u> (SD)	77.39 (7.91)	76.19 (7.45)	76.97 (8.11)	4054	ANOVA Df=2 F=1.26 Sig=0.28

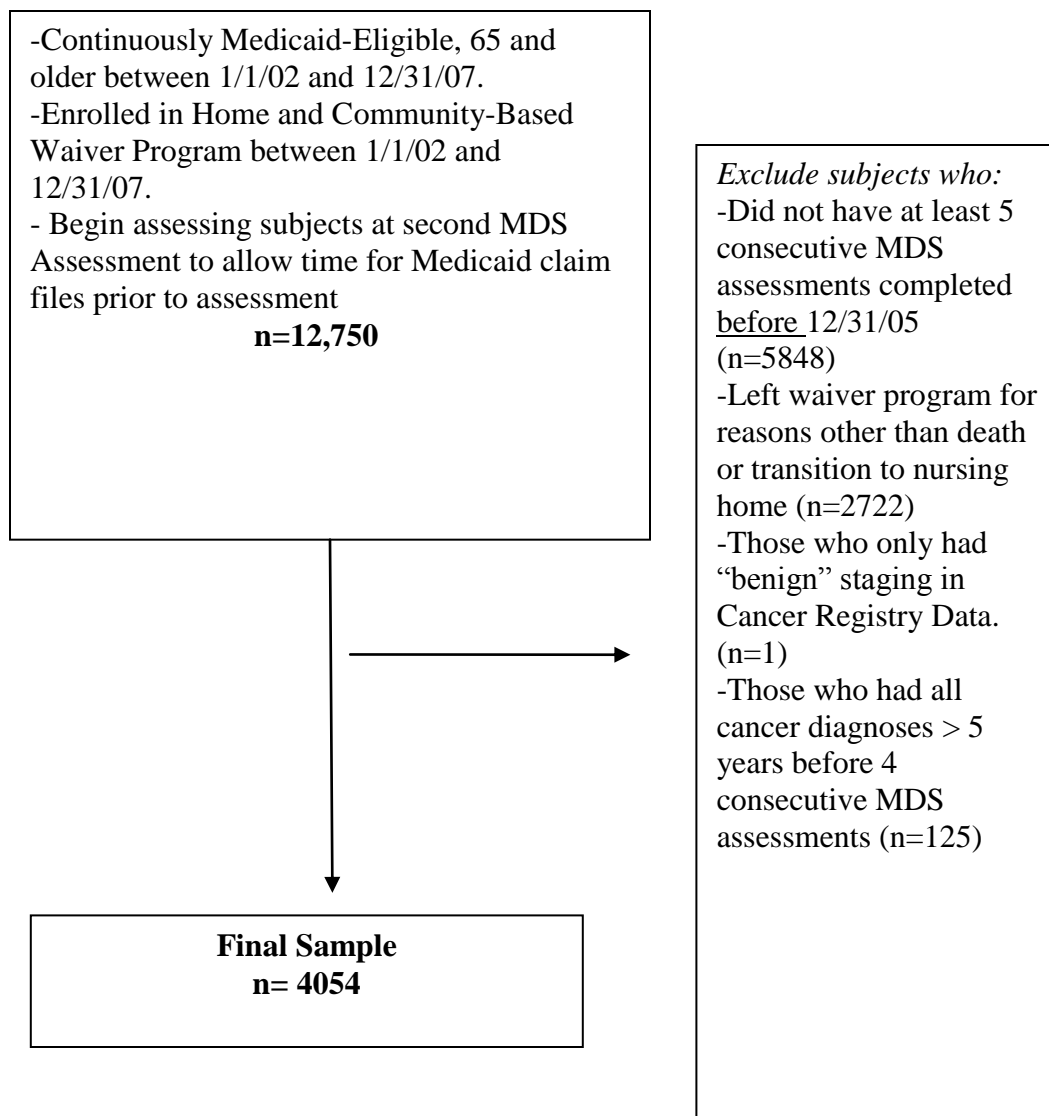


Figure 4. Final Exclusion Criteria Flow Chart for Determination of Sample

Measures

Operational definitions and measurement of study variables were presented in Chapter 4. The following section presents descriptive analyses results of sample response to study variables. The purposes of this study are focused on differences in the pain experience, pain management strategies, pain management outcomes and admission to a nursing home in respect to diagnosis of cancer. Therefore, each variable was examined in relation to the measure of diagnosis of cancer.

Cognitive Functioning

Cognitive functioning was represented by the dichotomized Cognitive Performance Scale (CPS) (Morris, et al., 1994) score. The CPS was comprised of four MDS-HC items: memory recall after 5 minutes, ability to make decisions, ability to make self understood and eating dependency. A scoring algorithm (Appendix C) used the scores for memory recall after 5 minutes, ability to make decisions, ability to make self understood and eating dependency to score the CPS score as follows: 0=cognitively intact, 1=borderline intact, 2=mild impairment, 3=moderate impairment, 4=moderately severe impairment, 5=severe impairment 6=very severe cognitive impairment.

The CPS score was then dichotomized as 0=cognitively intact (0 to 1) and ≥ 1 =indicative of cognitive impairment (≥ 2) (Morris, et al., 1994) (Table 6). Overtime (Table 6), the percentage of subjects who were cognitively impaired remained consistent in those with no cancer, initial phase or continuing/terminal phase. There was no significant association between cognitive functioning and diagnosis of cancer at each assessment time point.

Table 6

Significance of Differences in Cognitive Functioning by Diagnosis of Cancer at Each Assessment Time Point (n=4054)

Time Point	Cognitive Functioning 0=Cognitively Intact 1=Cognitively Impaired		Total Response n	X^2 of Cognitive Functioning by Diagnosis of Cancer at Each Time Point
	0 n (% of row)	1 n (% of row)		
1	2539 (63)	1501 (37)	4040	$X^2 = 1.47$ Df = 2 Sig = 0.48
2	2488 (62)	1551 (38)	4039	$X^2 = 0.60$ Df = 2 Sig = 0.74
3	2430 (60)	1610 (40)	4040	$X^2 = 0.19$ Df = 2 Sig = 0.91
4	2371 (59)	1669 (41)	4040	$X^2 = 2.31$ Df = 2 Sig = 0.31

Note. Response column does not include missing data

Behaviors Indicative of Depression

The measure of behaviors indicative of depression was represented by the Depression Rating Scale (DRS) (Burrows, et al., 2000). The DRS is comprised of 6 items from the MDS-HC that document behaviors indicative of depression: feelings of sadness, persistent anger, repetitive

anxious complaints, worried facial expressions, recurrent crying and withdrawing from social activities (Fries, James, & Aliaga, 2004; L. Li & Conwell, 2007). Item response coding is as follows for the 30 days before each MDS-HC assessment: 0= indicator not exhibited; 1=indicator exhibited daily or almost daily up to 5 days a week; 2=indicator exhibited daily or almost daily (6-7 days per week). Responses were then summed to create the DRS scale, with 0-12 possible and a higher number indicating more behaviors indicative of depression.

For the present study, the Cronbach's alpha for the DRS was 0.74, which is consistent with the DRS Cronbach's alpha of 0.74 presented by Li and Conwell (2007). Table 7 presents descriptive statistics for behaviors indicative of depression at each time point. A DRS score of a "3" or above is considered indicative of depression (Fries, James, & Aliaga, 2004; L. Li & Conwell, 2007). Using this criterion, 13-15% of subjects had a DRS score ≥ 3 at each time point (not in Tables).

There were no significant differences in mean behaviors indicative of depression in regards to diagnosis of cancer at each time point (Table 7). Mean behaviors indicative of depression across the four time points by diagnosis of cancer are presented in Figure 5. There was some variation in mean behaviors indicative of depression over the four time points by diagnosis of cancer. Most noticeably, subjects in the "initial phase" of cancer diagnosis appeared have a more pronounced increase in mean behaviors indicative of depression at Time 2 than subjects with no cancer or subjects in the "continuing/terminal phase". However, analysis via ANOVA showed no significant differences in mean behaviors indicative of depression in regards to diagnosis of cancer at Time 2 (Table 7).

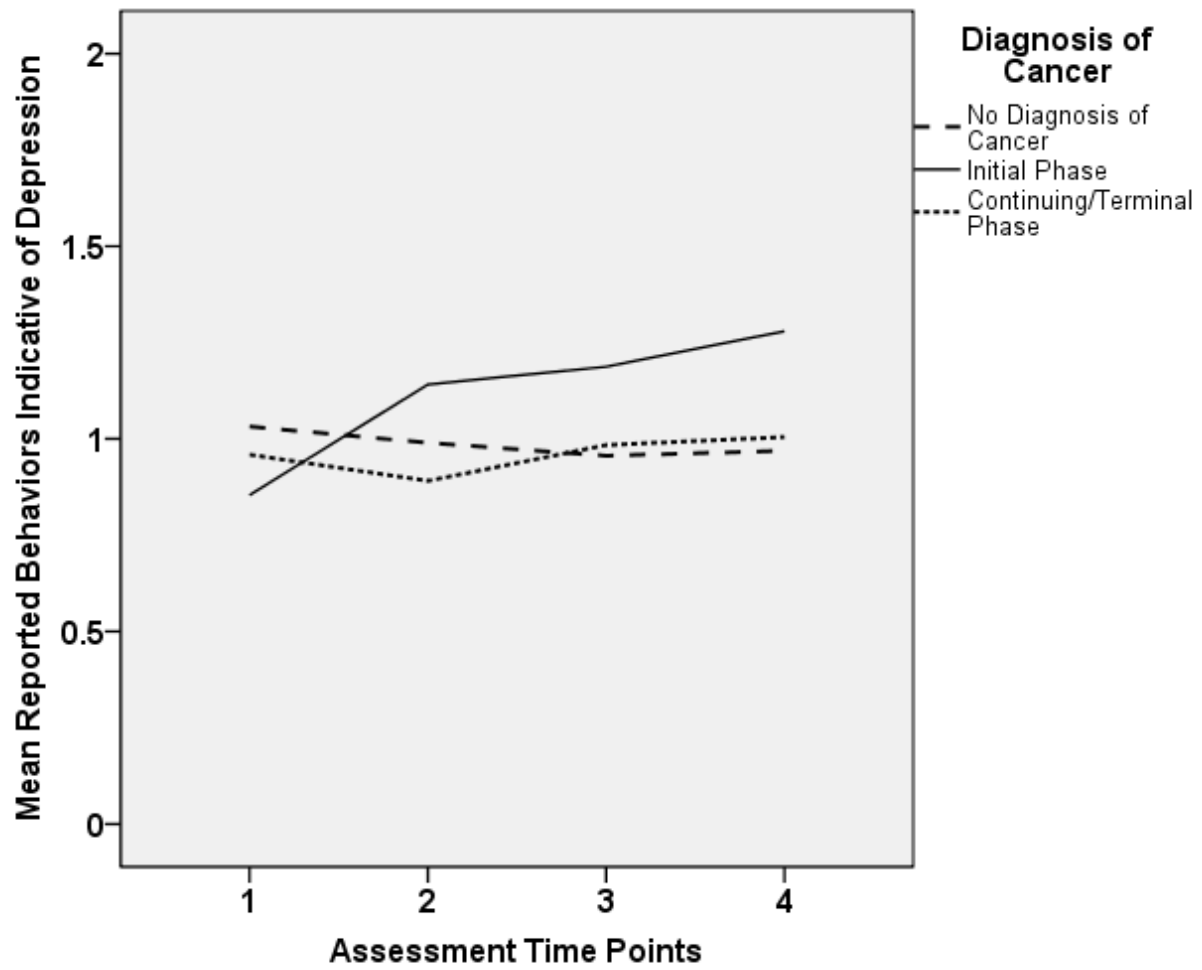


Figure 5. Mean Reported Behaviors Indicative of Depression by Cancer Diagnosis across Time Points (n=4054)

Table 7

Significance of Differences in Mean Behaviors Indicative of Depression by Diagnosis of Cancer at Each Assessment Time Point

Time	Mean (sd)	Response	ANOVA: Behaviors Indicative of Depression By Diagnosis of Cancer At Each Time Point
Time 1	1.03 (1.72)	4052	Df=2 F=0.62 Sig=0.54
Time 2	0.99 (1.69)	4052	Df=2 F=0.65 Sig=0.52
Time 3	0.99 (1.68)	4052	Df=2 F=0.76 Sig=0.47
Time 4	0.99 (1.70)	4051	Df=2 F=1.15 Sig=0.32

Note. Response column does not include missing data

Comorbid Conditions

Comorbid conditions were represented by a comorbid conditions measure indicating the summed, weighted effect of the presence of multiple diseases other than cancer (diabetes, chronic pulmonary disease, congestive heart failure, cerebrovascular disease, peripheral vascular disease, paralysis, acute myocardial infarction, old myocardial infarction, moderate/severe renal disease, diabetes with complications, ulcer disease, rheumatologic disease and mild liver disease) (Klabunde, et al., 2000) on pain, as measured by the Pain Scale (Fries, et al., 2001). As part of

the development process for the comorbid conditions index multinomial logistic regression models were used to make comparisons of the association of the pain scale (Fries, et al., 2001) with different comorbid condition measures: 1) Klabunde's (Klabunde, et al., 2000) method for a comorbid index measure; 2) a simple count of comorbid conditions and 3) Charlson's comorbidity index method (Charlson, et al., 1987).

Table 8

Model Fit Statistics for Multinomial Logistic Regression Models for the Association between the Pain Scale (0-3) and Different Measures of Comorbid Conditions

Comorbidity Measure	-2 LL	AIC	R²
Via Klabunde's method	10860.13	10874.13	0.02
Simple Comorbidity Count	10925.51	10933.51	0.002
Via Charlson's method	10931.19	10939.19	0.0006

The separate multinomial logistic regression models based on the different measures of comorbid conditions used the pain scale from Time 1 (Fries, et al., 2001) as the dependent variable and each comorbid measure as the independent variable. Results are presented in Table 8 . Based on the lower -2LL and AIC scores, as well as the higher R² value, the use of the measure of comorbid conditions developed through Klabunde and colleagues' method (Klabunde, et al., 2000) was supported. The final model included diabetes without complications, chronic pulmonary disease, peripheral vascular disease and rheumatologic disease which had a significant positive association with pain (Table 9).

Table 9

*Multinomial Logistic Regression Parameter Estimates for Final Comorbid Condition Model:
Pain Scale (0-3) = Comorbid Conditions*

Comorbid Conditions	DF	Estimate	Standard Error	Wald Chi-Square	P-value
Diabetes Without Complications	1	0.1497	0.06	6.51	0.01
Chronic Pulmonary Disease	1	0.3312	0.06	27.14	< 0.001
Peripheral Vascular Disease	1	0.2402	0.07	11.22	0.001
Rheumatologic Disease	1	1.0660	0.24	20.17	<0.001

The parameter estimates of the significant comorbid conditions were then added together to create the summed comorbid conditions index score. Parameter estimates for the final model are presented in Table 9. Bootstrap method was used (1000 repetitions) to determine the 95% confidence interval for the R^2 value (0.0174 -0.0193), which was consistent with the final model R^2 of 0.02. The above significant comorbid conditions coefficient values (developed from Time 1) were then applied to assessment time points 2, 3 and 4 data as well. For all time periods mean measure of comorbid conditions was approximately 0.22 (Table 10). There were no significant differences in the mean measure of comorbid conditions in regards to diagnosis of cancer at each time point (Table 10). Figure 6 shows there was little variability across time points in the mean measure of comorbid conditions among subjects in regards to diagnosis of cancer.

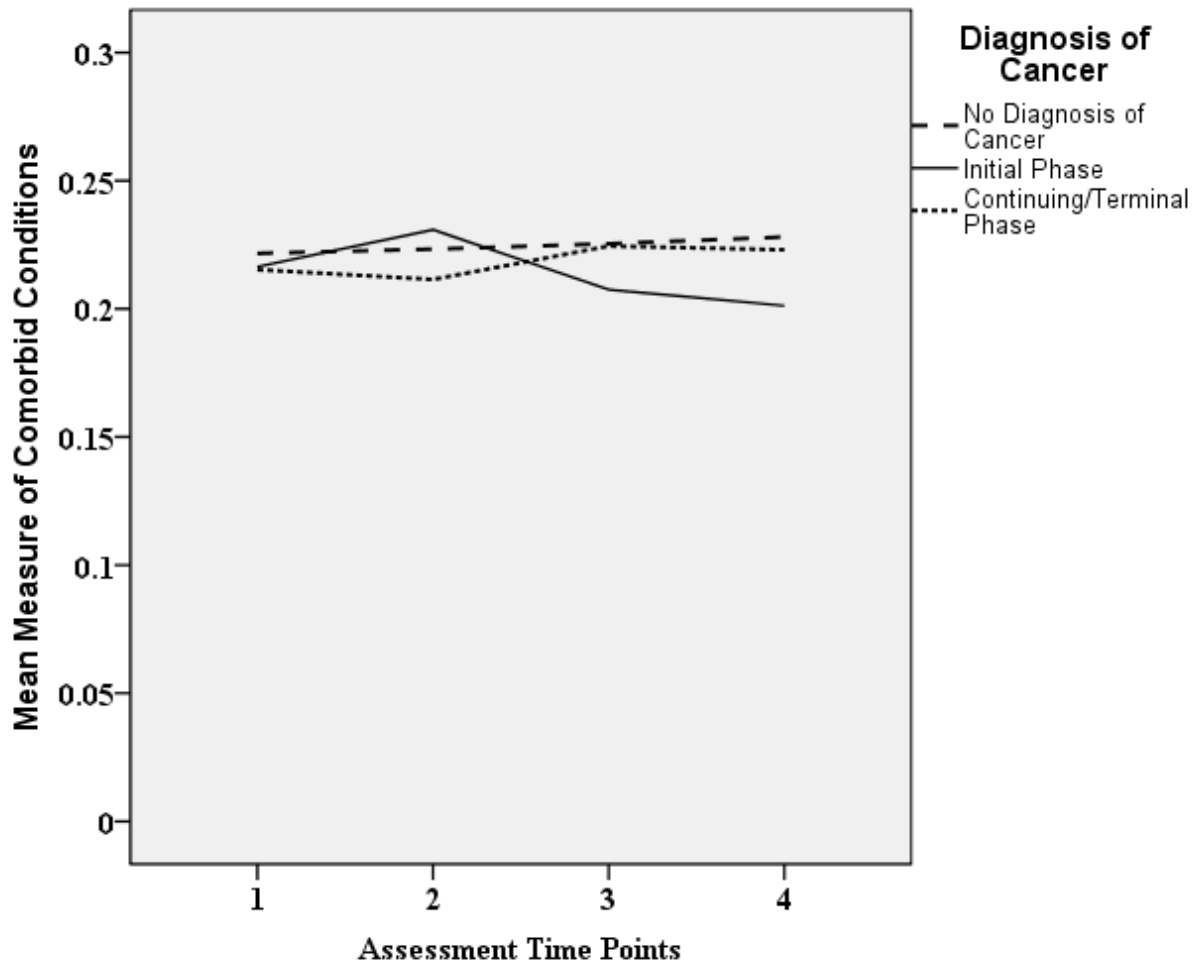


Figure 6. Mean Measure of Documented Comorbid Conditions by Diagnosis of Cancer at Each Assessment Time Point

Table 10

Significance of Differences in the Mean Measure of Comorbid Conditions by Diagnosis of Cancer at Each Assessment Time Point

Time	Mean (SD)	Response	ANOVA Mean Comorbid Condition by Diagnosis of Cancer At Each Time Point
Time 1	0.22 (0.25)	4054	Df=2 F=0.06 Sig.=0.94

Table 10 (Continued)

Time	Mean (SD)	Response	ANOVA Mean Comorbid Condition by Diagnosis of Cancer At Each Time Point
Time 2	0.22 (0.25)	4054	Df=2 F=0.23 Sig.=0.80
Time 3	0.23 (0.25)	4054	Df=2 F=0.20 Sig.=0.82
Time 4	0.23 (0.25)	4054	Df=2 F=0.42 Sig.=0.66

Cancer Site

Per the diagnosis of cancer measure, each subject was either noted to have “no cancer” or be in the initial or continuing/terminal phases of diagnosis of cancer. In addition to the diagnosis of cancer measure, *cancer site* was used to note the primary or initial anatomical location of the cancer for those in the initial or continuing/terminal phase of diagnosis of cancer. As presented in Chapter 4, preliminary analysis of cancer site data was completed and cancer sites with small numbers of subjects (for example Central Nervous System, Urinary, Upper Gastrointestinal) were consolidated into the “other” category. Table 11 presents the breakdown by cancer site of those with cancer at each time point. Overall, the percentage of each cancer remained approximately consistent over time. The number of those in each cancer site increased as the total number of those in the initial or continuing/terminal phase of diagnosis of cancer increased over time. Breast cancer was the most common cancer and female reproductive the least common at each time point.

Table 11

Number and Percentage of Cancer Site at each Assessment Time Point among Subjects with Cancer

Cancer Site (Column %)	Time 1 Sample (%) n=242	Time 2 Sample (%) n=257	Time 3 Sample (%) n=268	Time 4 Sample (%) n=280
Colon	37 (15)	41 (16)	44 (16)	45 (16)
Lung	22 (9)	23 (9)	22 (8)	22 (8)
Lymphoma /Leukemia	21 (9)	23 (9)	25 (9)	29 (10)
Breast	72 (30)	76 (30)	79 (30)	81 (30)
Female Reproductive	18 (7)	20 (8)	21 (8)	22 (8)
Prostate	25 (10)	27 (10)	29 (11)	31 (11)
Other Diagnosis	47 (19)	47 (18)	48 (18)	49 (17)

Note. The sample “n” at each time point only includes those with a diagnosis of cancer at each time point.

Cancer Stage

For those in the initial or continuing/terminal phases of diagnosis of cancer, the measure of *cancer stage* was used to denote the stage of cancer at diagnosis. The measure of cancer stage was developed using the Surveillance, Epidemiology and End Results (SEER) coding. Cancer stage at the each assessment for those with cancer is presented in Table 12. There was very little

change over time in the percentage of the different stages among subjects with cancer. Overall, the majority of cancers were stage 2-3 (local to regional at each assessment) at each time point.

Table 12

Number and Percentage of Stage of Cancer at Each Assessment Time Point among Subjects with Cancer

Cancer Stage	Time 1 Sample (%) (n=242)	Time 2 Sample (%) (n=257)	Time 3 Sample (%) (n=268)	Time 4 Sample (%) (n=280)
1=In-situ	21 (9)	21 (8)	22 (8)	23 (8)
2=Local	128 (53)	137 (53)	139 (52)	143 (51)
3=Regional	49 (20)	53 (25)	54 (20)	55 (26)
4=Distant	20 (8)	21 (8)	23 (9)	25 (9)
5=Unstaged	24 (10)	25 (10)	29 (11)	32 (29)
9=Invasive Unknown	0	0	1 (0.4)	1 (0.4)

Note. The sample “n” at each time point only includes those with a diagnosis of cancer

Pain

The main variable of interest for this study was pain, which was measured via the Pain Scale (Fries, et al., 2001). The Pain Scale is a hierarchal variable developed from two MDS-HC items which describe pain frequency and pain intensity (Chou & Chi, 2007; Fries, et al., 2001; L. Li & Conwell, 2007). The Pain Scale was coded 0=no pain, 1=less than daily pain, 2=daily, not unusually intense pain and 3, daily, unusually intense pain. The algorithm for the Pain Scale can be viewed in Appendix D. The two separate MDS-HC items that comprise the Pain Scale assess

pain frequency and pain intensity and responses at each time point are presented in Tables 13 and

14. In the MDS-HC, pain intensity is assessed only if pain frequency is ≥ 1 , therefore pain intensity is limited to subjects with pain frequency=2.

Table 13

Significance of Differences in Pain Frequency by Diagnosis of Cancer at Each Assessment Time Point (n=4054)

Assessment Time Point	Pain Frequency MDS-HC Item J8a			Response	X ² p-value for Pain Freq. by Diagnosis of Cancer
	0=No Pain	1=Less Than Daily Pain	2=Daily Pain		
Time 1	911 (22)	874 (22)	2267 (56)	4052	0.59
Time 2	915 (23)	890 (22)	2248 (55)	4053	0.81
Time 3	959 (24)	875 (22)	2217 (55)	4050	0.85
Time 4 (%)	940 (23)	873 (22)	2237 (55)	4050	0.52

Note. Response column does not include missing data

There were no significant differences in pain frequency or pain intensity by diagnosis of cancer at each time point (Tables 13 and 14). Table 15 presents the pain scale results at each time point. Over half of all subjects experienced daily pain and approximately 30% experienced daily pain that was unusually intense across the four assessments. The overall percentage breakdown across different pain levels (none, less than daily, daily not usually intense and daily unusually intense) remained relatively consistent across all four assessments (Table 15). Cross-tabulation of pain by diagnosis of cancer at each time point showed there were no significant differences in pain in regards to diagnosis of cancer at each time point (Table 15).

Table 14

Significance of Differences in Pain Intensity by Diagnosis of Cancer at Each Assessment Time Point for Subjects With Daily Pain

Time Point	Pain Intensity MDS-HC Item J8b		Response	X² p-value for Pain Intensity by Diagnosis of Cancer
	0=Pain Not Unusually Intense	1=Pain Unusually Intense		
Time 1 Sample (%)	1617 (54)	1400 (46)	3017	0.69
Time 2 Sample (%)	1624 (54)	1382 (46)	3006	0.22
Time3 Sample (%)	1615 (54)	1358 (46)	2973	0.60
Time 4 Sample (%)	1629 (54)	1360 (45)	2989	0.73

Note. Response column includes only those with Daily Pain at Each Time Point

Table 15

Significance of Differences in Pain Scale by Diagnosis of Cancer at Each Assessment Time Point (n=4054)

Time Point	Pain Scale				Response	X² p-value Pain by Diagnosis of Cancer
	0=No Pain	1=Less than daily pain	2=Daily, Not Unusually Intense	3=Daily, Unusually Intense		
Time 1	912 (23)	875 (22)	948 (24)	1237 (31)	3972	0.70

Table 15 (Continued)

Time Point	0=No Pain	Pain Scale 1=Less than daily pain	2=Daily, Not Unusually Intense	3=Daily, Unusually Intense	Response	X² p-value Pain by Diagnosis of Cancer
Time 2	920 (23)	888 (22)	959 (24)	1212 (31)	3979	0.79
Time 3	962 (24)	875 (22)	946 (24)	1202 (30)	3985	0.90
Time 4	944 (24)	870 (22)	969 (24)	1199 (30)	3982	0.67

Note. Response column does not include missing data

Prescribed Pain Medications

Prescribed pain medications were ascertained from mediations billed to the Medicaid Paid Claim Files in the 30 days prior to each of the four assessment dates. Drug coding within the Medicaid paid claim files was used to categorize the medications as 0=no pain medications prescribed, 1=non-opioid pain medications 2=opioid pain medications, 3=adjuvant pain medications. The descriptive statistics for prescribed pain medications across at each time point are presented in Table 16. The percentage of each level of Prescribed Pain Medications remained consistent over the four time points.

Table 16

Number and Percentage of Prescribed Pain Medication at Each Assessment Time Point (n=4054)

Prescribed Pain Medications				
Time	No Prescribed Pain Medications	Non-Opioid Pain Medications	Opioid Pain Medications	Adjuvant Pain Medications
	N (%)	N (%)	N (%)	N (%)
Time 1	2498	469	960	127
(row %)	(62)	(11)	(24)	(3)
Time 2	2450	443	1036	125
(row %)	(60)	(11)	(26)	(3)
Time 3	2461	437	1026	130
(row %)	(61)	(11)	(25)	(3)
Time 4	2427	453	1032	142
(row %)	(60)	(11)	(25)	(4)

At each assessment, diagnosis of cancer was not significantly associated with prescribed pain medications (Table 17). Cross-tabulation between Pain Scale and prescribed pain medication data at each time point is presented in Table 18. Interestingly, on average across the time points, 87% of those with “no pain” had no prescribed pain medications billed in the 30 days prior to each time point. On average across the time points, 43% of subjects with daily, unusually intense pain had opioid pain medications prescribed pain medications billed in the 30 days prior to each time point. Of concern is that on average across the time points, 40 % of subjects with daily, unusually intense pain had no pain medications billed in the 30 days prior to each time point.

Table 17

Significance of Differences in Prescribed Pain Medication by Diagnosis of Cancer at Each Assessment Time Point (n=4054)

Time Point	Diagnosis Of Cancer	Prescribed Pain Medication				X² Prescribed Pain Medication by Diagnosis of Cancer at Each Time
		0 No Pain Medication n (row %)	1 Non-Opioid Pain Medication n (row %)	2 Opioid Pain Medication n (row %)	3 Adjuvant Pain Medication n (row %)	
1 N=4054	0=No Cancer (n=3812)	2354 (62)	447 (12)	892 (23)	119 (3)	X² = 8.43 Df = 6 Sig = 0.21
	1=Initial Phase (n=96)	54 (56)	9 (10)	32 (33)	1 (1)	
	2=Continuing /Terminal Phase (n=146)	90 (62)	13 (9)	36 (25)	7 (5)	
2 N=4054	0=No Cancer (n=3797)	2303 (61)	417 (11)	958 (25)	119 (3)	X² = 4.91 Df = 6 Sig = 0.55
	1=Initial Phase (n=92)	56 (61)	9 (10)	26 (28)	1 (1)	
	2=Continuing /Terminal Phase (n=165)	91 (55)	17 (10)	52 (32)	5 (3)	

Table 17 (Continued)

Time Point	Diagnosis Of Cancer	Prescribed Pain Medication				X^2 Prescribed Pain Medication by Diagnosis of Cancer at Each Time
		0 No Pain Medication n (row %)	1 Non-Opioid Pain Medication n (row %)	2 Opioid Pain Medication n (row %)	3 Adjuvant Pain Medication n (row %)	
3 N=4054	0=No Cancer (n=3786)	2296 (61)	409 (11)	960 (25)	121 (3)	$X^2 = 3.26$ Df = 6 Sig = 0.78
	1=Initial Phase (n=80)	43 (54)	11 (14)	23 (29)	3 (4)	
	2=Continuing /Terminal Phase (n=188)	122 (65)	17 (9)	43 (23)	6 (3)	
4 N=4054	0=No Cancer (n=3374)	2249 (60)	431 (11)	960 (25)	134 (4)	$X^2 = 5.27$ Df = 6 Sig = 0.51
	1=Initial Phase (n=68)	46 (68)	6 (9)	14 (21)	2 (3)	
	2=Continuing /Terminal Phase (n=212)	132 (62)	16 (8)	58 (27)	6 (3)	

Table 18

Number and Percentage of Prescribed Pain Medication by Measure of Pain at each Assessment Time Point (n=4054)

Time Point	Pain Scale Freq (Row %)	Prescribed Pain Medications				Total
		0= No Pain Medication	1= Non-opioid Pain Medication	2= Opioid Pain Medication	3= Adjuvant Pain Medication	
Time 1 (N=3972)	0=No Pain	799 (88)	57 (6)	35 (4)	21 (2)	912
	1=Less that Daily Pain	601 (69)	123 (14)	124 (14)	27 (3)	875
	2=Daily pain, Not Unusually Intense	530 (56)	118 (12)	270 (28)	30 (3)	948
	3=Daily Pain, Unusually intense	516 (42)	159 (13)	511 (41)	48 (4)	1237
Time 2 (n=3979)	0=No Pain	796 (86)	63 (7)	45 (5)	16 (2)	920
	1=Less that Daily Pain	599 (67)	112 (13)	149 (17)	28 (3)	888
	2=Daily pain, Not Unusually Intense	528 (55)	110 (11)	289 (30)	32 (3)	959
	3=Daily Pain, Unusually intense	477 (39)	152 (13)	536 (44)	47 (4)	1212

Table 18 (Continued)

Time Point	Pain Scale Freq (Row %)	Prescribed Pain Medications				Total
		0= No Pain Medication	1= Non-opioid Pain Medication	2= Opioid Pain Medication	3= Adjuvant Pain Medication	
Time 3 (N=3985)	0=No Pain	832 (87)	57 (6)	53 (5)	20 (2)	962
	1=Less than Daily Pain	601 (69)	107 (12)	142 (16)	25 (3)	875
	2=Daily pain, Not Unusually Intense	489 (52)	120 (13)	301 (32)	36 (3)	946
	3=Daily Pain, Unusually intense	495 (41)	143 (12)	515 (43)	49 (4)	1202
Time 4 (N=3982)	0=No Pain	817 (86)	54 (6)	54 (6)	19 (2)	944
	1=Less than Daily Pain	582 (67)	111 (13)	141 (16)	36 (4)	870
	2=Daily pain, Not Unusually Intense	514 (53)	132 (14)	294 (30)	29 (3)	969
	3=Daily Pain, Unusually intense	473 (39)	142 (12)	528 (44)	56 (5)	1199

Hospice Services

The measure of hospice services was the reporting, scheduling and adherence of hospice services utilization by the HCBWP participant, per the MDS-HC. Hospice services was dichotomized as 0=hospice services not received, 1=hospice services received. Descriptive statistics for hospice over the four assessments are presented in Table 19. Less than 1% of subjects per assessment were receiving hospice services. Further analyses over the four assessments reveal very little change over time in the overall percentage of subjects who were receiving hospice services (Table 19).

Table 19

Significance of Differences in Hospice Services by Diagnosis of Cancer at Each Assessment Time Point

Time (Response for Hospice Services at Each Time Point)	Diagnosis Of Cancer (Response for Diagnosis of Cancer at Each Time Point)	Hospice Service		Fisher's Exact Test Hospice Services by Diagnosis of Cancer at Each Time
		0 (% of response for Diagnosis of Cancer at each Time Point)	1 (% of Diagnosis of Cancer at each Time Point)	
1 (n=3980)	0=No Cancer (3739)	3734 (99.9)	5 (0.1)	p=0.31
	1=Initial Phase (95)	95 (100)	0	
	2=Continuing/Terminal Phase (146)	145 (99.3)	1 (0.7)	

Table 19 (Continued)

Time (Response for Hospice Services at Each Time Point)	Diagnosis Of Cancer (Response for Diagnosis of Cancer at Each Time Point)	Hospice Service 0 (% of response for Diagnosis of Cancer at each Time Point)	0 (% of response for Diagnosis of Cancer at each Time Point)	Fisher's Exact Test Hospice Services by Diagnosis of Cancer at Each Time
2 (n=4047)	0=No Cancer (3790)	3783 (99.8)	6 (0.2)	p=1.00
	1=Initial Phase (92)	92 (100)	0	
	2=Continuing/Terminal Phase (165)	165 (100)	0	
3 (n=4050)	0=No Cancer (3782)	3774 (99.8)	8 (0.2)	p=1.00
	1=Initial Phase (80)	80 (100)	0	
	2=Continuing/Terminal Phase (188)	188 (100)	0	
4 (n=4047)	0=No Cancer (3767)	3761 (99.8)	6 (0.2)	p=0.16
	1=Initial Phase (n=68)	67 (98.5)	1 (1.5)	
	2=Continuing/Terminal Phase (212)	212 (100)	0	

Note. Response does not include missing data

The Fisher's exact test of the association between diagnosis of cancer and hospice services at each time point was insignificant. The Fisher's exact test was used instead of the Chi-Squared test as there were cross tabulation cells with counts of less than five. Interestingly,

almost all of subjects receiving hospice services did not have cancer except for 1 in the diagnosis of cancer continuing phase. Due to the extremely low response in the hospice services variable, hospice services was not included in further analyses.

Pain Control

Pain control, a pain management outcome, was measured via a single MDS-HC item, stating “pain is controlled by medication”, with the response of either 0=no pain, 1=medication offered, no control, 2=pain is partially or fully controlled by medication. Descriptive statistics for pain control across assessments is presented in Table 20. Percentages for the levels of pain control were consistent over time.

Cross-tabulation between pain control and pain and pain control and prescribed pain medications are presented in Tables 21 and 22, respectively. Pain control was highly sensitive to the Pain Scale, as approximately 95% of those without pain per the measure of pain were also noted as having no pain per the pain control measure over the four time points. On average over the four time points, 45% of those who had medication offered with no control had daily, unusually intense pain (Table 22). Of subjects who reported no pain at the four time points, on average only 13% had evidence of prescribed pain medications in the 30 days prior to each time point, leading to the question if this sub-group’s lack of pain is due to not having pain instead of pain being managed well by prescribed pain medication that was not captured in the 30 days before assessment time period (Table 22). Unfortunately, the Medicaid paid claim files did not capture the use of over the counter pain medications and perhaps this may be an explanation for the high percentage of subjects with no pain who also had no pain medications prescribed. Over the four assessments, diagnosis of cancer was not significantly associated with the measure of pain control (Table 20).

Table 20

Significance of Difference in Pain Control by Diagnosis of Cancer at Each Assessment Time Point (n=4054)

Time Point	Pain Control 0=No Pain	Pain Control 1=Medication Offered , No Control	Pain Control 2=Pain is partially or fully controlled	Response	X² Pain Control by Diagnosis of Cancer at Each Time
Time 1	894 (23)	100 (2)	2959 (75)	3953	X ² =5.41 Df =4 Sig = 0.25
Time 2	913 (23)	102 (3)	2954 (74)	3969	X ² =2.56 Df =4 Sig = 0.75
Time 3	951 (24)	107 (3)	2922 (73)	3980	X ² =2.82 Df =4 Sig = 0.59
Time 4	953 (24)	101 (3)	2930 (73)	3984	X ² =2.41 Df =4 Sig = 0.66

Note. Response column does not include missing data

Table 21

Number and Percentage for the Measure of Pain Control by Measure of Pain at Each Assessment Time Point

Time Point	Pain Control Freq (Row %)	Pain Scale				Total
		0=No Pain	1=Less than Daily Pain	2=Daily Pain, not Unusually Intense	3=Daily Pain, Unusually Intense	
Time 1 Response= 3875	0=No pain	847 (95)	25 (3)	11 (1)	7 (1)	890
	1=Medication offered, no control	2 (2)	28 (29)	17 (18)	49 (51)	96
	2=Pain is partially or fully controlled by medication	32 (1)	782 (27)	905 (31)	1170 (41)	2889
Time 2 Response= 3895	0=No pain	852 (93)	37 (4)	17 (2)	5 (1)	911
	1=Medication offered, no control	1 (1)	30 (30)	21 (21)	47 (47)	99
	2=Pain is partially or fully controlled by medication	39 (2)	785 (27)	907 (31)	1154 (40)	2885

Table 21 (Continued)

Time Point	Pain Control Freq (Row %)	Pain Scale				Total
		0=No Pain	1=Less than Daily Pain	2=Daily Pain, not Unusually Intense	3=Daily Pain, Unusually Intense	
Time 3 Response= 3914	0=No pain	896 (94)	33 (3)	14 (2)	5 (1)	948
	1=Medication offered, no control	1 (1)	33 (31)	26 (25)	45 (43)	105
	2=Pain is partially or fully controlled by medication	39 (1)	780 (27)	895 (31)	1147 (40)	2861
Time 4 Response= 3916	0=No pain	888 (94)	42 (4)	13 (1)	5 (1)	948
	1=Medication offered, no control	1 (1)	27 (27)	33 (33)	38 (39)	99
	2=Pain is partially or fully controlled by medication	33 (4)	778 (27)	913 (32)	1145 (40)	2869

Note. Response column does not include missing data

Table 22

Number and Percentage of Pain Control by Measure of Prescribed Pain Medication at each Assessment Time Point

Time Point	Pain Control Freq Row %	Prescribed Pain Medication				Response
		0=No Pain Meds	1=Non-Opioid Pain Meds	2=Opioid Pain Meds	3=Adjuvant Pain Meds	
Time 1 Response= 3953	0=No pain	785 (88)	49 (5)	36 (4)	24 (3)	894
	1=Medication offered, no control	60 (60)	9 (9)	27 (27)	4 (4)	100
	2=Pain is partially or fully controlled by medication	1569 (53)	404 (14)	890 (30)	96 (3)	2959
Time 2 Response= 3969	0=No pain	795 (87)	54 (6)	47 (5)	17 (2)	913
	1=Medication offered, no control	59 (58)	9 (9)	32 (31)	2 (2)	102
	2=Pain is partially or fully controlled by medication	1523 (52)	374 (13)	954 (32)	103 (3)	2954

Table 22 (Continued)

Time Point	Pain Control Freq Row %	Prescribed Pain Medication				Response
		0=No Pain Meds	1=Non-Opioid Pain Meds	2=Opioid Pain Meds	3=Adjuvant Pain Meds	
Time 3 Response= 3980	0=No pain	831 (87)	48 (5)	53 (6)	19 (2)	951
	1=Medication offered, no control	70 (65)	9 (8)	24 (22)	4 (4)	107
	2=Pain is partially or fully controlled by medication	1496 (51)	379 (13)	943 (32)	104 (4)	2922
Time 4 Response= 3984	0=No pain	822 (86)	56 (6)	54 (6)	21 (2)	953
	1=Medication offered, no control	61 (60)	11 (11)	25 (25)	4 (4)	101
	2=Pain is partially or fully controlled by medication	1482 (51)	384 (13)	949 (32)	115 (4)	2930

Note. Response column does not include missing data

Physical Function

Physical function was represented by a count of the following activities of daily living (ADL) that the HCBWP participant is dependent including dressing, personal hygiene, toilet use, bathing and eating. Mean physical function at each time point is presented in Table 23. There was no significant difference in mean physical function in regards to diagnosis of cancer at each

time point (Table 23). Across the four assessments, there was a mild increase in mean physical function (indicating an increase in the mean number of ADL dependencies) overtime with some variability among diagnosis of cancer (Figure 7). However, the ANOVA analysis results noted there was no significant differences in mean physical function in regards to diagnosis of cancer across time points (Table 23).

Table 23

Significance of Differences in Mean Physical Function by Diagnosis of Cancer at Each Assessment Time Point

Time Point	Mean (sd)	Total at Each Time	ANOVA for Physical Function by Diagnosis of Cancer at Each Time
Time 1	1.81 (1.55)	4053	Df=2 F=0.19 Sig=0.82
Time 2	1.85 (1.54)	4053	Df=2 F=0.13 Sig=0.88
Time 3	1.89 (1.55)	4053	Df=2 F=0.17 Sig=0.84
Time 4	1.96 (1.55)	4053	Df=2 F=0.01 Sig=0.99

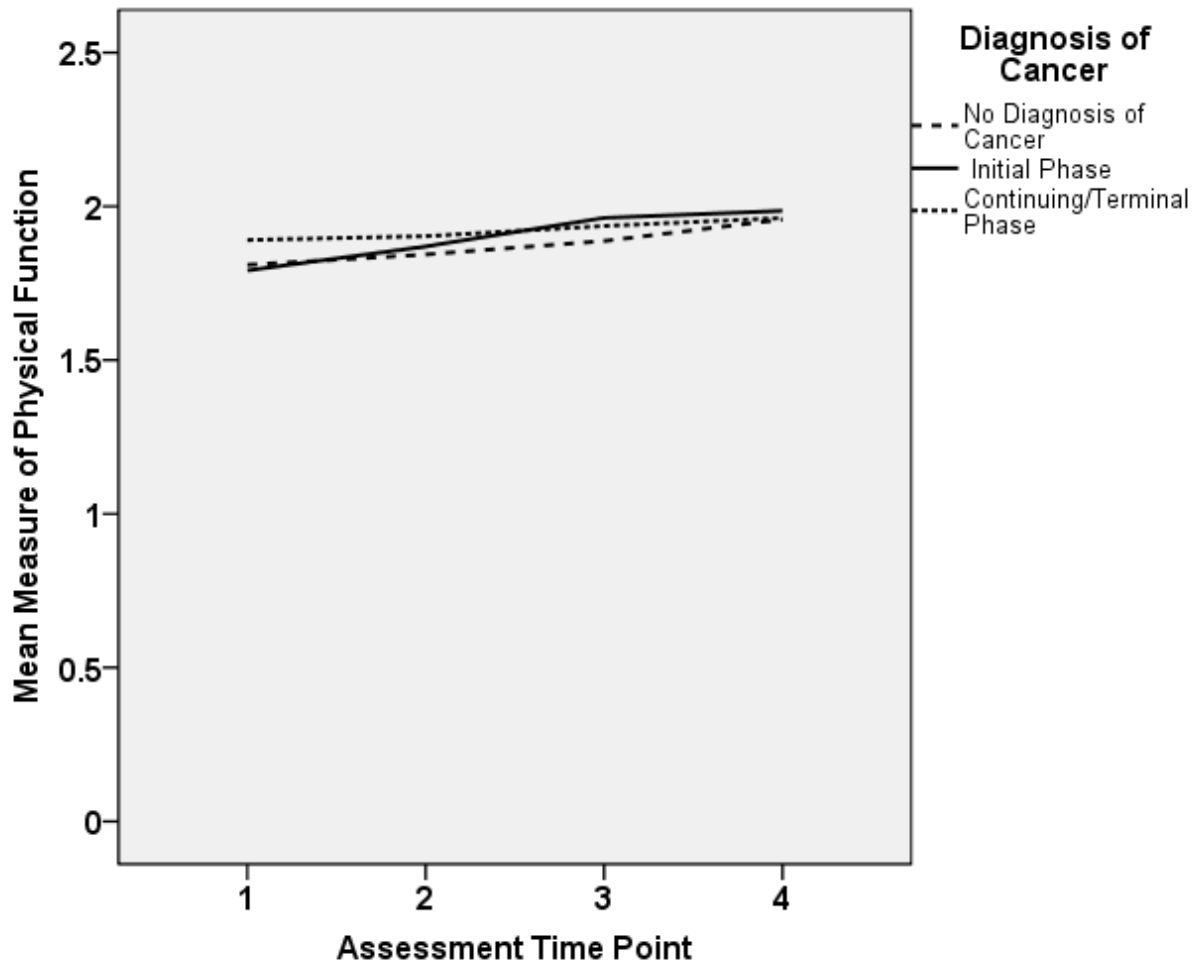


Figure 7. Mean Measure of Physical Function by Measure of Diagnosis of Cancer At Each Assessment Time Point

Admission to a Nursing Home

Admission to a Nursing Home measured whether a HCBWP participant is admitted to a nursing home while participating in the HCBWP and does not return to the HCBWP. Admission to a Nursing Home is dichotomous, with 0=remains in the HCBWP, 1=to a nursing home.

Descriptive statistics for Admission to a Nursing Home can be found in Table 24. Admission to nursing Home was not re-measured at each assessment, but was regarded as a single event.

Therefore, descriptive analysis was completed as a single event and not at each time point.

Approximately 66% of the subjects stayed in the HCBWP prior to 12/31/05. There was no significant association between admission to a nursing home and diagnosis of cancer (Table 25).

Table 24

Prior to 12 Percentage of Older Adult HCBWP Participants Admitted to Nursing Home /31/2005

Measure	Coding	Sample Response (%)	Response
Admission to Nursing Home	0=Subject stayed in HCBWP	0=2667 (66)	4054
	1=Subject admitted to Nursing Home	1=1387 (34)	

Table 25

Significance of Differences in the Measure of Admission to a Nursing Home Prior to 12/31/2005 by Diagnosis of Cancer

Diagnosis Of Cancer	Admission to a Nursing Home			X^2 Admission to a Nursing Home by Diagnosis of Cancer
	0 Remain in HCBWP	1 Admitted to Nursing Home	Total Response	
0= No Cancer (row %)	2506 (66)	1306 (34)	3812	$X^2 = 2.95$ Df = 2 Sig = 0.23
1= Initial Phase (row%)	70 (73)	26 (27)	96	
2= Continuing/Terminal Phase (row%)	91 (62)	55 (38)	146	

Time to Nursing Home Admission

Time to Nursing Home Admission was represented by the number of months from admission to the HCBWP until the admission of HCBWP participant to a nursing home. Subjects who stayed in the HCBWP past 12/31/2005 were censored, i.e. their time to nursing home admission was from the date of HCBWP admission to 12/31/2005. Time to nursing home admission was treated as a continuous variable. Mean time to nursing home admission was 33.48 months (sd=12.75) with a range of 3 months to 47 months. There were no significant differences in mean time to nursing home admission by diagnosis of cancer (Table 26).

Table 26

Mean Time to Nursing Home Admission by Diagnosis of Cancer

Diagnosis Of Cancer (response)	Mean Time to Nursing Home Admission (sd)	ANOVA Admission to a Nursing Home by Diagnosis of Cancer
0=No Cancer (3739)	33.53 (12.74)	Df =2 F=0.199 Sig = 0.82
1=Initial Phase (95)	30.93 (12.62)	
2=Continuing/Terminal Phase (146)	33.81 (12.75)	

Note. Response does not include missing data

Results

The models examining the relationship among pain, pain management strategies, pain management outcomes and nursing home admission were analyzed using SAS 9.2 (SAS

Institute, 2008) and PASW (2009) statistical software. Results are presented in relation to the three research questions.

Research Question 1: How does the pain experience differ between older adult HCBWP participants in regards to diagnosis of cancer over time? How is the relationship between the pain experience and diagnosis of cancer affected by sex, age, race, comorbid conditions, depression and cognitive functioning over time?

Generalized estimating equation (GEE) analysis models were used to examine the longitudinal association between pain and diagnosis of cancer as well as how this association was affected by sex, age, race, comorbid conditions, depression and cognitive functioning. Since the SAS and SPAA data analysis programs for GEE uses binary or count dependent variables (Liu, et al., 2009; Molenberghs & Verbeke, 2005) the dependent variable, pain, was dichotomized “0”=Pain Scale 0-1 (no pain, less than daily pain) and 1= (daily pain, both not unusually intense and unusually intense). An autoregressive (AR1) working correlation was specified as AR1 is a very parsimonious correlation model (two parameters) and accounts for correlation as a function of time (Fitzmaurice, et al., 2004). Estimate statements were used to generate odds ratios with 95% confidence intervals.

For this model, the dichotomized pain variable was the dependent variable with diagnosis of cancer (0=no cancer, 1=initial phase, 2=continuing/terminal) as an independent variable. Age, sex, race/ethnicity, cognitive functioning, comorbid conditions and behaviors indicative of depression were added to the model as covariates all at once. In addition to the above covariates, cancer site and cancer stage were added to the model initially. However, the model could not carry out successfully due to the small number of subjects with cancer which were further minimized by cancer site and cancer stage categories. Despite further consolidation of the levels

of cancer site and cancer stage, the model continued to not properly estimate the binomial structure. Therefore, the decision was made to do a sub-analysis with cancer site and cancer stage if diagnosis of cancer was noted to be significant in any of the study models. Insignificant variables were then removed one at a time and the model re-ran until the most parsimonious model was achieved. Time in the HCBWP and diagnosis of cancer were insignificant, indicating no significant effect from diagnosis of cancer or time in the HCBWP on likelihood of experiencing daily pain over time. Time in the HCBWP and diagnosis of cancer were left in the model as they were main variables of interest in this study.

Significant findings are described in the following (Table 27). Females were 1.78 times **more** likely to experience daily pain over time than males, after adjusting for other covariates. African American HCBWP participants were 0.74 times **less** likely to experience daily pain overtime than white HCBWP participants, after adjusting for other covariates. Age had a negative association with pain, such that for each year older a subject was, he or she was 0.99 times **less** likely to experience daily pain, after adjusting for other covariates. Subjects who were cognitively impaired were 0.72 times **less** likely to experience daily pain overtime than those who were cognitively intact, after adjusting for other covariates. As the measure of comorbid conditions increased by one unit, a subject was 2.32 time **more** likely to experience daily pain over time, after adjusting for other covariates. Finally, the measure of behaviors indicative of depression was positively associated with pain overtime, such that as behaviors indicative of depression increased by one, a subject was 1.06 times **more** likely to experience daily pain, after adjusting for other covariates.

Table 27

Parameter Estimates, Odds Ratios and Significance Values of Parsimonious Model for Generalized Estimating Equation Fitted to the Dependent Variable of No Pain/Less than Daily Pain vs. Daily Pain Using a Binomial Distribution (n=4054)

Variable	Parameter Estimate (95% CI)	Odds Ratio (95% CI)	Pr>X²
Diagnosis of Cancer			
No Cancer	Ref.	-----	-----
Initial Phase	0.18 (-0.04 – 0.39)	1.19 (0.96-1.48)	0.11
Continuing/Terminal Phase	0.06 (-0.17 – 0.28)	1.06 (0.85 – 1.33)	0.61
Sex			
Male	Ref.	-----	-----
Female	0.57 (0.43 – 0.72)	1.78 (1.53 – 2.05)	<0.001
Race			
White	Ref.	-----	-----
African American	-0.31 (-0.44 - -0.17)	0.74 (0.64 – 0.84)	<0.001
Other	-0.25 (-0.57 – 0.07)	0.78 (0.57 – 1.08)	0.13
Age			
	-0.01 (-0.019 - -0.004)	0.99 (0.98 – 1.00)	0.003

Table 27 (Continued)			
Variable	Parameter Estimate (95% CI)	Odds Ratio (95% CI)	Pr>X²
Cognitive Functioning			
Cognitively Intact	Ref.	-----	-----
Cognitively Impaired	-0.33 (-0.42 - -0.24)	0.72 (0.66 – 0.79)	<0.001
Comorbid Conditions	0.84 (0.59 – 1.09)	2.32 (1.80 – 2.99)	<0.001
Behaviors Indicative of Depression	0.06 (0.04-0.08)	1.06 (1.04-1.08)	<0.001
Time in HCBWP	-0.002 (-0.008 -0.004)	1.00 (0.99 -1.00)	0.49

A sub-analysis was then completed to examine what differences existed in the longitudinal association between daily not unusually intense pain or daily unusually intense pain and diagnosis of cancer as affected by sex, age, race, cognitive functioning , depression and comorbid conditions. This sub-sample was limited to subjects who had experienced daily pain at two or more time points (n=2243) which was then dichotomized into 0=not unusually intense pain, 1=unusually intense pain. GEE modeling was utilized with an autoregressive (AR1) working correlation. Insignificant variables were removed one by one and the GEE model re-ran.

Out of the above significant predictors of daily pain vs. not daily pain/no pain (sex, race, cognitive functioning, age, comorbid conditions and behaviors indicative of depression) only age and behaviors indicative of depression were predictors of not unusually intense pain vs.

unusually intense pain among subjects with daily pain (Table 28). As age increased by one year, a subject was 0.97 times **less** likely to experience unusually intense pain vs. not unusually intense pain, after adjusting for other covariates. As the measure of behaviors indicative of depression increased by 1, a subject was 1.04 times **more** likely to experience unusually intense pain, after adjusting for other covariates.

Table 28

Parameter Estimates, Odds Ratios and Significance Values of Parsimonious Model for Generalized Estimating Equation Fitted to the Dependent Variable of Daily Pain, Not Unusually Intense vs. Daily Pain, Unusually Intense Using a Binomial Distribution (n=2243)

Variable	Parameter Estimate (95% CI)	Odds Ratio (95% CI)	Pr>X²
Diagnosis of Cancer			
No Cancer	Ref.	-----	-----
Initial Phase	-0.19 (-0.54 – 0.15)	0.94 (0.68 – 1.30)	0.71
Continuing/Terminal	-0.20 (-0.51 – 0.10)	0.87 (0.65 – 1.17)	0.38
Age	-0.03 (-0.04 - -0.02)	0.97 (0.96-0.98)	< 0.001
Behaviors Indicative of Depression	0.03 (0.003 – 0.055)	1.04 (1.01– 1.07)	0.01
Time in Waiver Program	0.001 (-0.005 – 0.007)	1.00 (0.99 – 1.01)	0.31

Conclusion for Results of Research Question 1 Analysis

In conclusion, diagnosis of cancer was not significantly associated with the pain experience over time among older adult HCBWP participants. The pain experience was not significantly affected by the amount of time spent in the HCBWP. Females were more likely to experience daily pain than males. African American older adult HCBWP participants were less likely to experience daily pain than white older adult HCBWP participants. Cognitive functioning had a negative association with the pain experience: those with impaired cognitive functioning were less likely to experience daily pain than those who were cognitively intact. As the measure of comorbid conditions increased, the likelihood of experiencing daily pain increased as well over time. As age increased, not only did the likelihood of experiencing daily pain vs. no pain decrease but the likelihood of experiencing daily unusually intense pain vs. daily not unusually intense pain decreased as well. Finally, as behaviors indicative of depression increased, not only did the likelihood of experiencing daily pain vs. no pain increase but the likelihood of experiencing daily unusually intense pain vs. daily not unusually intense pain increased as well.

Research Question 2: How does the pain experience of older adult, HCBWP participants relate to prescribed pain management strategies and pain management outcomes and how does this relationship differ in regards to diagnosis of cancer over time? How are the relationships between the pain experience, pain management strategies, pain management outcomes and diagnosis of cancer affected by sex, age, race, comorbid conditions, depression and cognitive functioning over time?

Generalized estimating equation (GEE) analysis models were used to examine the longitudinal association between pain management strategies (prescribed pain medications), pain

management outcomes (physical function and pain control) and diagnosis of cancer and how these associations were affected by pain, sex, age, race, depression, cognitive functioning, comorbid conditions and time in the HCBWP. As mentioned earlier in this chapter, further analysis with the pain management strategy of hospice services was not completed due to extremely low response number of those who received hospice services (Tables 19 and 20).

For the GEE models examining prescribed pain medications and pain control a binomial distribution was utilized. The nominal variable, prescribed pain medications, was dichotomized as no prescribed pain medications vs. non-opioid pain medications, opioid pain medications and adjuvant pain medications as well as non-opioid pain medications vs. opioid pain medications. A Poisson distribution was used for the GEE model examining physical function, as physical function was a count variable of the total number of activities of daily living the subject was dependent in. An autoregressive (AR1) working correlation was specified for all models as AR1 is a very parsimonious correlation model (two parameters) and accounts for correlation as a function of time (Fitzmaurice, et al., 2004). Estimate statements were used to generate odds ratios with confidence intervals. Research Question 2 analyses were limited to subjects with daily pain at two or more time points (n=2243). Of special interest was the examination of subjects who reported daily pain and had no prescribed pain medication vs. opioid pain medications prescribed, as approximately half of the subjects with daily pain did not have any prescribed pain medications across all time points (Table 18).

Dependent variables were developed as follows:

- 1) For the pain management strategy of prescribed pain medications, multiple analyses were performed. The measure of prescribed pain medications was originally coded as 0=no pain medications, 1=non-opioid pain medication,

2=opioid pain medications, 3=adjuvant pain medications. The measure of prescribed pain medications was developed from the Medicaid paid claim files, a process which was described in Chapter 4. In order to perform the GEE modeling, the measure of prescribed pain medications was dichotomized through the use of dummy variables. “No pain medications” was the reference level and denoted as “0” and compared to “non-opioid”, “opioid” and “adjuvant” in separate models. In addition, opioid pain medications were compared to a reference level of non-opioid.

- 2) The pain management outcome of physical function was represented by a count of the following activities of daily living (ADL) that the older adult HCBWP participant with daily pain is dependent in: dressing, personal hygiene, toilet use, bathing and eating. Physical function score ranged from 0 to 5, with a higher score indicating more dependency with ADLs.
- 3) The pain management outcome of pain control was originally operationalized as the HCBWP participant’s or the HCBWP participant’s or proxy’s response to the MDS-HC item “pain is controlled by medication” with possible responses as 0=no pain, 1=medication offered, no control and 2=pain is partially or fully controlled by medication. For the GEE model, the dependent variable needed to be dichotomous. Dummy variables were constructed for no pain vs. medication offered no control and no pain vs. pain is partially or fully controlled by medication among older adult HCBWP participants with daily pain.

In summary, research question 2 examined differences in the pain management strategies and pain management outcomes among older adults HCBWP participants in regards to diagnosis

of cancer as well as the effects of the pain experience, age, sex, race/ethnicity, cognitive functioning, behaviors indicative of depression, comorbid conditions on the differences. Results of the GEE analyses follow.

Research Question 2: Pain Management Strategies

Prescribed Pain Medications. Generalized Estimating Equation (GEE) models were used to explore for differences in prescribed pain medications among older adult HCBWP participants *with daily pain* (n=2243) in regards to diagnosis of cancer and how this association was affected by age, sex, race/ethnicity, cognitive functioning, behaviors indicative of depression, comorbid conditions and time in the HCBWP.

Separate models were used for each comparison: no pain medications vs. non-opioid (Table 29), no pain medications vs. opioid pain medications (Table 30), no pain medications vs. adjuvant pain medications (Table 31) and non-opioid vs. opioid pain medications (Table 32). All variables (age, sex, race/ethnicity, cognitive functioning, behaviors indicative of depression, pain, comorbid conditions and time in the HCBWP) were added to each GEE model. Insignificant variables were then removed one by one and the model re-ran. Diagnosis of cancer, time in the HCBWP and pain were left in each model, even if insignificant, as they were key study variables.

No prescribed pain medications vs. Non-opioid pain medications. Only diagnosis of cancer and pain were significant predictors of whether non-opioid pain medications were prescribed vs. if no pain medications were prescribed over time among older adult HCBWP participants with two or more assessments of daily pain (Table 29). Age, sex, race/ethnicity, cognitive functioning, behaviors indicative of depression, comorbid conditions and time in the

HCBWP were not significantly associated with likelihood of being prescribed non-opioid pain medications vs. no prescribed pain medications over time.

Table 29

Parameter Estimates, Odds Ratios and Significance Values of Parsimonious Model for Generalized Estimating Equation Fitted to the Dependent Variable of Non-Opioid Prescribed Pain Medications vs. No Prescribed Pain Medications Using a Binomial Distribution (n=2243)

Variable	Parameter Estimate (95% CI)	Odds Ratio (95% CI)	Pr> χ^2
Diagnosis of Cancer			
No Cancer	Ref.	_____	_____
Initial Phase	-0.99 (-1.93 – -0.06)	0.37 (0.14 – 0.94)	0.04
Continuing/Terminal	-0.31 (-0.73 – 0.11)	0.73 (0.48 – 1.12)	0.15
Pain			
Not Daily unusually intense	Ref	-----	-----
Daily unusually intense	0.24 (0.07-0.42)	1.28 (1.07 – 1.52)	0.01
Time in Waiver Program	-0.002 (-0.02 – 0.01)	0.99 (0.98 – 1.01)	0.75

When compared to subjects with no diagnosis of cancer, subjects in the initial phase of diagnosis of cancer were 0.37 times **less** likely to have non-opioid pain medications prescribed vs. no pain medications prescribed, after adjusting for other covariates. When compared to subjects who did not have daily unusually intense pain, subjects with daily unusually intense

pain were 1.28 times **more** likely to have non-opioid pain medications prescribed than no pain medications, after adjusting for other covariates.

Because diagnosis of cancer was significantly associated with the prescription of non-opioid pain medications vs. no pain medications, a sub-analysis was performed with cancer site and cancer stage. Neither cancer site ($p=0.07$) or cancer stage ($p=0.27$) were significantly associated with the prescription of non-opioid pain medications vs. no pain medications among older adult HCBWP participants.

In summary, pain and diagnosis of cancer were significant predictors of the prescription of non-opioid pain medications vs. no prescribed pain medications among older adult HCBWP participants experiencing daily pain over time. Having daily, unusually intense pain **increased** the likelihood of an older adult HCBWP participant having non-opioid pain medications prescribed for them. Older adult HCBWP participants who were in the initial phase of diagnosis of cancer were **less** likely than subjects with no diagnosis of cancer of having non-opioid pain medications prescribed for them. There were no significant associations between cancer site and cancer stage and the likelihood of being prescribed non-opioid pain medications vs. no prescribed pain medications among older adult HCBWP participants.

The assessment of predictors of whether an older adult HCBWP participant had non-opioid pain medications prescribed was complicated by the fact that many non-opioid pain medications are available over the counter and therefore, would not be captured on the Medicaid paid claim file data. The use of over the counter non-opioid pain medications by older adult HCBWP participants cannot be known via the data used for this study and therefore this analysis may have been affected by the under-reporting of non-opioid pain medication use.

No prescribed pain medications vs. opioid pain medications. Pain, age, sex, race/ethnicity, cognitive functioning, comorbid conditions and time in the HCBWP were significant predictors of the prescription of opioid pain medications vs. no pain medications (Table 30) among older adult HCBWP participants with two or more assessments of daily pain. Diagnosis of cancer was not significantly associated with the prescription of opioid pain medications vs. no prescribed pain medications. Significant results among older adult HCBWP participants with two or more assessments of daily pain were as follows:

Pain. Pain was positively associated with the prescription of opioid pain medications when compared with no prescribed pain medications. Subjects with daily unusually intense pain were 1.72 times **more** likely to have opioid pain medications prescribed when compared to subjects without daily unusually intense pain, after adjusting for other covariates.

Age. As subject age increased by one year, subjects was 0.96 times **less** likely to have opioid pain medications prescribed vs. no pain medications, after adjusting for other covariates.

Race/Ethnicity. African American HCBWP participants were 0.63 times **less** likely have opioid pain medications prescribed vs. no pain medications prescribed over time than white older adult HCBWP participants, after adjusting for other covariates. There was no significant difference in the likelihood of older adult HCBWP participants in the “other” race/ethnicity group having prescribed opioid pain medications vs. no pain medications when compared to white older adult HCBWP participants.

Sex. When compared to males, females were 1.46 times **more** likely to have opioid pain medications prescribed than have no pain medications prescribed, after adjusting for other covariates.

Cognitive Functioning. Cognitive functioning was negatively associated with prescribed pain medications such that subjects who were cognitively impaired were 0.67 times **less** likely to be prescribed opioid pain medications vs. no pain medications over time than subjects who were cognitively intact over time.

Comorbid Conditions. As the measure of comorbid conditions increased by one unit, a subject was 1.67 times **more** likely of being prescribed opioid pain medication vs. no pain medications over time, after adjusting for other covariates.

Time in the HCBWP. As time in the HCBWP increased by one month, subjects were 1.01 times **more** likely to be prescribed opioid pain medications vs. no pain medications.

Table 30

Parameter Estimates, Odds Ratios and Significance Values of Parsimonious Model for Generalized Estimating Equation Fitted to the Dependent Variable of Opioid Prescribed Pain Medications vs. No Prescribed Pain Medications Using a Binomial Distribution (n=2243)

Variable	Parameter Estimate (95% CI)	Odds Ratio (95% CI)	Pr> χ^2
Diagnosis of Cancer			
No Cancer	Ref.	-----	-----
Initial Phase	-0.12 (-0.50 – 0.25)	0.88 (0.60 – 1.29)	0.52
Continuing/Terminal	-0.08 (-0.40 – 0.23)	0.92 (0.67 – 1.26)	0.61

Table 30 (Continued)

Variable	Parameter Estimate (95% CI)	Odds Ratio (95% CI)	Pr> χ^2
Pain			
Not daily, not unusually intense	Ref.	-----	-----
Daily, unusually intense	0.54 (0.41 – 0.67)	1.72 (1.51 – 1.96)	<0.001
Sex			
Male	Ref	-----	-----
Female	0.38 (0.17 – 0.59)	1.46 (1.19 – 1.81)	<0.001
Age			
	-0.03 (-0.04 - -0.02)	0.96 (0.95-0.98)	<0.001
Race/Ethnicity			
White	Reference	-----	-----
African American	-0.45 (-0.64 - -0.27)	0.63 (0.52 – 0.76)	<0.001
Other	-0.29 (-0.73 – 0.15)	0.75 (0.48 – 1.16)	0.20
Cognitive Functioning			
Cognitively Intact	Ref	-----	-----
Cognitively Impaired	-0.36 (-0.50 - -0.21)	0.70 (0.60 – 0.80)	<0.001

Table 30 (Continued)

Variable	Parameter Estimate (95% CI)	Odds Ratio (95% CI)	Pr>X²
Comorbid Conditions	0.51 (0.24 – 0.79)	1.67 (1.27 – 2.20)	<0.001
Time in the HCBWP	0.01 (0.003 – 0.024)	1.01 (1.00– 1.02)	0.01

In summary, pain, age, sex, race/ethnicity, cognitive function, comorbid conditions and time in the HCBWP were all significantly associated with the prescription of opioid pain medications vs. no pain medications over time among older adult HCBWP participants. When compared to older adult HCBWP participants not experiencing daily unusually intense pain, older adult HCBWP participants with daily unusually intense pain were significantly more likely to have opioid pain medications prescribed for them, vs. no pain medications. As the age of older adult HCBWP participants increased, the likelihood of being prescribed opioid pain medications decreased. Female older adult HCBWP participants were more likely than male older adult HCBWP participants to have opioid pain medications prescribed for them. African American older adult HCBWP participants were less likely than their white counterparts to have opioid pain medication prescribed for them, as are cognitively impaired older adult HCBWP participants when compared to cognitively intact older adult HCBWP participants. Finally, the likelihood of being prescribed opioid pain medications increased as the measure of comorbid conditions or time in the HCBWP also increased.

As noted earlier in this section, the examination of subjects who reported daily pain and had no prescribed pain medication vs. opioid pain medications prescribed was of special interest,

as approximately half of the subjects with daily pain did not have any prescribed pain medications across all time points (Table 18). The results of this analysis suggest that subjects who reported daily pain and were not prescribed opioid pain medications were more likely to be experiencing not unusually intense daily pain, be older, be African American, be cognitively impaired, have less comorbid conditions and had spent less time in the HCBWP than older adult HCBWP participants who were prescribed opioid pain medications.

No prescribed pain medications vs. adjuvant prescribed pain medications. Adjuvant prescribed pain medications are “...non-opioid medications that have pain-relieving effects in certain conditions, but whose primary or initial indication was not for the treatment of pain” (American Pain Society, 2005, p. 73). Medications that are used as adjuvant pain medications include anticonvulsants, antidepressants, and local anesthetics (American Pain Society, 2005). Adjuvant medications diminish pain by altering nerve function (Kalso, 2005).

Diagnosis of Cancer, pain, age, and race/ethnicity were significant predictors of the prescription of adjuvant pain medications vs. no pain medications (Table 31). Significant results among older adult HCBWP participants with two or more assessments of daily pain were as follows:

Diagnosis of Cancer. Subjects in the initial phase of diagnosis of cancer were 0.41 times **less** likely than subjects with no diagnosis of cancer to have adjuvant pain medications prescribed vs. no pain medications prescribed. There was no significant difference in the likelihood of having adjuvant pain medications prescribed vs. no pain medications prescribed between subjects in the continuing/terminal diagnosis of cancer and subjects with no diagnosis of cancer.

Because diagnosis of cancer was significantly associated with the prescription of adjuvant pain medications vs. no pain medications, a sub-analysis was performed with cancer site and cancer stage. With the addition of cancer site to the model containing the above significant variables, the model failed to converge and error messages were produced. Cancer site was removed from the model. Cancer stage, when added separately to the model, did not significantly associate ($p=0.61$) with the prescription of adjuvant pain medications vs. no pain medications among older adult HCBWP participants. Therefore, cancer stage was not associated with the prescription of adjuvant pain medications vs. no prescribed pain medications overtime, after adjusting for other covariates.

Pain. Pain was positively associated with the prescription of adjuvant pain medications when compared with no prescribed pain medications. Subjects with daily unusually intense pain were 1.41 times **more** likely to have adjuvant pain medications prescribed than no pain medications when compared to subjects without daily unusually intense pain, after adjusting for other covariates. Therefore, daily unusually intense pain was significantly associated with the prescribing of adjuvant pain medications, such that older adult HCBWP participants with daily unusually intense pain were more likely to have adjuvant pain medications prescribed to them compared to older adult HCBWP participants experiencing daily pain that was not unusually intense.

Age. As subject age increased by one year, subjects were 0.95 times **less** likely to have adjuvant pain medications prescribed vs. no pain medications over time, after adjusting for other covariates.

Race/Ethnicity. In regards to race, African Americans were 0.47 times **less** likely to be prescribed adjuvant pain medications vs. no prescribed pain medications over time than white

subjects, after adjusting for other covariates. There was no significant difference in the likelihood of being prescribed adjuvant pain medications vs. no pain medications between white subjects and subjects in the “other” race/ethnicity category.

Table 31.

Parameter Estimates, Odds Ratios and Significance Values of Parsimonious Model for Generalized Estimating Equation Fitted to the Dependent Variable of Adjuvant Prescribed Pain Medications vs. No Prescribed Pain Medications Using a Binomial Distribution (n=2243)

Variable	Parameter Estimate (95% CI)	Odds Ratio (95% CI)	Pr>X ²
Diagnosis of Cancer			
No Cancer	Ref.	_____	_____
Initial Phase	-0.90 (-1.72 – -0.08)	0.41 (0.18 – 0.92)	0.03
Continuing/Terminal	-0.12 (-0.82 – 0.57)	0.88 (0.45 – 1.78)	0.73
Pain			
Not daily unusually intense	Ref.	_____	_____
Daily, unusually intense	0.34 (0.07– 0.61)	1.41 (1.08-1.84)	0.01
Age	-0.05 (-0.08 – - 0.03)	0.95 (0.93 – 0.97)	<0.001

Table 31 (Continued)

Variable	Parameter Estimate (95% CI)	Odds Ratio (95% CI)	Pr> X^2
Race			
White	Ref.	—	—
African American	-0.76 (-1.24 - -0.28)	0.47 (0.29 – 0.75)	0.002
Other	-0.26 (-1.30 – 0.77)	0.77 (0.27 – 2.17)	0.62
Time in Waiver Program	0.02 (-0.002– 0.035)	1.02 (1.00– 1.03)	0.08

In summary, diagnosis of cancer, pain, age and race/ethnicity were significantly associated with the prescription of adjuvant pain medications vs. no prescribed pain medications over time among older adult HCBWP participants. As with the prescription of non-opioid pain medications, older adult HCBWP participants in the initial phase of diagnosis of cancer were less likely than older adult HCBWP participants without cancer to have adjuvant pain medications prescribed for them. Older adult HCBWP participants with daily unusually intense pain were significantly more likely to have adjuvant pain medications prescribed than older adult HCBWP participants without daily unusually intense pain. African American older adult HCBWP participants were less likely than white older adult HCBWP participants to have adjuvant pain medications prescribed. Finally, as age increased among older adult HCBWP participants, the likelihood of having adjuvant pain medications prescribed decreased.

Opioid pain medications vs. Non-Opioid Pain Medications. Pain, age, sex, race/ethnicity, cognitive functioning, comorbid conditions and time in the HCBWP were significant predictors of the prescription of opioid pain medications vs. the prescription of non-opioid pain medications (Table 32) among older adult HCBWP participants with two or more assessments of daily pain. There was no significant association between diagnosis of cancer and the likelihood of being prescribed opioid pain medications vs. non-opioid pain medications among older adult HCBWP participants. Significant results among older adult HCBWP participants with two or more assessments of daily pain were as follows.

Pain. Pain was positively associated with the prescription of opioid pain medications when compared with the prescription of non-opioid pain medications. Subjects with daily unusually intense pain were 1.33 times **more** likely to have opioid pain medications prescribed than non-opioid pain medications when compared to subjects without daily unusually intense pain, after adjusting for other covariates.

Sex. When compared to males, females were 1.36 times **more** likely to have opioid pain medications prescribed rather than non-opioid pain medications prescribed, after adjusting for other covariates.

Age. As subject age increased by one year, subjects were 0.97 times **less** likely to have adjuvant pain medications prescribed vs. no pain medications over time, after adjusting for other covariates.

Race/Ethnicity. In regards to race, African Americans were 0.73 times **less** likely to be prescribed opioid pain medications vs. non-opioid pain medications over time than “white” subjects, after adjusting for other covariates. There was no significant difference in the

likelihood of being prescribed opioid pain medications vs. non-opioid pain medications between “white” subjects and subjects in the “other” race/ethnicity category.

Cognitive functioning. Subjects who were cognitively impaired were 0.70 times **less** likely than cognitively intact subjects to be prescribed opioid pain medications vs. non-opioid pain medications over time, after adjusting for other covariates.

Comorbid conditions. As the measure of comorbid conditions increased by one unit, subjects were 2.04 times **more** likely to be prescribed opioid pain medication vs. non-opioid pain medications over time, after adjusting for other covariates.

Time in the HCBWP. As time in the HCBWP increased by one month, subjects were 1.01 times **more** likely to be prescribed opioid pain medications than non-opioid pain medications over time, after adjusting for other covariates.

In summary, pain, age, sex, race/ethnicity, cognitive function, comorbid conditions and time in the HCBWP were all significantly associated with the prescription of opioid pain medications vs. non-opioid pain medications over time. When compared to older adult HCBWP participants not experiencing daily unusually intense pain, older adult HCBWP participants with daily unusually intense pain were significantly more likely to have opioid pain medications prescribed for them, vs. non-opioid pain medications. As the age of older adult HCBWP participants increased, the likelihood of being prescribed opioid pain medications vs. non-opioid pain medications decreases. Female older adult HCBWP participants are more likely than male older adult HCBWP participants to have opioid pain medications vs. non-opioid pain medications prescribed for them. African American older adult HCBWP participants are less likely than their white counterparts to have opioid pain medication vs. non-opioid pain medications prescribed for them, as are cognitively impaired older adult HCBWP participants

when compared to cognitively intact older adult HCBWP participants. Finally, the increased likelihood of being prescribed opioid pain medications vs. non-opioid pain medications increased as the measure of comorbid conditions or time in the HCBWP increased.

The predictors of the likelihood of being prescribed opioid pain medications vs. non-opioid pain medications were the same as the predictors of the likelihood of being prescribed opioid pain medications vs. no pain medications. As noted earlier in this section, older adult HCBWP participants may have been taking over the counter non-opioid pain medications that were not captured in the Medicaid paid claim files and therefore were not included in the prescription of non-opioid pain medication. The resulting identical predictors for the prescription of opioid pain medications vs. no prescribed pain medications and opioid pain medications vs. non-opioid pain medication suggest that there were not many differences between the prescription of non-opioid pain medications and no prescribed pain medications when comparing to the prescription of opioid pain medications. Strengthening the argument that use of non-opioid pain medications may not have been fully accounted for with this dataset.

Table 32

Parameter Estimates, Odds Ratios and Significance Values of Parsimonious Model for Generalized Estimating Equation Fitted to the Dependent Variable of Opioid Prescribed Pain Medications vs. Non-Opioid Prescribed Pain Medications Using a Binomial Distribution (n=2243)

Variable	Parameter Estimate (95% CI)	Odds Ratio (95% CI)	Pr>X²
Diagnosis of Cancer			
No Cancer	Ref.	-----	-----
Initial Phase	0.62 (0.04 – 1.20)	1.86 (1.04 – 3.32)	0.04
Continuing/Terminal	0.08 (-0.35 – 0.52)	1.09 (0.70– 1.69)	0.70
Pain			
Not Daily unusually intense	Ref.	-----	-----
Daily, unusually intense	0.28 (0.10 – 0.46)	1.33 (1.11 – 1.58)	0.002
Sex			
Male	Reference	-----	-----
Female	0.31 (0.02 – 0.60)	1.36 (1.02-1.82)	0.03
Age			
	-0.03 (-0.04 – - 0.02)	0.97 (0.95-0.98)	<0.001

Table 32 (Continued)

Variable	Parameter Estimate (95% CI)	Odds Ratio (95% CI)	Pr>X²
Race			
White	Reference	-----	-----
African American	-0.31 (-0.57 - -0.06)	0.73 (0.57 – 0.93)	0.02
Other	-0.42 (-1.00 – 0.16)	0.66 (0.37 – 1.18)	0.16
Cognitive Functioning			
Cognitively Intact	Ref	-----	-----
Cognitively Impaired	-0.35 (-0.54 - -0.16)	0.70 (0.58 – 0.85)	<0.001
Comorbid Conditions	0.71 (0.30 – 1.13)	2.04 (1.35 – 3.09)	<0.001
Time in Waiver Program	0.01 (0.002– 0.03)	1.01 (1.00– 1.03)	0.03

Summary of Pain Management Strategies: Prescribed Pain Medications. In summary, results indicated that diagnosis of cancer (initial phase vs. no diagnosis of cancer) was negatively associated with the prescription of non-opioid and adjuvant pain medication (vs. no pain medications). These findings should be examined further in future research to determine differences in the pain experience and personal and health and illness characteristics of older adult HCBWP participants in the initial phase from those with no diagnosis of cancer or those further along in their cancer treatment. In the present study, descriptive analysis had not shown a

significant association between the measure of diagnosis of cancer and personal and health and illness factors.

The results of these analyses which found significant associations between the prescription of opioid pain medications and pain, age, sex, race/ethnicity, cognitive functioning, comorbid conditions are similar to results of previous research that were presented in Chapter 3 (American Geriatrics Society Panel on Persistent Pain in Older Persons, 2002; Bruckenthal, 2008; Bruckenthal & D'Arcy, 2007; Reynolds, et al., 2008; Won, et al., 2004). The significant time effect on the prescription of opioid pain medication indicated that the longer the older adult participated in the HCBWP, the more likely he or she was to be prescribed opioid pain medications. Whether this significant time effect is specific to the HCBWP or there is an overall time effect for the likelihood being prescribed opioid pain medications would need to be clarified in future research. The fact that age and likelihood of being prescribed opioid pain medications had a negative association over time certainly points to a significant time effect specific to the HCBWP.

The prescription of non-opioid pain medications vs. no prescribed pain medications was significantly associated with pain and diagnosis of cancer. As discussed earlier, the analysis of predictors of the prescription of non-opioid pain medications may have been limited by the use of over the counter non-opioid pain medications that were not captured in the Medicaid paid claim files. The consistent use of a write-in medication section in the MDS-HC documenting all medication would assist in assessing the association between personal, health and illness and environmental characteristics in future research.

The prescription of adjuvant pain medications vs. no prescribed pain medications was significantly associated with diagnosis of cancer, pain, age and race/ethnicity. The negative

association between age and race/ethnicity may be explained in part by drug-related and health system-related factors. Adjuvant pain medications are primarily medications which have central nervous system actions. For example, Elavil is a tricyclic antidepressant while Tegretol has been used for seizures and both drugs have a sedating effect. Healthcare providers may be reluctant to prescribe sedating drugs to older adults. Additionally, adjuvant pain medications may be primarily used by healthcare providers associated with pain clinics, a specialty practice. African American older adult HCBWP participants may have less access to specialty health services like pain clinics than their white counterparts.

Research Question 2: Pain Management Outcomes

Generalized Estimating Equation (GEE) models were used to examine the association between pain management outcomes of physical function and pain control among older adult HCBWP participants *with daily pain* and diagnosis of cancer and how this association was affected by age, sex, race/ethnicity, cognitive functioning, behaviors indicative of depression, comorbid conditions and time in the HCBWP. Separate models were used for physical function and pain control. All variables including pain, prescribed pain medication, age, sex, race/ethnicity, cognitive functioning, behaviors indicative of depression, pain, comorbid conditions and time in the HCBWP were added to each GEE model. Insignificant variables were then removed one by one and the model re-ran. Diagnosis of cancer, time in the HCBWP and pain were left in each model, even if insignificant, as they were key study variables.

Physical Function. A GEE model was used to explore differences in physical function among older adult HCBWP participants who experienced daily pain in regards to diagnosis of cancer and how this association was affected by pain, age, sex, race/ethnicity, cognitive functioning, behaviors indicative of depression, comorbid conditions, prescribed pain

medications and time in the HCBWP. To review, the pain management outcome of physical function is represented by a count of the following activities of daily living (ADL) that the HCBWP participant is dependent in: dressing, personal hygiene, toilet use, bathing and eating. Physical function score ranged from 0 to 5, with a higher score indicating more dependency with ADLs.

Pain, race/ethnicity, cognitive functioning, behaviors indicative of depression and time in the HCBWP were significantly associated with physical function over time (Table 33) among older adult HCBWP participants with two or more assessments of daily pain. There was no significant association between diagnosis of cancer and physical function over time among older adult HCBWP participants with two or more assessments of daily pain. Significant results among older adult HCBWP participants with two or more assessments of daily pain were as follows:

Pain. Pain was positively associated with physical function. Subjects with daily unusually intense pain were 1.05 times **more** likely to experience physical function dependencies when compared to subjects without daily unusually intense pain, after adjusting for other covariates.

Race. In regards to race, African Americans were 1.36 times **more** likely to experience physical function dependencies when compared to white subjects, after adjusting for other covariates. There was no significant difference in the likelihood of experiencing physical function dependencies between “white” subjects and subjects in the “other” race/ethnicity category.

Cognitive Functioning. When compared to cognitively intact subjects, subjects with cognitive impairment were 1.19 times **more** likely to experience an increase in physical function dependencies over time, after adjusting for covariates.

Behaviors Indicative of Depression. The measure of behaviors indicative of depression had a positive, significant association with physical function over time, such that subjects were 1.01 times **more** likely to experience dependencies in physical function as behaviors indicative of depression increased 1 point, after adjusting for other covariates.

Time in the HCBWP. As time in the HCBWP increased by one month, subjects were 1.01 times **more** likely to experience physical function dependencies, after adjusting for other covariates.

In summary, pain, race/ethnicity, cognitive functioning, behaviors indicative of depression and time in the HCBWP were all significantly associated with the measure of physical function (the total number of activities of daily living the older adult HCBWP participant was dependent, or needed assistance with) over time. Older adult HCBWP participants who experienced daily unusually intense pain were more likely to experience physical function dependencies than those not experiencing daily unusually intense pain. African American older adult HCBWP participants were more likely than white older adult HCBWP participants to experience physical function dependencies. A higher likelihood of having physical function dependencies was experienced by the cognitively impaired as well as those with increasing behaviors indicative of depression. There was a significant time effect on physical function, such that as an older adult spent more time in the HCBWP, they experienced an increase in physical function dependencies. Diagnosis of cancer was not a significant predictor of physical function over time among older adult HCBWP participants.

Table 33

Parameter Estimates, Odds Ratios and Significance Values of Parsimonious Model for Generalized Estimating Equation Fitted to the Dependent Variable of Physical Function Using a Poisson Distribution (n=2243)

Variable	Parameter Estimate (95% CI)	Odds Ratio (95% CI)	Pr>X^2
Diagnosis of Cancer			
No Cancer	Ref.	-----	-----
Initial Phase	0.04 (-0.05 – 0.14)	1.04 (0.94 – 1.15)	0.38
Continuing/Terminal	0.11 (-0.004 – 0.22)	1.12 (0.99 – 1.25)	0.06
Pain			
Not daily, unusually intense pain	Ref.	-----	-----
Daily, unusually intense	0.05 (0.003-0.094)	1.05 (1.00 – 1.10)	0.04
Race			
White	Ref.	-----	-----
African American	0.31 (0.24 – 0.38)	1.36 (1.27 – 1.46)	<0.001
Other	0.13 (-0.07 – 0.33)	1.13 (0.92 – 1.38)	0.21

Table 33 (Continued)

Variable	Parameter Estimate (95% CI)	Odds Ratio (95% CI)	Pr>X ²
Cognitive Functioning			
Cognitively Intact	Ref	-----	-----
Cognitively Impaired	0.17 (0.12 – 0.23)	1.19 (1.13 – 1.2)	<0.001
Behaviors Indicative of Depression	0.01 (0.005 – 0.024)	1.01 (1.00 – 1.02)	0.003
Time in Waiver Program	0.008 (0.007 – 0.011)	1.009 (1.007– 1.011)	<0.001

Pain Control. The next GEE model was used to explore for differences in pain control among older adult HCBWP participants with two or more assessments of daily pain in regards to diagnosis of cancer and how this association was affected by age, sex, race/ethnicity, cognitive functioning, behaviors indicative of depression, comorbid conditions, prescribed pain medications, hospice services and time in the HCBWP. Dummy variables were constructed for pain control: 0= no pain vs. medication offered, no control and 1= no pain vs. pain is partially or fully controlled by medication. Initial modeling of 0= no pain vs. medication offered produced an error statement for the hessian matrix not being positive definite. The decision was then made to revise the pain control measure again to be coded as 0= medication offered, no control, 1= pain is partially or fully controlled by medication. The GEE model was re-ran with the revised

measure of pain control as the dependent variable. The algorithm converged for this new model and no error statement was generated.

Statistically insignificant variables were removed one by one and the GEE model re-run. Results of the final model are presented in Table 34. There was no significant association between prescribed pain medications and pain control over time. Although statistically insignificant, pain, time in the HCBWP and diagnosis of cancer were left in the model as they were variables of interest in the study. Only behaviors indicative of depression had a significant association with pain control. As behaviors indicative of depression increased by one point, subjects were 0.92 times **less** likely to experience partial or full control of pain with medication over time, after adjusting for other covariates.

Table 34

Parameter Estimates, Odds Ratios and Significance Values of Parsimonious Model for Generalized Estimating Equation Fitted to the Dependent Variable of Pain Control Using a Binomial Distribution (n=2243)

Variable	Parameter Estimate (95% CI)	Odds Ratio (95% CI)	Pr>X ²
Diagnosis of Cancer			
No Cancer	Ref.	_____	_____
Initial Phase	-0.22 (-0.75 – 0.31)	0.80 (0.47 – 1.36)	0.41
Continuing/Terminal	-0.45 (-1.04 – 0.14)	0.64 (0.35-1.15)	0.14

Table 34 (Continued)

Variable	Parameter Estimate (95% CI)	Odds Ratio (95% CI)	Pr>X²
Pain			
Not daily, unusually intense	Ref.	—	—
Daily, unusually intense	-0.29 (-0.69 – 0.12)	0.75 (0.50 – 1.12)	0.16
Behaviors Indicative of Depression	-0.08 (-0.14 – -0.02)	0.92 (0.87 – 0.98)	0.01
Time in Waiver Program	-0.002 (-0.03 – 0.02)	0.99 (0.97 – 1.02)	0.86

In summary, the measure of pain control was dichotomized as medication offered no control vs. pain is partially or fully controlled by medication. There was no significant association between diagnosis of cancer and pain control over time. Surprisingly, there was no significant association between either pain or prescribed pain medication and pain control over time as well. The measure of behaviors indicative of depression was significantly associated with pain control. As the measure of behaviors indicative of depression increased, the likelihood of full or partial control of pain with medication decreased over time. These results suggest that the presence of depressive symptoms may cause pain to be refractory to treatment. While evidence addressing the association between depressive symptoms and pain medication among older adults is limited, pain-related research has found that pain is associated with depressive

symptoms among older adults, with the presence of one increasing the likelihood of occurrence and worsening the prognosis of the other (Geerlings, et al., 2002; L. Li & Conwell, 2007; Reyes-Gibby, et al., 2002).

An additional analysis was performed to examine if the presence of behaviors indicative of depression and prescribed pain medication were associated with pain control (0=medication offered no control, 1=pain is partially or fully controlled by medication). The measure of behaviors indicative of depression was the dichotomized Depression Rating Scale, with a score ≥ 3 indicative of depression (Burrows, et al., 2000) (0=not indicative of depression, 1=indicative of depression). The measure of prescribed pain medication was dichotomized into two variables. Non-opioid pain medication was categorized as 0= no prescribed pain medication, 1=prescribed non-opioid pain medication. Opioid pain medication was categorized as 0= no prescribed pain medication, 1=prescribed opioid pain medication. Non-opioid pain medication was not significantly associated with pain control ($p=0.45$) while opioid pain medications were significantly associated with pain control. When compared to older adult HCBWP participants with no prescribed pain medications, older adult HCBWP participants with prescribed opioid pain medications were 0.22 times **less** likely to experience partial or full controlled by medication. When the dichotomized measure of behaviors indicative of depression was added to the opioid pain medication model, prescribed opioid pain medications continued to be a significant negative predictor of partial or full control of pain by medication ($p=0.03$). Behaviors indicative of depression was also a significant negative predictor of partial or full control of pain by medication ($p=0.01$). When compared to older adult HCBWP participants with a DRS score of <3 , older adult HCBWP participants with a DRS score of > 3 were 0.37 times **less** likely to experience partial or full control of pain by medication.

Conclusion of Results for Research Question 2 Analyses

Research question 2 examined the associations between pain, pain management strategies and pain management outcomes in regards to diagnosis of cancer and how these associations were influenced by age, sex, race/ethnicity, cognitive functioning, behaviors indicative of depression and comorbid conditions. Diagnosis of cancer had a limited effect in Research Question 2 analyses. Older adult HCBWP participants with daily pain and in the initial phase of diagnosis of cancer were less likely to prescribed non-opioid and adjuvant pain medications when compared to older adult HCBWP participants without cancer. Diagnosis of cancer was not associated with the pain management outcomes of physical function or pain control. Pain and factors within the domains of person and health and illness did have effects on pain management strategies and pain management outcomes, while accounting for diagnosis of cancer in the analytic models.

Pain was consistently associated with the pain management strategy of prescribed pain medications. Older adult HCBWP participants with daily unusually intense pain were significantly more likely than older adult HCBWP participants without daily unusually intense pain to be prescribed non-opioid, opioid and adjuvant pain medications vs. no prescribed pain medications as well as opioid pain medications vs. non-opioid pain medications. Pain was significantly associated with physical function. Older adults with daily unusually intense pain were more likely to experience dependencies in activities of daily living over time than older adult HCBWP participants. Pain was not associated over time with pain control among older adult HCBWP participants. Prescribed pain medications were not associated with the pain management outcomes of physical function or pain control over time among older adult HCBWP participants.

The influence of the personal and health and illness factors of age, sex, race/ethnicity, cognitive functioning, behaviors indicative of depression and comorbid conditions on pain management strategies and pain management outcomes were somewhat inconsistent. Regarding age and sex, as age increased, the likelihood of being prescribed opioid pain medications decreased and females were **more** likely than males to have opioid pain medications prescribed vs. non-opioid pain medications. However, age and sex were not significantly associated with the pain management outcomes of physical function and pain control.

Race/ethnicity had a consistent impact on pain management strategies and pain management outcomes, with African American older adult HCBWP participants **less** likely to have opioid and adjuvant pain medications prescribed as well as more likely to experience dependencies in activities of daily living than white older adult HCBWP participants. Older adult HCBWP participants who were cognitively impaired were **less** likely to be prescribed opioid pain medications and more likely to experience more physical function dependencies than cognitively intact older adult HCBWP participants, after adjusting for other covariates. Cognitive function was not significantly associated with pain control. The measure of behaviors indicative of depression was not associated with the prescription of pain medications but was associated with the pain management outcomes of physical functioning and pain control, likely due to depression's disabling effect on physical function (L. Li & Conwell, 2009) and its worsening effect on pain (Geerlings, et al., 2002; L. Li & Conwell, 2007; Reyes-Gibby, et al., 2002). Finally, as the measure of comorbid conditions increased, the likelihood of an older adult HCBWP participant being prescribed opioid pain medications vs. non-opioid pain medications also increased

Research Question 3: How do the pain experience, pain management strategies and pain management outcomes of older adult, HCBWP participants predict the admission and time to admission of older adult HCBWP participants to a nursing home and how does this relationship differ in regards to diagnosis of cancer while accounting for sex, age, race, comorbid conditions, depression and cognitive functioning?

For research question 3, analyses were performed that included subjects who stayed in the HCBWP and those who were admitted to a nursing home in order to investigate whether variables defining the pain experience, pain management strategies and pain outcomes related to admission to a nursing home and time to admission. Subjects who died or left the program for reasons other than admission to a nursing home were excluded from this analysis.

Nursing Home Admission

Logistic regression was used for the first part of this analysis to determine significant predictors of the “event” which was admission to a nursing home prior to 12/31/05. Predictors included: diagnosis of cancer, age, sex, race, cognitive functioning, behaviors indicative of depression, prescribed pain medications, hospice services, diagnosis of cancer, comorbid conditions, physical function and pain control. Insignificant predictors were removed one by one and the logistic regression model re-ran until a final, parsimonious model was achieved.

Significant predictors of admission to a nursing home included pain, age, race/ethnicity, cognitive functioning and comorbid conditions (Table 35). Diagnosis of cancer, while insignificant, was left in the model as it was a variable of interest for the study. Regarding pain, subjects experiencing daily, unusually intense pain were 0.75 times **less** likely than subjects with no pain of being admitted to a nursing home. Age was a positive significant predictor of nursing home admission: as subject age increased by one year, subjects were 1.07 times **more** likely to

be admitted to a nursing home, after adjusting for other covariates. African American subjects were 0.62 times **less** likely to be admitted to a nursing home than white subjects, after adjusting for other covariates. Cognitively impaired subjects were 1.23 times **more** likely to be admitted to a nursing home than cognitively intact subjects, after adjusting for other covariates. Comorbid conditions was a significant predictor of nursing home admission: as the measure of comorbid conditions increased by one unit, subjects were 1.35 times **more** likely of being admitted to a nursing home, after adjusting for other covariates.

Table 35

Coefficient, Standard Error, Odds Ratios and Confidence Interval from Logistic Regression Model for Admission to Nursing Home

Variable	B	SE	Odds Ratio	95% CI of the Odds Ratio	P-Value
Diagnosis of Cancer					
No Cancer	Ref.	-----	-----	-----	-----
Initial Phase	-0.23	0.24	0.79	0.49- 1.26	0.33
Continuing/Terminal Phase	0.14	0.18	0.58	0.80-1.65	0.45
Pain					
No Pain	Ref.	-----	-----	-----	-----
Less than daily pain	-0.13	0.10	0.88	0.72 – 1.07	0.19
Daily not unusually intense	-0.18	0.10	0.84	0.69 – 1.02	0.08
Daily, unusually intense	-0.29	0.10	0.75	0.62 – 0.91	0.003

Table 35 (Continued)

Variable	B	SE	Odds Ratio	95% CI of the Odds Ratio	P-Value
Age	0.07	0.005	1.07	1.06-1.08	<0.001
Race/Ethnicity					
White	Ref	-----	-----	-----	-----
African American	-0.48	0.09	0.62	0.52-0.73	<0.001
Other	0.14	0.19	1.16	0.79-1.69	0.45
Cognitive Functioning					
Cognitively Intact	Ref.	-----	-----	-----	-----
Cognitively Impaired	0.21	0.07	1.23	1.07-1.42	0.004
Comorbid Conditions	0.30	0.14	1.35	1.01-1.79	0.04

Time to Nursing Home Admission

Next, Cox proportional hazards models were used to analyze the association between the above significant predictors of nursing home admission, diagnosis of cancer and time to nursing home admission. Proportional hazard assumptions were met as log minus log plots of time to nursing home admission showed parallel lines for pain, race/ethnicity and cognitive functioning (not shown in Figures). Kaplan-Meier models were used to determine the unadjusted mean number of days to nursing home admission by categorical covariates.

To review, significant predictors of the logistic regression analysis examining admission to a nursing home included pain, age, race/ethnicity, cognitive functioning and comorbid

conditions. Of the variables that were significant in predicting nursing home admission, only pain did not contribute to time to nursing home admission as its overall significance increased to 0.091 from 0.034 in the logistic regression model (Table 36). The measure of pain was however, left in the final Cox model as pain was a variable of interest for this study.

Table 36

Coefficient, Standard Error, Hazard Ratios and Confidence Intervals from Cox Proportional Hazard Model for Time to Nursing Home Admission

Variable	B	SE	Hazards Ratio	95% CI of Hazard Ratio	P-value
Diagnosis of Cancer					
No Cancer	Ref.	-----	-----	-----	-----
Initial Phase	-0.005	0.20	0.99	0.67- 1.47	0.98
Continuing/Terminal Phase	0.51	0.14	1.05	0.80-1.38	0.71
Pain					
No Pain	Ref.	-----	-----	-----	-----
Less than daily pain	-0.07	0.08	0.93	0.80 – 1.08	0.36
Daily not unusually intense	-0.12	0.08	0.88	0.76– 1.03	0.11
Daily, unusually intense	-0.19	0.08	0.83	0.71 – 0.96	0.09
Age	0.05	0.004	1.05	1.05-1.06	<0.001

Table 36 (Continued)

Variable	B	SE	Hazards Ratio	95% CI of Hazard Ratio	P-value
Race/Ethnicity					
White	Ref	-----	-----	-----	-----
African American	-0.44	0.07	0.64	0.56-0.74	<0.001
Other	0.03	0.15	1.03	0.77-1.37	0.45
Cognitive Functioning					
Cognitively Intact	Ref.	-----	-----	-----	-----
Cognitively Impaired	0.31	0.06	1.37	1.22-1.53	<0.001
Comorbid Conditions					
	0.30	0.11	1.35	1.08-1.67	0.008

Results showed that as subject age increased, the time to nursing home admission decreased, or happened sooner. Comorbid conditions were positively associated with nursing home admission, as the measure of comorbid conditions increased, time to nursing home admission decreased. African American subjects experienced a decreased hazard of being admitted to a nursing home when compared to white subjects. African American subjects on average stayed in the HCBWP approximately 2.5 months longer prior to nursing home admission than white subjects. Subjects who were cognitively impaired had an increased hazard of being admitted when compared to cognitively intact subjects. Cognitively impaired subjects had on

average 2.3 less months in the HCBWP prior to admission to a nursing home than cognitively intact subjects.

Conclusion of Research Question 3 Analyses

In conclusion, diagnosis of cancer was not significantly associated with the admission of older adult HCBWP waiver program participants to a nursing home or time to admission to a nursing home. Pain, age, race/ethnicity, cognitive functioning and comorbid conditions were significantly associated with the admission of older adult HCBWP participants to a nursing home. Older adult HCBWP participants with daily unusually intense pain were less likely than those without pain to be admitted to a nursing home than those with no pain, although pain did not have an impact on the time to nursing home admission. As the measure of comorbid conditions increased among older adult HCBWP participants, hazard of being admitted to a nursing home also increased. Older adult HCBWP participants who were African American stayed longer in the HCBWP than white participants and cognitively impaired participants had less time in the HCBWP before admission to a nursing home when compared to cognitively intact older adult HCBWP participants.

In the following discussion section, the results of above analyses will be summarized and discussed in relation to the findings of previous research and the study conceptual model.

Discussion of Study Results

This study was developed to examine the pain experience, pain management strategies, pain management outcomes and nursing home admission of older adult HCBWP participants in regards to diagnosis of cancer. Previous research had found that older adults with cancer are more likely to experience pain when compared to older adults without cancer (Buchanan, et al., 2005; Reyes-Gibby, Aday, et al., 2007; Rodin, 2008). Older adults who experience pain are at

risk for not having their pain assessed and managed appropriately for a variety of patient and system-related reasons and are therefore likely to experience poor pain management and poor pain management outcomes (American Geriatrics Society Panel on Persistent Pain in Older Persons, 2002). Very little was known about the pain experience, pain management strategies and pain management outcomes of older adult HCBWP participants with and without cancer or how the pain experience, pain management strategies and pain management outcomes of older adult HCBWP participants are associated with nursing home admission.

The conceptualization of the longitudinal associations between diagnosis of cancer and the pain experience, pain management strategies, pain management outcomes and admission to a nursing home as influenced by age, sex, race, cognitive functioning, behaviors indicative of depression and comorbid conditions were depicted in the conceptual model developed for this study (Figure 2). The development of the study conceptual model was guided by the Symptom Management Theory (Dodd, et al., 2001; Humphreys & et al., 2008) which described interactive relationships between the pain experience, pain management strategies, pain management outcomes and the domains of person and health and illness. The following discussion of the study findings will be presented in relation to the study conceptual model (Figure 2) and to literature findings presented in Chapter 3.

The Pain Experience

The pain experience is the complex process of perceiving, evaluating, and responding to a sensory input (Dodd, et al., 2001; Humphreys & et al., 2008; Kandle, et al., 2000; Turk & Okifuji, 1999). The pain experience was conceptualized as being influenced by factors within the domain of person (age, sex, race/ethnicity, cognitive functioning and behaviors indicative of depression) and the domain of health and illness (diagnosis of cancer and comorbid conditions).

Research Question 1 focused on differences in the pain experience of older adult HCBWP participants in regards to diagnosis of cancer and how this association was influenced by age, sex, race, cognitive functioning, behaviors indicative of depression and comorbid conditions over time.

In the present study, daily pain was experienced by over half of the subjects at each assessment, with approximately 30% experiencing daily pain that was unusually intense. The prevalence of pain has been reported to be between 28% and 72% in community-dwelling older adults (Landi, et al., 2001; Reyes-Gibby, Aday, et al., 2007; Thomas, et al., 2004). Therefore, subjects in the present study were in the middle range of pain prevalence reported in previous research for community dwelling older adults. Time in the HCBWP was not significantly associated with the pain experience, i.e. the pain experience did not change significantly over time while adjusting for other covariates. However, the study was limited to a time span of about 15 months on average so changes in the pain experience may not have been detectable over this amount of time.

Results from the present study found no significant difference in the pain experience of older adult HCBWP participant in regards to diagnosis of cancer over time, after adjusting for other covariates. This result was contrary to previous research that found that older adults with cancer were more likely to experience pain when compared to older adults without cancer (Buchanan, et al., 2005; Reyes-Gibby, Aday, et al., 2007; Rodin, 2008). The finding of no significant difference in the pain experience in regards to diagnosis of cancer cannot simply be attributed to the fact that the present study was longitudinal and previous research primarily cross-sectional, i.e. that the pain experience is not different over time in regards to diagnosis of cancer. Descriptive research at each time point also found no significant difference in the pain

experience in regards to diagnosis of cancer (Table 15). The ability to detect differences in the pain experience in regards to diagnosis of cancer may have been compromised by the small sample size of older adult HCBWP participant who had cancer, with 6% of subjects at each time point having a diagnosis of cancer. This was less than the 11% of HCBWP participants found to have a diagnosis of cancer by Fries, James and Aliaga (2004) and the 11% of nursing home residents found to have a diagnosis of cancer at admission to a nursing home (Buchanan, et al., 2005; Rodin, 2008).

Although there were no differences in the pain experience of older adult HCBWP participants in regards to diagnosis of cancer, associations between the pain experience and age, sex, race/ethnicity, cognitive functioning, behaviors indicative of depression and comorbid conditions (factors within the domains of person and health and illness) that were found in previous research were confirmed as well as clarified and expanded by the present study. Being female increased the likelihood of experiencing daily pain over time. The presence of comorbid conditions and behaviors indicative of depression were positively associated with the pain experience: as each of the measures increased, the likelihood of the older adult HCBWP participant experiencing daily pain increased over time. In comparison, age, being of African American race and having impaired cognitive functioning were negatively associated with the pain experience, such that the likelihood of experiencing daily pain decreased. Finally, not only were age and behaviors indicative of depression significantly associated with whether pain was daily or not daily, but also if pain was unusually intense vs. not unusually intense.

The results from the present study are consistent with previous findings as well as support the association between the pain experience and domains of person and health and illness as depicted in the study conceptual model (Figure 2). This study found that the associations

between pain and age, sex, race/ethnicity, cognitive functioning and behaviors indicative of depression were longitudinal in nature, whereas previous research was primarily cross-sectional. Additionally, there was no significant time effect on pain experience: i.e. the pain experience was not associated with time in the HCBWP, indicating that pain did not change significantly over time. Whether this limited change is due to pain not actually changing over time or to an insensitive measure of pain in the MDS-HC is unknown. However, pain was a significant predictor of prescribed pain medication and pain control was highly sensitive to the Pain Scale, as approximately 95% of those without pain per the measure of pain were also noted as having no pain per the pain control measure over the four time points. Thus, the measure of pain appears to be closely related to other indicators of pain in the study. The association between pain and prescribed pain medications and pain control will be discussed further in the following section. It is hoped that future versions of the MDS-HC include comprehensive and sensitive pain measures that would allow for more detailed measures of pain frequency, pain severity and pain interference.

Pain Management Strategies

The pain management strategies dimension included what is done for and by the older adult HCBWP participant to manage pain (Dodd, et al., 2001; Humphreys & et al., 2008) and included prescribed pain medications and hospice services. The pain management strategies dimension was conceptualized as being influenced by factors within the domain of person (age, sex, race/ethnicity, cognitive functioning and behaviors indicative of depression), the domain of health and illness (diagnosis of cancer and comorbid conditions) and the pain experience. Pain management strategies are based on the assessment of the older adult HCBWP participant's pain experience (Bruckenthal & D'Arcy, 2007; Dodd, et al., 2001). The first part of Research

Question 2 examined differences in the association between the pain experience and pain management strategies in regards to diagnosis of cancer and how this association was influenced by age, sex, race, cognitive functioning, behaviors indicative of depression and comorbid conditions over time.

Hospice Services. Regarding hospice services, only 1% of subjects at each assessment received hospice services which equated to 6-8 subjects per assessment. Only 1 subject who was receiving hospice services had a diagnosis of cancer, the others had terminal conditions other than cancer. There was no significant association between diagnosis of cancer and hospice services among older adult HCBWP participants across time points. The very small sample of older adult HCBWP participants receiving hospice services was a limitation to further examining hospice services in regards to diagnosis of cancer and adjusting for covariates via GEE modeling.

Researchers have found limited use of hospice services in long term care facilities by those with terminal diagnoses (Buchanan, et al., 2005; Duncan, et al., 2009). Barriers to the use of hospice services in long term care facilities include conflict between the hospice and nursing home care models and shifting hospice demographics in the context of eligibility and payment policies (Buchanan, et al., 2005; Duncan, et al., 2008; Stevenson & Bramson, 2009). As the U.S. population continues to age, end of life and hospice services will become an increasingly important issue to address (Ersek & Wilson, 2003). If both Medicare and Medicaid paid claim files could be used for future research then billing for hospice services could be assessed for and may be preferable to the hospice services measure in the MDS-HC, leading to a more sensitive measure of hospice services. The outcomes of hospice services, as a pain management strategy,

could therefore be assessed and assist in the development of policies regarding the inclusion of hospice services in HCBWP.

Prescribed Pain Medications. This study found that older adult HCBWP participants with two or more assessments of daily pain and in the initial phase of diagnosis of cancer were less likely to be prescribed non-opioid and adjuvant pain medications vs. no prescribed pain medications when compared to older adult HCBWP participants with two or more assessments of daily pain and without a diagnosis of cancer. Why diagnosis of cancer had a negative association with prescribed non-opioid and adjuvant pain medications is not understood. Results of the initial descriptive research showed that diagnosis of cancer was not significantly associated with other patient-related variables. Therefore, there were not any apparent differences between those with and without cancer.

Based on previous research, it was hypothesized that older adults with cancer would have more pain management strategies than older adults without a diagnosis of cancer, as older adults with cancer are more likely to experience pain when compared to older adults without a history of cancer in both community and nursing home settings (Buchanan, et al., 2005; Reyes-Gibby, Aday, et al., 2007; Rodin, 2008). However, the results of this present study have found not only no significance differences in the pain experience of older adults in regards to diagnosis of cancer but also a negative association between diagnosis of cancer and the prescription of non-opioid and adjuvant pain medications. Concerns about the ability of the measure of prescribed pain medication to capture the prescription of non-opioid pain medications have been presented earlier in this chapter. Because many non-opioid pain medications are available over the counter, Medicaid would not have been billed for them and therefore not recorded. Future research examining the pain medication use of older adult HCBWP participants would benefit

from the consistent use of a current medication log in the MDS-HC to document all medications, including over the counter, the participant is on.

Pain was the most consistent predictor of the prescription of the different pain medications over time among older adult HCBWP participants with daily pain. Subjects with daily, unusually intense pain were significantly more likely to be prescribed non-opioid, opioid and adjuvant pain medications over time than subjects without daily unusually intense pain. These results are consistent with the conceptualization (Figure 2) that the pain management strategy of prescribed pain medication is based on the patient report (verbal or behavioral) of his or her pain experience. Therefore, the report of pain would warrant the management of pain, with the increased severity of pain (unusually intense vs. not unusually intense) increasing the likelihood of pain medication being prescribed. In addition to being influenced by the pain experience, the measure of prescribed pain medication was associated over time with age, sex, race/ethnicity, cognitive functioning, behaviors indicative of depression, comorbid conditions and time in the HCBWP among older adult HCBWP participants with daily pain.

Age. Older adults are at increased risk of not receiving adequate prescribed pain medications when compared to younger adults (Landi, et al., 2001; Shega, et al., 2006; Won, et al., 2004; Zyczkowska, et al., 2007). The findings from the present study confirm findings of previous research, as the age of older adult HCBWP participants increased, the likelihood of being prescribed pain medications diminished over time.

Sex. Regarding sex, the present study found that female older adult HCBWP participants with daily pain were more likely than males to have opioid pain medications prescribed. There were no differences between the sexes in the prescription of non-opioid or adjuvant pain medications. The results of previous research regarding the association of sex and the

prescription of pain medications have been inconsistent. While one study found lower opioid use by older adult male nursing home residents (Won, et al., 2004), another found no difference in pain medication use between sexes among community dwelling older adults (Soldato, et al., 2007). The results of the present research describe a significant association between sex and prescribed pain medications over time in older adult HCBWP participants.

Race/Ethnicity. Overall, in previous research white adults have been significantly more likely to receive appropriate prescribed pain medications than adults from other racial groups and Hispanics with similar pain levels (Cintron & Morrison, 2006; J. A. Cleeland, et al., 2005; Green, et al., 2003; Rodin, 2008). Specific to older adults residing in nursing homes, Won et al. (2004) found a lower use of opioid pain medications by black nursing home residents when compared to white nursing home residents.

In the present study, race/ethnicity was associated with the prescription of opioid and adjuvant pain medications. African American older adult HCBWP participants with daily pain were less likely to be prescribed opioid and adjuvant pain medications over time when compared to white older adult HCBWP participants in daily pain. One possible explanation for this finding may have to do with the fact that adjuvant pain medications are medications that have a pain relieving effect, but whose primary or initial indication was not for the treatment of pain (American Pain Society, 2005). Therefore, primary care doctors may not be as familiar with the use of adjuvant pain medications for pain management as pain specialists are. If there is differential access to pain specialists among race then this may explain why black older adult HCBWP participants were less likely to have adjuvant pain medications prescribed.

Cognitive Functioning. Cognitive function has been associated with the prescription of pain medication for older adults in previous research. Reynolds, Hanson, Devellis Henderson

and Steinhauser (2008) found that among nursing home residents, as the degree of cognitive impairment increased, the less likely the nursing home resident was to receive treatment for pain. Eighty-percent of cognitively intact nursing home residents received pain medications, while only 56% of those with cognitive impairment received pain medications (Reynolds, et al.). The present study found that cognitively impaired older adult HCBWP were less likely to receive opioid pain medications than cognitively intact subjects. There was no significant association between cognitive functioning and the prescription of non-opioid pain medication or adjuvant pain medications vs. no pain medications.

Pain management begins with the assessment of the patient's pain experience (Dodd, et al., 2001). Pain may be challenging for healthcare providers to accurately assess in older adults with cognitive changes or communication difficulties if pain-related behaviors must be assessed in place of verbal reports of pain (Delgado-Guay & Bruera, 2008; Goldstein & Morrison, 2005). Cognitive impairment may result in underreported pain and a poor pain assessment. Pain management strategies are conceptualized as being based on the patient's report of their pain experience. If the pain assessment is poor, the resulting pain management strategies may therefore be poor as well. This effect was seen in the present study, as older adult HCBWP participants with cognitive impairment were less likely to experience pain, as documented, and less likely to receive opioid pain medications.

Comorbid Conditions. The presence of comorbid conditions influences the provision of pain management among older adults (Duncan, et al., 2008; Goldstein & Morrison, 2005; McNeill, et al., 2007). The presence of comorbid conditions in older adults may act as a barrier to pain management, as clinicians may be more cautious in prescribing pain management due to

side effects of medications and interactions with medications prescribed for comorbid conditions (Duncan, et al., 2008; Goldstein & Morrison, 2005; McNeill, et al., 2007).

However, results from the present study suggest that as the measure of comorbid conditions increases, the likelihood of the prescription of opioid pain medications actually increased. Pain occurs in older adults because of the presence of comorbid conditions that are commonly associated with increased age and pain such as arthritis, diabetes and peripheral vascular disease (Bruckenthal & D'Arcy, 2007; Davis & Srivastava, 2003; Freedman, 2002). As the measure of comorbid conditions was a weighted index of conditions that were associated with pain, these results suggest that the more pain-associated comorbid conditions a subject had, the more likely he or she was to have opioid pain medications prescribed.

Time in the HCBWP. As time in the HCBWP increased the likelihood of being prescribed opioid or vs. no pain medications and opioid pain medications vs. non-opioid pain medications also increased. There was no significant time effect for the prescription of non-opioid pain and adjuvant pain medications. As stated earlier in this chapter, the measure of prescribed pain medications may not have captured the use of non-opioid pain medications, as many non-opioid pain medications are available over the counter and therefore, would not have been billed to Medicaid. If not all non-opioid pain medications were accounted for then a time-related effect may have been insignificant. Overall, the study results suggest that the likelihood of pain medications stronger than non-opioid pain medications being prescribed may be due, albeit in a small way, to the amount of time spent in the HCBWP. As the older adult HCBWP participant spends time in the HCBWP he or she may have more access to health care services than before they entered the HCBWP and therefore more likely to be prescribed opioid pain medications.

The study results support findings from previous research that pain, age, sex, race/ethnicity, cognitive functioning and comorbid conditions were all significantly associated with the prescription of pain medications overtime among older adult HCBWP participants with two or more assessments of daily pain. The results also are in agreement with the study conceptual model, as factors within the pain experience and domains of person and health and illness impact prescribed pain medications. However, diagnosis of cancer, as a health and illness factor, was not significantly associated with prescribed pain medications over time among older adult HCBWP participants. The small sample of hospice services was a limitation. Future access to both Medicaid and Medicare paid claim files for this dual eligible population would likely lead to a larger sample of HCBWP participants who have received hospice services. Future research could then better examine the association of person and health and illness factors and pain with hospice services.

These study results serve to clarify the associations between prescribed pain medications and pain, age, sex, race/ethnicity, cognitive functioning, behaviors indicative of depression, comorbid conditions and time in the HCBWP. The present research also adds to the science as previous research was primarily cross-sectional and this study was longitudinal. Results from this study note that the significant associations between prescribed pain medications, age, sex, race/ethnicity, cognitive functioning, behaviors indicative of depression, pain and comorbid conditions continue over-time in older adult HCBWP participants and are not just limited to a single observation.

In the following section, discussion regarding the second part of research question 2 is presented. The second part of Research Question 2 examined differences in the association between pain management outcomes, the pain experience and pain management strategies in

regards to diagnosis of cancer and how this association was influenced by age, sex, race, cognitive functioning, behaviors indicative of depression and comorbid conditions over time. The following summarizes study findings in relation to the conceptual model and the literature review in Chapter 3, beginning with the outcome of pain control.

Pain Management Outcomes

Outcomes are the end results of care (Patrick, 1997). The pain management outcomes dimension, as depicted in Figure 2, includes the end results of pain management strategies, which are influenced by pain management strategies and the pain experience (Dodd, et al., 2001; Humphreys & et al., 2008). For this study, pain management outcomes included pain control and physical function that were examined over time while the older adult participated in the HCBWP. The pain management outcomes dimension was conceptualized as being influenced by factors within the domain of person (age, sex, race/ethnicity, cognitive functioning and behaviors indicative of depression), the domain of health and illness (diagnosis of cancer and comorbid conditions) and the dimensions of the pain experience and pain management.

Pain Control. Pain control was conceptually defined as an outcome of pain management by which pain is limited or decreased (Allard, et al., 2001; Christine Miaskowski, et al., 2002; Oliver, et al., 2001; Shvartzman, et al., 2003). Initial descriptive analysis of the measure of pain control indicated that pain control was highly sensitive to the measure of pain, as approximately 94% of those without pain per the measure of pain at each time point were also noted as having no pain per the pain control measure. Of those who had medication offered with no control, on average 45% had daily, unusually intense pain over the four time points (Table 21). Of those subjects who received opioid pain medications at each time point, approximately 93% had partial or full control of pain, indicating a good outcome from the prescription of opioid pain

medications (Table 22). Of subjects who reported no pain at each time point, on average only 13% had evidence of prescribed pain medications in the 30 days prior to each time point, leading to the question if this sub-group's lack of pain is due to not having pain instead of pain being managed well by prescribed pain medication that was not captured in the 30 days before each time period.

In the GEE model with pain control as the dependent variable, only behaviors indicative of depression had a significant association with pain control, after controlling for other covariates. As behaviors indicative of depression increased, the likelihood of a subject experiencing partial or full control of pain with medication decreased after adjusting for other covariates. While evidence addressing the association between depression and pain control among older adults is limited, pain-related research has found that pain is associated with depression among older adults, with the presence of one increasing the likelihood of occurrence and worsening the prognosis of the other (Geerlings, et al., 2002; L. Li & Conwell, 2007; Reyes-Gibby, et al., 2002). Therefore, the presence of depression may cause pain to be refractory to treatment, decreasing the likelihood of pain control. There was no significant association between prescribed pain medications and pain control over time after adjusting for other covariates.

As noted earlier in Chapter 5, there were issues with the measure of pain control. Pain control had to be dichotomized to use it as a dependent variable in the GEE models, but the variable had to be re-dichotomized as the first dichotomization caused the hessian matrix to not be positive definite. The revised measure of pain control may not have been sensitive to differences across the covariates. Future research could evaluate the pattern of change in the measure of pain overtime in response to the presence of prescribed pain medications. Pain control is a very important factor in the treatment of pain. If pain management strategies do not

result in pain control, then pain management strategies must be altered and the pain experience reevaluated to determine if pain control has occurred (NCCN, 2006).

Physical Function. The pain management outcome of physical function was represented by a count of the following activities of daily living (ADL) that the HCBWP participant is dependent in: dressing, personal hygiene, toilet use, bathing and eating. Physical function was conceptualized as an outcome of pain management as previous research has shown that pain has a significant, negative effect on physical function and activities of daily living (Onder, et al., 2006; Reyes-Gibby, et al., 2002; Soldato, et al., 2007). Among older adults either residing in a nursing home or in the community, pain has been positively associated with walking and mobility problems, functional limitations and requiring assistance with activities of daily living. (Jakobsson, et al., 2003). While previous research has noted that older adults who had had cancer were more likely to have mobility and ADL deficiencies than older adults without cancer (Keating, et al., 2005) the present study found that there was no significant association between diagnosis of cancer and physical function over time. One possible explanation for this finding could be that the older adult HCBWP population is a very frail population as they must meet nursing home care criteria in order to enter the HCBWP. A diagnosis of cancer may therefore not significantly add to the health-related burden they already experience. Pain, race, cognitive functioning, behaviors indicative of depression and time in the HCBWP were found to be significant predictors of physical function over time among older adult HCBWP participants with daily pain.

Pain. Among older adults either residing in a nursing home or in the community, pain has been positively associated with walking and mobility problems, functional limitations and requiring assistance with activities of daily living. (Jakobsson, et al., 2003; Soldato, et al., 2007).

The present study found that the impact on physical function was limited to daily pain, when compared to those with less than daily pain or no pain. Subjects with daily pain-unusually intense were more likely than subjects with not daily unusually intense pain to experience an increase in physical function dependencies over time, after adjusting for other covariates.

Race/Ethnicity. Cleeland, Palmer and Venzke (2005) reported that black adults experience higher pain-related disability compared to white adults. Results from the present study concur with Cleeland, Palmer and Venzke's findings, as black HCBWP program participants were more likely to experience an increase in physical function dependencies over time when compared to white subjects, after adjusting for other covariates.

Differences in physical functioning between white and black older adult HCBWP are not fully understood. In regards to the pain experience, black older adult HCBWP participants were less likely to report daily pain than white older adult HCBWP participants. Regarding the prescription of pain medications, black older adult HCBWP participants differed from white older adult HCBWP participants in the prescription of opioid and adjuvant pain medications being less likely. Therefore, there was less pain documented in African American older adult HCBWP participants, but also less prescribing of pain medications among African American older adult HCBWP participants when compared to white older adult HCBWP participants.

Cognitive Functioning. The significant impact of cognitive functioning on physical functioning has been presented in previous research. Older adults who are cognitively impaired are significantly more likely to be physically disabled when compared to cognitively intact older adults (L. Li & Conwell, 2009; McGuire, Ford, & Ajani, 2006). In the present research, older adult HCBWP participants with daily pain and cognitive impairment were more likely than cognitively intact subjects to experience an increase in physical function dependencies over time,

after adjusting for covariates. Cognitive impairment has a negative impact on the ability and independence of the older adult HCBWP participant to complete ADLs.

Behaviors indicative of depression. Among older adults in the community, depression has a worsening effect on physical functioning (Callahan et al., 2005; L. Li & Conwell, 2009). In the present study, the measure of behaviors indicative of depression had a positive, significant association with physical function over time, such that as behaviors indicative of depression increased, the likelihood of experiencing an increase in the number of physical function dependencies also increased.

Time in the HCBWP. Finally, as time in the HCBWP increased by one month, the likelihood of experiencing an increase in the number of physical function dependencies increased over time. The significant time factor may signify that over Time 1 to Time 4, dependencies in ADLs continue to worsen over time after adjusting for covariates and in spite of care services received through the HCBWP

In summary, within the study conceptual model (Figure 2), the pain management outcomes of pain control and physical function were conceptualized at being impacted by the pain experience, pain management strategies and the domains of person and health and illness. Pain control is the result of pain assessment and analgesic treatments (Allard, et al., 2001; Shvartzman, et al., 2003). In the present study, pain control was not associated with either the pain experience or pain management strategies over time. Pain control was associated with behaviors indicative of depression over time, while controlling for other covariates. This finding is easily understandable in light of the knowledge that pain is associated with depression among older adults, with the presence of one increasing the likelihood of occurrence and worsening the

prognosis of the other (Geerlings, et al., 2002; L. Li & Conwell, 2007; Reyes-Gibby, et al., 2002).

In regards to physical functioning, race, cognitive functioning, behaviors indicative of depression, pain and time in the HCBWP were all found to be significant predictors of physical function over time among older adult HCBWP participants. As with the measure of pain control, the measure of prescribed pain medications was not associated with physical function over time among older adult HCBWP participants. These study results serve to clarify the longitudinal associations between pain management outcomes and factors within the dimensions of the pain experience, pain management strategies and the domains of person and health and illness.

Admission to a Nursing Home & Time to Nursing Home Admission

Admission to a Nursing Home, as conceptualized in Figure 2, is conceptually defined as the movement of older adult, HCBWP participants to a nursing home facility, without returning to the HCBWP. Admission to a Nursing Home is part of the healthcare services continuum of older adults, where older adults move from community to institutionalization (L. Li & Zullo, 2003; Williams, 2001). A goal of the HCBWP is to prevent or delay admission to a nursing home (Fries, et al., 2002).

Time to Nursing Home Admission was conceptualized as the amount of time in months that a HCBWP participant spends in the HCBWP prior to admission to a nursing home, without returning to the HCBWP. Previous research has indicated that the strongest predictors of nursing home placement among a general population of community-dwelling older adults were black race or Hispanic ethnicity, ADL/physical deficiencies, behavioral issues, cognitive impairment, prior nursing home use, urinary incontinence, depression and impaired peak flow (Gaugler, et al., 2000; Gaugler, et al., 2009; McCallum, et al., 2005; Yaffe, et al., 2002). In the study conceptual

model (Figure 2), admission to a nursing home and time to admission to a nursing home were conceptualized as being associated with the dimensions of pain experience, pain management strategies and pain management outcomes as well as the domains of person and health and illness. In the present study, diagnosis of cancer was not a significant predictor of the admission of older adult HCBWP participants to a nursing home or time to nursing home admission. In the sample, 6% of older adult HCBWP participants had a diagnosis of cancer. This compares to 11% of nursing home residents who have a diagnosis of cancer at admission (Buchanan, et al., 2005; Rodin, 2008).

Significant predictors of admission to a nursing home included pain, age, race/ethnicity, cognitive functioning and comorbid conditions. Surprisingly, physical function was not a predictor of nursing home admission among older adult HCBWP participants. As HCBWPs supply assistance with ADLs, physical function needs may be met by HCBWPs so physical function deficits are no longer a driving force for admission to a nursing home. Of the variables that were significant in predicting nursing home admission, only pain did not contribute to time to nursing home admission.

Pain. Regarding pain, subjects experiencing daily, unusually intense pain had a lower likelihood than that of subjects with no pain of being admitted to a nursing home. Pain was not significantly associated with time to nursing home admission

Age . Age was a positive significant predictor of nursing home admission. As age increased by one year the likelihood of being admitted to a nursing home also increased. For each year increase in subject age, the hazard of experiencing a nursing home admission increased after adjusting for other covariates, meaning less time in the HCBWP before being admitted to a nursing home. Luppa, Luck, Matschinger, Konig and Reidel-Heller (2010) also found increasing

age to decrease the amount of time to nursing home admission (or increasing the hazard of admission) for community-dwelling older adults. These results are not surprising given that the average age of nursing home admission for those 65 and older is 82.6 (Sahyoun, Pratt, Lentzner, Dey, & Robinson, 2001).

Race/Ethnicity. Nursing home residents are 90% white (Agency for Healthcare Research and Quality, 2000) while the sample of the present study for older adult HCBWP participants was 74% white. African American older adult HCBWP participants were less likely to be admitted to a nursing home than white subjects, after adjusting for other covariates. African American subjects experienced a decreased hazard of being admitted to a nursing home when compared to white subjects. African American subjects on average stayed in the HCBWP approximately 2.5 months longer before admission to a nursing home than white subjects. The present study findings are different from findings by Yaffe and colleagues (2002), who found patient characteristics that were predictive of nursing home placement included black race or Hispanic ethnicity, living alone, one or more ADL dependencies, high cognitive impairment and one or more difficult behaviors.

Cognitive Functioning. In the literature the strongest predictors of nursing home placement among a general population of community-dwelling older adults were ADL/physical deficiencies, cognitive impairment, prior nursing home use, urinary incontinence, depression and impaired peak flow (Gaugler, et al., 2007; McCallum, et al., 2005). The odds of being admitted to a nursing home were higher for the cognitively impaired than cognitively intact subjects, after adjusting for other covariates. Subjects who were cognitively impaired had an increased hazard of being admitted when compared to cognitively intact subjects. Cognitively impaired subjects had on average 2.3 less months in the HCBWP prior to admission to a nursing home than

cognitively intact subjects. As cognitive functioning has an impact on physical functioning and behaviors, it is logical that cognitive functioning would increase the likelihood of admission to a nursing home as well as decrease the time the admission to a nursing home. HCBWP care services including respite care for caregivers as well as education for caregivers in managing patient behaviors may assist in delaying time to nursing home admission from a HCBWP.

Comorbid Conditions. The measure of comorbid conditions was a significant predictor of nursing home admission. As the measure of comorbid conditions increased by one unit, the odds of nursing home admission increased as well. Comorbid conditions were positively associated with time to nursing home admission. As the measure of comorbid conditions increased the time to nursing home admission was shortened. For the present study, the comorbid conditions included comorbid conditions significantly associated with pain.

In summary, this study sought to determine if there were differences in the admission of older adult HCBWP participants in regards to diagnosis of cancer and if the relationship is influenced by sex, age, race, comorbid conditions, depression and cognitive functioning. The study conceptual model presented the admission of older adult HCBWP participants as being influenced by the pain experience, pain management strategies and pain management outcomes over time, as influenced by personal and health and illness factors. Diagnosis of cancer was not significantly associated with admission to a nursing home or time to admission to a nursing home. As noted earlier in this chapter, HCBWP participants must meet nursing home-level needs criteria and are therefore already compromised and frail. Cancer may not have added significantly more burden to what the participant was already experiencing.

Analyses were centered on the role of pain, pain management strategies and pain management outcomes on admission to a nursing home. Pain was significantly associated with

admission to a nursing home, but was not significantly associated with time to nursing home admission. Prescribed pain medications and the pain management outcomes of physical function and pain control were not significantly associated with admission of older adult HCBWP participants to a nursing home. Age, race/ethnicity, cognitive functioning and comorbid conditions were significantly associated with both admission to a nursing home and time to admission to a nursing home. The present study results point to a diminished role for pain, pain management strategies and pain management outcomes as predictors of nursing home admission and an emphasis instead on the role of personal and health and illness factors on the admission of older adult HCBWP participants to a nursing home.

Study Limitations

The study had limitations which are presented and discussed in the following. First, the study was a secondary analysis of pre-existing data. Therefore, the analysis was limited to what data was already collected and by what instruments the data was collected with. The pain items in the MDS Version 1 data that were used for this study were quite limited, asking “Frequently complains or shows evidence of pain in the past 7 days” with response as no pain, pain less than daily or pain daily and “pain is unusually intense” with response as no or yes. Because of the limited possible responses, the items may have not been sensitive to change over time or specific. However, the MDS-HC pain items did assess multiple dimensions of pain and for the present study frequency and intensity were examined. Measurement of the multiple dimensions of pain is preferred to a measure of only pain intensity as pain is multidimensional and intensity, the sensory aspect of pain, is only one dimension. Williamson and Hoggart (2005) state that “... the reliance on pain intensity alone suggests that it is the only dimension of pain that is important to assess and record, although this is not the case” (p. 799) supporting the need to utilize pain

measures that address more than pain intensity alone. More recent versions of the MDS-HC have more detail in the possible responses to pain items, allowing for more sensitive measurement of pain in future research.

The present study limited the analyses to MDS-HC assessments 2-5, for a total of four assessments. These assessments were chosen as they would allow for approximately 12 -15 months of data. Analyses were limited to four assessments as the number of assessments among the subjects varied greatly. Because these assessments were at the beginning of the older adults' time in the HCBWP the study may have failed to capture changes in key study variables that may take place after a longer period of time in the HCBWP. Future research should utilize more time points, or perhaps examine change after a major health-related event such as diagnosis of cancer to determine if changes in pain, pain management or pain management strategies occur after such a health related change.

Pain management strategies were limited to what was in the Medicaid paid claim files. While this limited information regarding the use of over the counter pain medications, there also was a lack of information regarding the use of non-pharmacological pain management strategies such as ice, heat, exercise, meditation or massage, for example. Non-pharmacological therapies have an important role in pain management (JCAHO, 2000). The accounting for the use of non-pharmacological pain management strategies may assist researchers in explaining low or no pain levels in those without prescribed pain medications among older adult HCBWP participants.

There was the small number of non-white older adult HCBWP participants represented in the sample. As the study is a secondary analysis of existing data, the inclusion of minority groups in the study were as they were already represented in the existing data set. In the present study, 74% of subjects were white and 22% were African American. The remaining minority groups

were represented by very small numbers and were consolidated into one group for analysis. Therefore, generalizability of study results to older adult HCBWP participants may be limited.

The measure of physical functioning was limited to activities of daily living, including Physical function is represented by a count of the following activities of daily living including dressing, personal hygiene, toilet use, bathing and eating. The measure of physical functioning did not measure Instrumental Activities of Daily Living (IADL) and therefore, changes in the ability of the older adult HCBWP participant were not examined.

The researcher was not able to detect if a comorbid condition was the index disease or if cancer was. Comorbid conditions were conceptualized as the "...the co-occurrence of health conditions or diseases in reference to an index disease" (Yancik, et al., 2007, p. 276) and for the purposes of this research the researcher conceptualized cancer as the index disease. The researcher may therefore have underestimated the effect of comorbid conditions on the pain experience, pain management strategies, pain management outcomes and admission of older adult HCBWP participants to nursing homes.

Interactions between variables were not examined with the present research, as they were outside the scope and time constraints of the present research. The research acknowledges the importance of interactions between variables in explaining phenomena in nursing practice. Of particular interest is to examine the interaction between age and cognitive functioning in relation to the pain experience, pain management strategies, and pain management outcomes.

In Chapter 4, results from a pre-study power analysis were presented. For an actual power of .90, the required total sample size was 6189 subjects: 928 in the group with a diagnosis of cancer and 5261 in the group without a diagnosis of cancer. Effect size would be 0.11, indicating a small effect (Cohen, 1988). For the present study, the final total sample was 4054

individuals at each time point, with on average 243 individuals with cancer at each time point included. The sample size and ratio of those with a diagnosis of cancer to those without cancer in the present study were smaller than the sample size needed to detect differences predicted by the pre-study power analysis. Therefore, the ability to detect differences in the pain experience in regards to diagnosis of cancer may have been hampered by the smaller sample size. However, the purpose of sampling is to be a representation of the population of interest so that the results of the research (with the sample) can be then be applied to the population as a whole (Burns & Grove, 2005; Israel, 2009). The present study examined data from all older adult HCBWP participants from 1/1/2003 to 12/31/2005. Because the sample included all older adult HCBWP participants the study sample can instead be considered a population, as no additional subjects could be added to the sample. Therefore, the issue of sample size may not be appropriate for this study.

Finally, the percentage of older adult HCBWP participant with cancer was approximately 6% over the four assessment time point. This was less than the 11% of older adult HCBWP participants found to be diagnosed with cancer by Fries, James and Aliaga (2004). The measure of diagnosis of cancer for the present study may have underestimated the number of older adult HCBWP participants with cancer.

Conclusion of Chapter 5

In conclusion, study results suggest that diagnosis of cancer had a limited association with the pain experience, pain management strategies, pain management outcomes and admission to a nursing home among older adult HCBWP participants. The pain experience was significantly associated with personal factors of age, sex, race/ethnicity, cognitive functioning,

behaviors indicative of depression and the health and illness factor of comorbid conditions. The pain experience was not influenced by the diagnosis of cancer.

Regarding pain management strategies, due to the limited number of subjects receiving hospice services at each time point, further analyses of hospice services with Generalized Estimating Equations was not carried out. Prescribed pain medications were most consistently associated with pain over time. Older adult HCBWP participants who were in the initial phase of diagnosis of cancer were less likely to have non-opioid and adjuvant pain medications prescribed than older adult HCBWP participants without a diagnosis of cancer. Significant predictors of the prescription of opioid pain medications vs. no pain medications or non-opioid pain medications included pain, age, sex, race/ethnicity, cognitive function, comorbid conditions and time in the HCBWP.

Pain, race/ethnicity, cognitive functioning, behaviors indicative of depression and time in the HCBWP were significantly associated with the physical functioning of older adult HCBWP participants over time. The pain management outcome of pain control was significantly associated with the measure of behaviors indicative of depression. Significant predictors of the admission of older adult HCBWP participants to a nursing home included pain, age, race/ethnicity, cognitive functioning and comorbid conditions. Time to nursing home admission was associated with age, race/ethnicity, cognitive functioning and comorbid conditions.

Next, Chapter 6 will present the contributions to science made by this study as well as clinical, research and policy implications.

CHAPTER 6

Contributions to Science

While many of these results were in agreement with previous research examining the pain experience, pain management strategies and pain management outcomes of older adults, the science was extended to include older adult HCBWP participants, a population at high risk for cancer and poor pain management due to age and poverty.

The science of pain, pain management and pain management outcomes among older adults was extended through the use of longitudinal analyses of the four assessment time points, as previous research regarding pain, pain management and pain management outcomes has been cross-sectional. The study results serve to clarify the associations between prescribed pain medications and pain, age, sex, race/ethnicity, cognitive functioning, behaviors indicative of depression, comorbid conditions and time in the HCBWP. The present research adds to the science as previous research was primarily cross-sectional and this study was longitudinal. Results from this study note that the significant associations between prescribed pain medications, age, sex, race/ethnicity, cognitive functioning, behaviors indicative of depression, pain and comorbid conditions continue over-time in older adult HCBWP participants and are not just limited to a single observation.

This study utilized a novel combination of data from the MDS-HC, Medicaid paid claim files, Michigan Cancer Registry and Death Certificate data to examine the pain experience, pain management strategies, pain management outcomes of older adult HCBWP participants and admission of older adult HCBWP participants to a nursing home.

Implications

Historically, nurses have been responsible for providing comfort and alleviating suffering from pain. The nursing profession's focus on the alleviation of pain continues to be at the forefront of practice and research directives. Nurses are to address issues such as physical comfort, discomfort and pain via nursing interventions (American Nurses Association, 2008, 2010). Research examining symptoms, such as pain, has been prioritized by the National Institute of Nursing Research in order to improve patient quality of life (National Institute of Nursing Research, 2006b). Results from the present study have important implications for nursing clinical practice and research, which are presented in the following sections.

Implications for Clinical Practice

The results of the present study found that diagnosis of cancer had a limited association with the pain experience, pain management strategies, pain management outcomes and admission of older adult HCBWP participants to nursing homes. However, the assumption that the diagnosis of cancer has no affect on the pain experience, pain management strategies, pain management outcomes, and nursing home admission among older adult HCBWP participants cannot be made based on the results of the present study alone as previous research has found that older adults with cancer are more likely to experience pain when compared to older adults without cancer (Buchanan, et al., 2005; Reyes-Gibby, Aday, et al., 2007; Rodin, 2008).

Personal factors and the presence of comorbid conditions were strongly associated with the pain experience, pain management strategies, pain management outcomes of older adult HCBWP participants over time. Pain is a highly personal experience, being "...whatever the experiencing person says it is, existing whenever he/she says it does" (McCaffery, 1968). Individual-related characteristics contribute to the multidimensional nature of pain (American

Pain Society, 2005; Armstrong, 2003; Dodd, et al., 2001; Humphreys & et al., 2008) and are associated with the experience of pain among older adults. The following clinical implications are focused on the nurse's (including nurses in advanced practice, case management, clinical settings, education, administration, education and policy) acknowledgement and promotion via education and policy development of personal and health and illness-related characteristics that influence the pain experience, pain management strategies, pain management outcomes of older adults and admission of older adult HCBWP participants to nursing homes.

- Nurses must foster an appreciation of how person and health and illness-related factors impact the pain experience, pain management strategies and pain management outcomes of older adult HCBWP participants.
 - Before pain management strategies can be implemented the assessment of the patient's pain experience must be completed. While the patient's verbal report is the "gold standard" for pain assessment, poor cognitive functioning may impact the ability of the patient to convey his or her pain experience. Results from the present study found that those with cognitive impairment were less likely to have daily pain when compared to cognitively intact older adult HCBWP participants over time. Therefore, nurses must be aware of methods other than verbal report when assessing for pain in the cognitively impaired including observation of facial expressions (grimacing), changes in activity level, body movements (guarding) that may indicate pain (Curtiss, 2010; Herr et al., 2006). Pain assessment includes other methods beyond the numeric rating scale (pain on a 0-10 scale). Nurse faculty should include alternative methods of assessing pain, such as facial expressions, body movements, in nursing education .

Nurses function as educators of both waiver staff and family members assisting with the care of HCBWP participants. Nurses working with waiver agencies can educate staff working with participants regarding differences in assessment of the pain experience of cognitively impaired participants. Nurses working for waiver agencies can educate family members about ways the cognitively impaired HCBWP participant may express pain.

- Results from the present study noted that age was negatively associated with the likelihood of experiencing daily pain and the likelihood of having adjuvant and opioid pain medications prescribed for older adult HCBWP participants. Not only must clinicians be aware of their own opinions regarding pain and pain management among persons 65 and above but they must educate older patients that pain is not “just to be expected” as part of aging and therefore not worthy of proper management (Delgado-Guay & Bruera, 2008; Goldstein & Morrison, 2005). Careful assessment of the multiple dimensions of pain (severity, frequency, interference) can ascertain the patient’s perception of the level of pain as well as its impact on the lives of older adults. Nurses can educate older adult HCBWP participants that pain is not to be expected as a result of aging and therefore just “put up with”. Nurses can educate patients and family members about pain management options for older adults.
- While the measure of behaviors indicative of depression was associated with an increased likelihood of experiencing daily pain, it was not associated with the likelihood of having prescribed pain medications. The measure of behaviors indicative of depression was associated with pain control, with higher levels of

behaviors indicative of depression resulting in a decreased likelihood of having partial or full control of pain via medications. Clinicians and nurses must be aware of the effect of depression on the pain experience, as well as how the presence of depression may make pain refractory to treatment with pain management strategies. Strategies for clinicians and nurses would include screening older adults that present with pain for depression, aggressively treating depression and referring to pain management specialists if pain is not responsive to pain management. If the HCBWP participant is exhibiting behaviors indicative of depression, nurses working with waiver agencies could educate the participant and family members to notify the health care provider for worsening symptoms or encourage the participant to seek treatment for depression.

- The goal of the HCBWP is to prevent or delay nursing home admission (Fries, et al., 2002). The present study found that age, race/ethnicity, cognitive functioning and comorbid conditions were significantly associated with the admission of older adult HCBWP participants to a nursing home. Older age, race/ethnicity, cognitive functioning and comorbid conditions were significantly associated with time to admission of older adult HCBWP participants to a nursing home. Higher age, white race/ethnicity, impaired cognitive functioning and comorbid conditions are risk factors for nursing home admission among older adult HCBWP participants.

Clinicians working in the state programs overseeing the HCBWP as well as working in the waiver agencies must be aware of factors that may lead to a nursing home admission and develop care strategies to help mitigate the effect of these factors on the admission of older adult HCBWP participants to nursing homes. Strategies that may

assist in delaying and/or preventing admission to a nursing home include aggressive management of comorbid conditions. Nurses in the waiver agency can educate the patient and family members to utilize medications/treatments and monitor comorbid conditions. Older adult HCBWP participants who are at risk for nursing home admission should be closely assessed for care needs in order to develop care plans to best support the participant in his or her environment.

Summary of Implications for Clinical Practice. In summary, nursing implications from this study arise from the impact of person and health and illness factors on the associations between the pain experience, pain management strategies, pain management outcomes and admission of HCBWP participants to a nursing home. Careful assessment of the pain experience and development of pain management strategies and HCBWP care strategies must be completed while taking into account personal and health and illness factors that place the older adult HCBWP participant at risk for daily pain, poor pain management outcomes and admission to a nursing home. Nurses assume a leadership role within the waiver program as they assess the patient as well as family needs, utilizing the results of the assessment to develop a plan of care including education of the participant and family members to maximize the participant's quality of life.

Implications for Research

- Future research regarding the pain experience, pain management strategies, pain management outcomes and admission of older adult HCBWP would involve testing significant associations from the present study with alternative measures also found in the MDS-HC. For example, preliminary work completed by the researcher has found that an MDS-HC item asking if a participant is receiving treatment for depression may be a more

sensitive measure for depression than the DRS scale used to represent behaviors indicative of depression.

In the present study, physical function was measured by the total number of dependent ADL. This measure of physical function was utilized because it was a count variable and could easily be used in GEE modeling with the specification of a Poisson distribution. Additionally, concurrent research with the same data set was being carried out and also utilized the ADL count variable as well. For consistency across studies, the researcher chose to use the same measure of physical function.

An alternative measure of ADL is the ADL Scale, created by developers of the MDS. The Activities of Daily Living Scale (ADLS) (Landi, et al., 2000; Morris, et al., 1999) is comprised of the observed ability of the HCBWP participant in regards to mobility in bed, transferring, locomotion, dressing, eating, toilet use and personal hygiene over the previous 7 days as measured by MDS-HC items (Section P, Question 2) comprising the ADLS (Landi, et al., 2000; Morris, et al., 1999). Responses to each item address the amount of assistance the MIChoice participant needs with mobility in bed, transferring, locomotion, dressing, eating, toilet use and personal hygiene over the previous 7 days: 0=independent, 1=supervision, 2=limited assistance, 3=extensive assistance and 4=total dependence 5=Activity did not occur, regardless of ability . Additional research testing associations found in the current study with alternative measures will assist in determining the most sensitive measures within MDS-HC data.

- Future Research Question

- What is the association between the Activities of Daily Living Scale and the pain experience, pain management strategies and pain management

outcomes and how is this association affected by age, sex, race/ethnicity, cognitive functioning, behaviors indicative of depression and comorbid conditions over time among older adult HCBWP participants.

- The present study was limited to Medicaid paid claim files to examine pain management strategies as Medicare paid claim files were not available to the researcher. In a dual eligible population such as older adult HCBWP participants, pain management strategies such as pain management procedures (i.e. nerve injections or other pain clinic-related procedures and physical therapy) would be billed primarily to Medicare. Access to Medicare paid claim files would allow the researcher to determine if pain management procedures had taken place in addition to any prescribed pain medications billed to Medicaid paid claim files and Medicare Part D (after 1/1/2006).

- Future Research Question

- What pain management procedures did older adult HCBWP participants receive, as evidenced in Medicare claim files? Do older adult HCBWP participants who received pain management procedures also have prescribed pain medications? What differences exist in prescribed pain medications between older adult HCBWP participants with and without pain management procedures?
- What is the pain experience among older adult HCBWP participants who received pain management procedures?
- What differences exist in the pain experience of older adult HCBWP participants who receive pain management procedures when compared to

older adult HCBWP participants who received only prescribed pain medications?

- The original plan for this dissertation was to compare pain, pain management and pain management outcomes between older adult HCBWP participants and older adult nursing home residents. Prior research had noted poor pain management and pain management outcomes in nursing homes, despite high rates of pain among older adult nursing home residents (American Geriatrics Society Panel on Persistent Pain in Older Persons, 2002; Fisher, et al., 2002; Reynolds, et al., 2008; Sawyer, et al., 2006; Teno, et al., 2001; Won, et al., 2004). HCBWPs provide nursing home-level services for persons who would otherwise be admitted to nursing homes for care with the goal of the HCBWP being to prevent or delay nursing home admission (Fries, et al., 2002).

Nursing homes and HCBWP are supposed to both draw from the same population, therefore person and health-related characteristics between the two groups should be similar (Fries, James, Hammer, et al., 2004; L. Li & Zullo, 2003). Research is needed to examine how the pain experience, pain management strategies and pain management outcomes among older adult HCBWP differs from the pain experience, pain management strategies and pain management outcomes of older adults in nursing homes. If HCBWPs are to be a preferred method of caring for frail older adults over nursing home care, knowledge is needed to determine if pain management services provided in the HCBWP are preferable to nursing home pain management services, as well as to determine what pain management services are needed. However, at the time of dissertation development nursing home MDS data was not accessible. The dissertation was revised to work with the data that was available at that time. If in the future there is

access to nursing home MDS data, this comparative study should be completed. Not only would this research examine differences in the pain experience, pain management strategies and pain management outcomes between HCBWP participants and nursing home residents, but research results may assist governmental agencies in better targeting HCBWP services and delaying nursing home admission.

- Future Research Questions

- How does the pain experience differ between older adult HCBWP participants and nursing home residents at admission? Are differences in the pain experience between the two groups associated with sex, age, race, comorbid conditions, depression and cognitive functioning over time?
- What differences exist in pain management strategies among older adult HCBWP participants and nursing home residents over time? Are differences in pain management strategies between the two groups associated with sex, age, race, comorbid conditions, depression and cognitive functioning over time?
- What differences exist in the associations between the pain experience, pain management strategies and pain management outcomes among older adult HCBWP participants and nursing home residents over time? Are differences in the associations between the pain experience, pain management strategies and pain management outcomes of the two groups associated with sex, age, race, comorbid conditions, depression and cognitive functioning over time?

- This study found that subjects experiencing daily, unusually intense pain had a lower likelihood than that of subjects with no pain of being admitted to a nursing home. Pain was not significantly associated with time to nursing home admission. Because those with cognitive impairment were less likely to experience pain and older adult HCBWP participants with daily unusually intense pain were less likely to be admitted to a nursing home, future research should examine the possible mediating or moderating effect of cognitive function on the association between the pain experience and the admission of older adult HCBWP participants to a nursing home.
 - Future Research Question
 - Does cognitive functioning have a mediating or moderating effect on the association between pain and admission to a nursing home among older adult HCBWP participants?
- In the present study, race/ethnicity was associated with the prescription of opioid and adjuvant pain medications. African American older adult HCBWP participants with daily pain were less likely to be prescribed opioid and adjuvant pain medications over time when compared to white older adult HCBWP participants in daily pain. One possible explanation for this finding may have to do with the fact that adjuvant pain medications are medications that have a pain relieving effect, but whose primary or initial indication was not for the treatment of pain (American Pain Society, 2005). Therefore, primary care doctors may not be as familiar with the use of adjuvant pain medications for pain management as pain specialists are. If there is differential access to pain specialists among race then this may explain why black older adult HCBWP participants were less likely to have adjuvant pain medications prescribed. Future research examining the

billing of pain specialist services to Medicaid and Medicare by race would be beneficial in understanding the prescribing of pain medications in regards to race.

- Future Research Questions:
 - What differences are there among older adult HCBWP participants in the prescribing of adjuvant pain medications by race and/or ethnicity?

Implications for Policy

The present study found that over half of older adult HCBWP participants reported daily pain and 40% of those with daily unusually intense pain had no prescribed pain medications in the 30 days prior to each time point (assessment). The financial costs of pain management to the health care system have been reported to exceed \$4000.00 per year for persons with chronic pain (Turk, 2002). If cost containment within HCBWP is of concern to policy makers pain, pain management and pain management outcomes among HCBWP participants would benefit from changes in the MDS-HC pain measures and more thorough documentation of both over the counter and prescribed pain medication.

For the present study, data from the MDS-HC Version 1 was used. Michigan's HCBWP was supposed to update to Version 3 and has not done so yet. While the MDS-HC Version 3 includes a more detailed pain measures than Version 1, HCBWP-related research would benefit more from a pain measure, such as the numeric pain scale, which has been found to be reliable and valid among various populations (Jensen, 2003). The numeric rating scale would be a more sensitive measure of pain and changes in pain over time than the pain items used in the MDS-HC Version 1.

Research examining pain management strategies would benefit from improved documentation of all medications (including over the counter pain medications) that a participant

is taking. The present study was limited to examining prescribed pain medications only. Changes in policies regarding the documentation of all medications would enable researchers to examine all medications the participant is taking at each assessment, allowing research addressing associations between the pain experience and pain medications. In summary, in order to further examine issues of pain, pain management and pain management outcomes among older adult HCBWP participants policy must change the measures used to document the assessment of pain and use of over the counter pain medications and prescribed pain medications.

Conclusion of Dissertation

The primary purpose of this study was to examine longitudinal differences in the pain experience, pain management strategies and pain management outcomes among older HCBWP participants with respect to diagnosis of cancer while participating in the HCBWP. The secondary purpose of this study was to determine what differences exist in how the pain experience, pain management strategies and pain management outcomes among older adult, HCBWP participants associates with the admission of older adult HCBWP participants to a nursing home, with respect to diagnosis of cancer, over the course of time while participating in the HCBWP.

Diagnosis of cancer, as measured in the present study, had limited association with the pain experience, pain management strategies and pain management outcomes of older adult HCBWP participants. Diagnosis of cancer was negatively associated with the prescription of non-opioid and adjuvant pain medications among older adult HCBWP participants. These results are contrary to previous research which found that persons with cancer were more likely to experience pain than persons with no diagnosis of cancer (Buchanan, et al., 2005; Reyes-Gibby, Aday, et al., 2007; Rodin, 2008). Significant findings of associations between the pain

experience, pain management and pain management outcomes and person and health and illness factors were consistent with findings from primarily cross-sectional pain-related research among older adult populations.

While findings from this study were consistent with previous findings, the present study added to the science by focusing on older adult HCBWP participants, a population of which very little is known regarding pain, pain management or pain management outcomes. Additionally, the present study was longitudinal, where other pain-related research among older adults has been primarily cross-sectional. Longitudinal associations between pain, pain management and pain management outcomes and person-related factors (age, sex, race/ethnicity, cognitive functioning and behaviors indicative of depression) and health and illness factors (comorbid conditions) were noted by findings in the present study. This study utilized a novel data set comprised of data from the Minimum Data Set Home Care, Michigan Medicaid Paid Claim Files, Michigan Cancer Registry and Michigan Death Certificate data.

APPENDICES

Appendix A

Demographic Items from MDS-HC Face Sheet

Age: Section A Item 2-“Date of Birth” =empty space to write in date of birth

Sex: Section A Item 3- “Gender” select circle corresponding to “Male” or “Female”

Race/Ethnicity: Section A Item 7a- “Race fill only one White, Asian/Pacific Islander, Black, American Indian/Eskimo/Aleut”.

Appendix B

Table 37

Items of the Adapted Cognitive Performance Scale Utilizing MDS-HC Items

MDS-HC Item	Response	Intent of Item
Memory Short term memory OK-seems/ appears to recall after 5 minutes?	0 =Memory OK 1 =Memory problem	To determine client's ability to recall what was learned or known after 5 minute.
Cognitive skills for daily decision making How well client made decisions about organizing the day (when to get up or have meals, which clothes to wear or activities to do)?	0 =Independent-decisions consistently reasonable 1 =Modified independence-some difficulty in new situations 2 =moderately impaired-decisions poor, cues, supervision required 3 =Severely impaired-never/rarely made decisions	To determine client's ability to make everyday decisions about the task's or activities of daily living.
Communication: Making self understood Expressing information content-however able	0 =Understood-client expressed ideas clearly 1 =Usually understood-difficulty finding words or finishing thoughts 2 =Sometimes understood-ability limited to making concrete requests 3 =Rarely/never understood	To determine resident's ability to express or communicate requests, needs, opinions, urgent problems and social conversation (whether in speech, writing, sign language or a combination of these.

Table 37 (Continued)

MDS-HC Item	Response	Intent of Item
Self-Performance in eating Eating-including taking in food by any method, including tube feedings	<p>Requires:</p> <p>0=Independent-no help or oversight or help/oversight provided only 1 or 2 times in the last 7 days</p> <p>1=Supervision-Oversight, encouragement or cueing provided 3 or more times the last 7 days or supervision (3 or more times) plus physical assistance provided</p> <p>2=Limited assistance-Client highly involved in activity; received physical help in guided maneuvering of limbs or other non-weight bearing assistance 3 or more times</p> <p>3=Extensive assistance-While client performed part of activity, over past 7-day period, help of the following type(s) were provided 3 or more times: weight bearing support OR full performance by another during part, but not all of the past 7 days.</p> <p>4=Total dependence-Full performance of activity by another during entire 7 days</p> <p>5= Activity did not occur during the entire 7 days</p>	How client eats and drinks (regardless of skill).

Appendix C

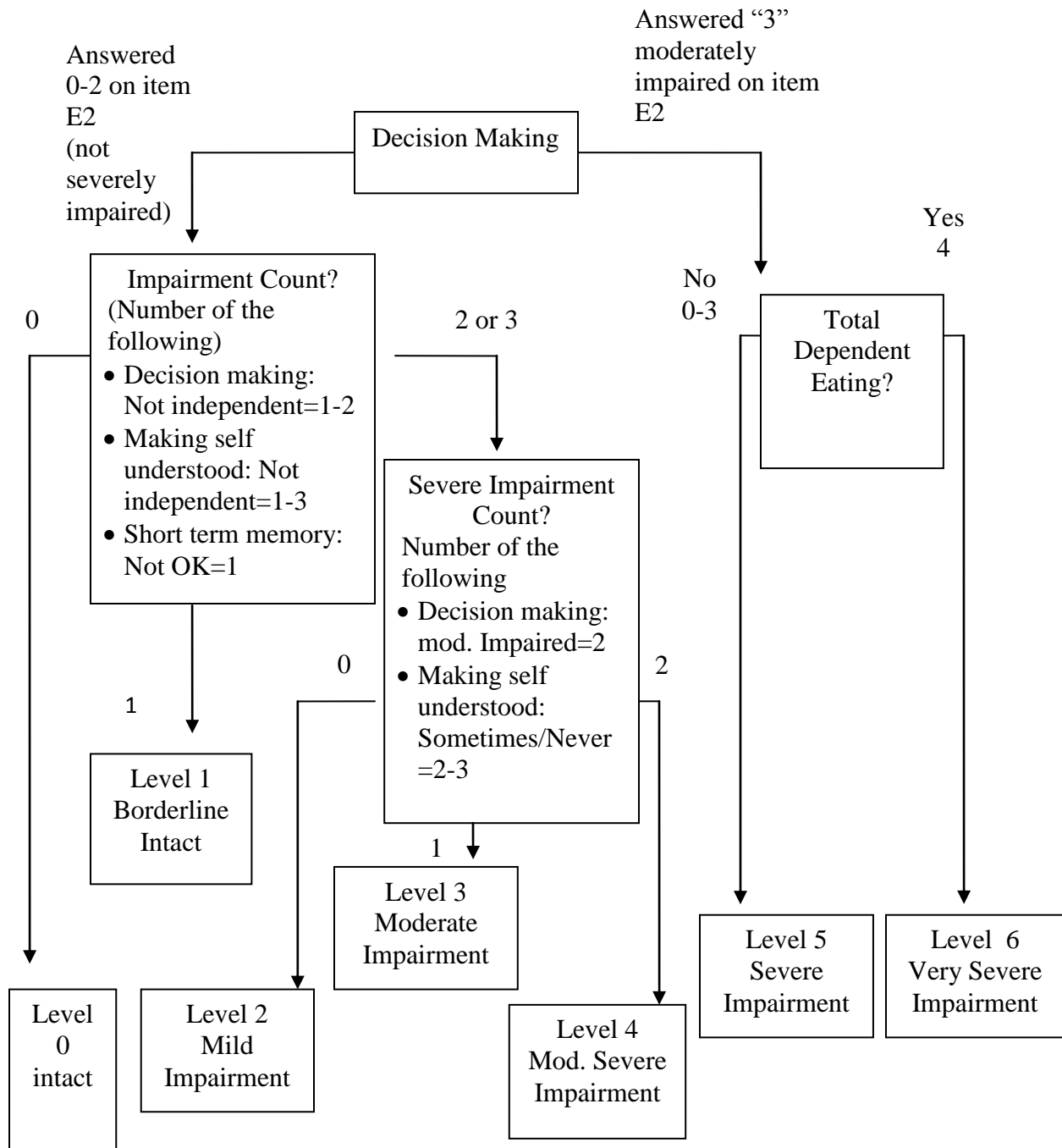


Figure 8. Diagram Depicting Scoring Rubric for Cognitive Performance Scale

Note. From "MDS Cognitive Performance Scale" by J.N. Morris, Fries, B.E., Mehr, D.R., Hawes, C., Phillips, C., Mor, V. and Lipsitz, L.A., 1994, *Journal of Gerontology*, 49, p. M 178. Reproduced with permission from Oxford University Press and authors.

Appendix D

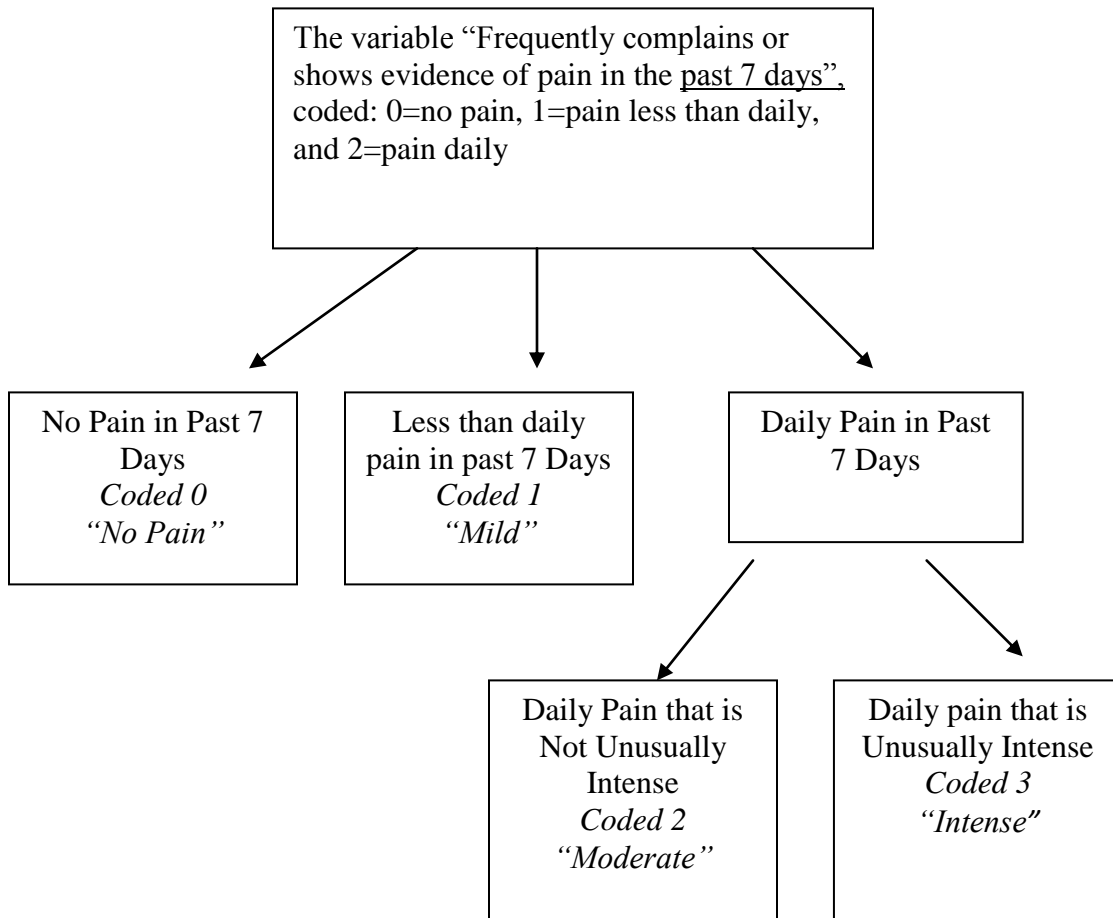


Figure 9. Diagram Depicting the Scoring of Pain Scale

Appendix E

MDS-HC Items for Pain Management Outcomes of Physical Function and Pain Control

Physical Function

- MDS-HC Section P titled “Physical Functioning”
 - Item 2 titled “ADL Self Performance”
 - “The following address the client’s physical functioning in routine physical activities of daily life, for example dressing, eating, etc. in the last 7 days considering all episodes of these activities. For clients who performed an activity independently be sure to determine and record whether others encouraged the activity or were present to supervise or oversee the activity
0 =Independent-no help or oversight or help/oversight provided only 1 or 2 times in the last 7 days.
1= Supervision-Oversight, encouragement or cueing provided 3 or more times during the last 7 days or supervision (3 or more times) plus physical assistance provided only 1 or 2 times during the last 7 days.
2=Limited Assistance-Client highly involved in activity, received physical help in guided maneuvering of limbs or other non-weight bearing assistance 3 or more times.
3=Extensive Assistance-While client performed part of activity over last 7 day period, help of the following types were provided 3 or more times: Weight bearing support or Full performance by another during part but not all of the last 7 days
4=Total Dependence- Full performance of activity by another during the entire 7 days
5=Activity did not occur- during the entire 7 days, regardless of ability”

2d: Dressing: Including laying out of clothes, retrieving clothes from closet, putting clothes on and taking clothes off. Choose performance 1-5 (as noted above).

2e) Eating: Including taking food by any method, including tube feedings Choose performance 1-5 (as noted above).

Appendix E (Continued)

2f) Toileting: Including using the toilet room of commode, bedpan, urinal, transferring on/off toilet, cleaning self after toilet use, changing pad, managing special required (ostomy, catheter) and adjusting clothes. Choose performance 1-5 (as noted above).

2g) Personal Hygiene: Including combing hair, brushing teeth, shaving, applying makeup, washing/drying face and hands and perineum (excludes baths and shower). Choose performance 1-5 (as noted above).

- Item 3 Titled “Bathing”
Bathing-in the last 7 days (include shower, full tub or sponge bath; exclude washing back or hair. Choose performance 1-5 (as noted above).

Pain Control

- MDS-HC Section J titled “Health Conditions and Preventative Health Measures”
 - Item 8e: “Pain controlled by medication”
 - 0=no pain
 - 1=medication offered, no control
 - 2=pain is partially or fully controlled with medication

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