Older Adults' Perceptions of Pain Medications

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DOCTOR OF PSYCHOLOGY

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Abstract

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Chronic pain is prevalent in older adults and is often untreated or insufficiently well managed. Pain in the elderly leads to significantly reduced quality of life and may be a major factor in loss of independence. Research has shown that due to a variety of concerns, physicians are often hesitant to prescribe pain medications for the elderly, and that older adults are often reluctant to utilize pain medications even when they are prescribed. Compounding the problem is the fact that older adults often employ highly risk-averse emotional heuristics in the decision to use pain medications. This dissertation explores those heuristics, in particular, the emotional heuristics, utilized by older adults when considering whether and how to take their pain medications.

Following an overview of the major issues related to pain management in the elderly, this dissertation presents findings of home interviews with an ethnic and socioeconomically diverse sample of eleven community-dwelling older adults (ages 63 – 86), all of whom are under a physician's care for pain, regarding their pain experience and their perceptions of their pain medications. After identification of key themes via qualitative data analysis, interview videos were edited to create a 30-minute DVD of participants, highlighting major themes uncovered from the interviews.

Results show that regardless of physician or medication recommendations, the participants each crafted highly individual processes for their pain management and their use of pain medication. Emotional heuristics were very much in use, especially as they related to fears of addiction and experience of past addiction in themselves and loved ones. Most participants were also active consumers of written, broadcast or internet information on pain medications, their side effects and their risks. A key determinant of strategy was socioeconomic status, which determined the kinds of complementary interventions that were possible and utilized. This dissertation closes with reflections on how older adults manage their chronic pain, implications for intervention, concluding remarks and suggestions for further research.

Dedication

This work is dedicated to my family—Jamie, Sam and Grace—without whom such an endeavor would simply have been impossible. Their ongoing love, support and encouragement sustained me through many challenging and doubt-filled moments.

I would also like to dedicate this work to my parents, Bob and Sue, my brother Rob, and my sister, Laurie, who have always cheered me on, without question, and regardless how daunting the task. I would like to extend a special appreciation to Rob, who although he left us too early, continues to inspire me to live my life as fully as possible and with my priorities clear.

Finally, I would like to dedicate this work to this study's participants who welcomed me into their homes and shared openly and honestly, their thoughts and feelings, as well as their hope for better pain management interventions.

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There are many people who helped me complete this work, but first among those I would like to acknowledge is Dr. Diane Zelman, my chairperson. From early on, I had a broad idea where I wanted to go with this work, but no clear path for how to get there. Dr. Zelman's vision, guidance, coaxing and challenging led to me to produce something even beyond my original goals.

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Introduction

Chronic pain in older adults is considered an individual, social, medical and economic crisis. It has often been described as epidemic as the percentage of older individuals in our population continues to grow.

Physicians, nurses, caregivers and family members have long known that older adults' pain-related attitudes, experiences and management needs are unique from younger members of society. Unique attitudes regarding pain management among the elderly are usually presented as anecdotal information in chronic pain literature, and only recently has this phenomenon come under the purview of researchers.

The goal of this dissertation was to gain a deeper understanding of older adults' perceptions of pain medications. To orient the reader, Chapter II, the Literature Review, presents a compendium of major issues in pain management in the elderly. The review begins with discussions of epidemiology of pain in the elderly; the reciprocal relationship between pain and depression; and barriers to assessment and treatment of pain. Current clinical thought and expert (consensus) opinions on pain treatment in the elderly are summarized. Chapter III, Method, presents the details of this qualitative study that used filmed home interviews to explore attitudes towards pain medications among a sample of 11 community-dwelling elders who have moderate to severe daily chronic pain. The filmed interviews were used to create a 30-minute DVD that highlights key themes representing how, why and when elders use their pain medication. Chapter IV, Results, provides a summary of the major findings from this study. Chapter V, Discussion, provides an in-depth review and interpretation of these findings, final conclusions and suggestions for further research.

It is hoped that these findings will help add to this growing body of research in the field of pain management for the elderly.

Literature Review

Pain in Older Adults

Epidemiology. Older adults experience more chronic illness and pain than any other age group in the United States (Brown, 2007), and pain is considered epidemic in this population. Research has shown that half of the elder adults who live independently and three-fourths who live in a care facility suffer from persistent pain (National Pain Foundation, Seniors and Pain, 2010). As we age, the body's ability to fight off disease declines, resulting in greater susceptibility to painful conditions in general, as well as conditions associated with pain such as: herpes zoster, cancer, diabetes and stroke. Muscles and joints experience a general decline rendering them more rigid, which results in less fluid muscular movement (Jacques, 2009) and the resulting restrictions in movement (combined with a reduction in balance) also make older adults more vulnerable to falls and painful fractures. The most common physical source of pain is arthritis with osteoarthritis (OA), the most prevalent, affecting 12.4 million of those 65 plus (Centers for Disease Control, 2010).

According to the National Pain Foundation website (National Pain Foundation, Pain causes, 2010), other painful conditions experienced by those 65 and older are: low back pain (~31%), neck pain (~15%), migraine or severe headaches (~5%) and facial pain (~2%). Painful knees and hips are common symptoms among older adults, with ~30% of adults 65 plus reporting knee pain or stiffness in the past 30 days and 15% reporting hip pain or stiffness. Other research shows that gender is significantly

associated with pain, with older women more likely to report pain than their male counterparts (Chou & Chi, 2005).

The epidemiology of pain and painful conditions among the elderly is increasingly well researched and documented, although less is known about the contributions of changes in the nervous system as we age. In an effort to better understand these processes, a laboratory study by Farrell and Gibson (2007) looked at the differences between how the young (mean age = 25.0) and old (mean age = 70.3) experience pain. Although there does not appear to be a difference between how the young and the old experience absolute pain, there does appear to be a difference between how they experience pain over the course of time. The study found that there is an aging effect on temporal summation, in that pain responses to electrical stimuli occurred at much lower frequencies in the older group compared with younger participants. The authors concluded that this suggests plasticity in the descending pain inhibitory sensory mechanisms changes as one ages. This study challenges other research that imply older age (especially 75 plus) is "almost protective against chronic pain" (Martinez, 2010).

Impact of Pain on Elder's Function: Reciprocal Relationship Between Pain and Depression

A key challenge during the elder years is to maintain a high quality of life during a period often marked by significant and varied losses (Bulut, 2009). These losses include loss of loved ones, loss of health, loss of income, loss of physical strength and for many, loss of independence. Pain has a significant impact on an older adult's experience of these losses and in some instances, may actually cause these losses through restriction of activities such as socializing and self-care. For community-dwelling older adults, the

onset of considerable pain is often an important turning point in the ability to maintain independence. As individuals with pain restrict their activities—especially those that include caring for themselves—they may require intervention and support by social service organizations, which may lead to moving into housing that provides a higher level of care with greater insurance of safety. To evaluate the reduction in daily activities that result from osteoarthritis, Gignac and colleagues (2006) performed a qualitative and quantitative review to examine the effect osteoarthritis (OA) had on older adults' view of aging. The study conducted 16 focus groups—10 groups consisting of those with OA and six groups of individuals without OA. The group participants were 53 women and 37 men (aged 39–88 years, mean age 57 years). All participants were asked about changes in health, the impact of these changes and self-management strategies. Quantitative information was gathered from completed standardized measures including the Short Form 36 (SF-36), the Western Ontario and McMaster Universities Osteoarthritis Index (WOMAC), and the Disabilities of the Arm, Shoulder and Hand questionnaire (DASH). The authors reported that important activities were affected by their condition. Physical activities most frequently mentioned as challenged by OA were: leisure and social activities, participation in the community, employment, and heavy housework. Social interactions were affected by symptoms that affected mood and increased OA sufferer's frustration with others. This study documented OA's influence on both functional disability and pain severity, both descriptively and numerically (Gignac et al., 2006).

Pain and depression are often comorbid; they are prevalent in the older adult population and they mutually influence each other. A study of pain among older adults reported that the odds of poor physical functioning were 11.2 times greater among those

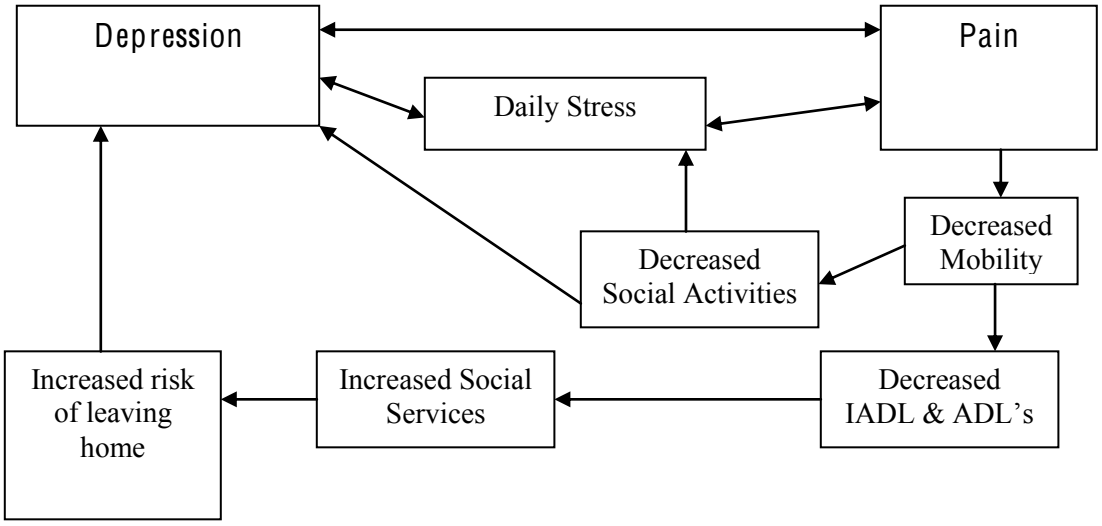
with comorbid chronic pain and depression than among those experiencing chronic pain alone (Mossey & Gallagher, 2004). Adding to the complexity of this relationship is the multifactorial natures of both pain and depression, which reciprocally influence each other. In 2002, Geerlings, Twisk, Beekman, Deeg, and van Tilburg explored the pain-depression relationship among elderly participants by conducting a 3-year, longitudinal study looking for mediating factors between aging, gender, pain and depression. The researchers found that pain and depression were both persistent over time, but depression to a lesser degree (persistence of pain, without depression over time occurred in 69% of the sample whereas depression, without pain over time occurred in 38% of the participants). Painful conditions at the previous measurement predicted depression at the next assessment, and pain could be predicted by depression from the previous assessment. This finding confirms that over time, pain and depression are reciprocally related and have nearly the same predictive value.

In 2005, Chou and Chi conducted a 12-month, longitudinal study to determine the reciprocal relationship between pain and depression among 318 elderly Chinese primary care patients and found that pain at baseline significantly predicted depression one year later, but depression at baseline only marginally predicated pain one year later. Another finding was that social support, physical disability, or social functioning did not mediate the impact of pain on depression, suggesting that the impact of pain on depression cannot be attributed only to loss of function, and underscores the need for understanding the multifactorial natures of pain and depression.

In a further attempt to disentangle the relationship between pain and depression through the identification of mediating factors, Tsai and colleagues investigated various

predictors of depression by testing a theory that they call the "middle-range theory of chronic pain" (Tsai, Tak, Moore & Palencia, 2003). Using a sample of 71 adults, age 60 plus, with physician-diagnosed arthritis, the researhcers found that pain, disability, social support, age, and gender are predictors of daily stress and daily stress further predicts depression. Pain, disability and social support contributed to 35% of the variance in daily stress.

Figure 1. Theoretical Relationship between Pain and Depression



Chronic pain is often also associated with cognitive deficits, as evidenced by decreased scores on tests of attention and working memory among individuals with significant pain, suggesting another route by which chronic pain can lead to significant functional impairment and decreased quality of life. In 2007, Dick and Rashiq conducted a study to examine how attention and memory are disrupted by chronic pain. A sample of 24 participants (18 female/6 males) who had a baseline pain intensity of at least 4 on a 0 to 10 scale, and pain lasting 6 months or longer, were recruited from a pain center in

Alberta. Tests of working memory and attention were administered before and after pain treatments. Measures selected were the Reading Span Test (RST) as a measure of verbal working memory; Spatial Span Test (SST) as a measure of spatial working memory; and the Test of Everyday Attention (TEA) that provides information on sustained and selective attention. Pain was measured using the McGill Pain Questionnaire (MPQ) and the Pain Catastrophizing Scale. Anxiety and depression were measured using the Hospital Anxiety and Depression Scale (HADS) and self-reported hours of sleep, medication use, and medical and pain histories were recorded. Results were that two-thirds of the participants had scores in the clinically impaired range on attentional tasks regardless of age, education, sleep disruption and reported degree of pain relief from medication. Participants with the highest level of pain impairment had significantly greater difficulties during tests of working memory. This study suggests that real cognitive deficits occur among individuals experiencing chronic pain and that these deficits are not necessarily ameliorated by the use of pain medications. An alternate possibility is that pain medications potentially contribute to these deficits. This idea has been studied, and some research indicates that performance on neuropsychological tests is neither affected by nor improved in individuals who are prescribed opioids, indicating that the impact of pain on cognition cannot be solely attributed to medication side effects.

Suicide among seniors is a significant health problem in North America, and elderly persons with severe pain and other medical illnesses have an increased risk of suicide (Warner, 2010). In 2008, Voaklander et al. found that individuals taking stronger pain medications were at a greater risk of suicide. Reviewing prescription renewal histories, the researchers found that chronic pain, often comorbid with depression, was

likely a strong contributing factor and that suicide attempts may be more lethal, as the elderly have a greater tendency to use more determined methods of suicide, such as hanging and firearms (Voaklander et al., 2008).

Other consequences of persistent pain in the elderly include: anxiety and agitation, loss of appetite, weight loss, poor nutrition, and sleep disturbances (both initiating and maintaining sleep). Decreased ambulation and deconditioning from lack of activity is associated with a variety of pathophysiology in the elderly, such as deep vein thrombosis, pulmonary embolism, decubitus and infection (Barkin, Barkin & Barkin 2005).

Types of Pain

Common types of pain experienced by older adults are musculoskeletal, internal organ, cancer-related and depression-associated pain (Jacques, 2009). These broad categories of pain can be broken down into more specifically defined types, differentiated by the pain source. This distinction is important because both the experience of pain and the treatment strategy differs among types of pain.

Nociceptive pain is caused by tissue inflammation, bone or muscle deformation, ongoing injury or destruction, inflammatory or traumatic arthritis, myofascial pain syndromes and ischemic disorders. Neuropathic pain results from damage to the brain, brain stem, spinal cord or local nerves and involves the peripheral or central nervous system. Examples include: diabetic neuropathy, post-stroke central pain, post herpetic neuralgia and postamputation phantom limb pain (American Geriatric Society, 2002). Mixed or unspecified pain is usually regarded as having mixed or unknown origin and includes both nociceptive and neuropathic pain. Examples include recurrent headaches

and some vasculitic pain syndromes. Conversion disorders or psychogenic pain are conditions in which cognitive and emotional processes are believed to be responsible for the onset, severity, exacerbation or persistence of pain. The site of the pain experience varies, but typically includes headaches and gastrointestinal pain.

Treatment of Pain

Expert opinion on pain treatments for older adults.

In 2002, the American Geriatric Society published guidelines called the "Management of Persistent Pain in Older Persons." The goal of the publication was to provide the reader with (a) an overview of the principles of pain management as they apply specifically to older people and (b) specific recommendations to aid in decision making about pain management for this population. The convened panel included experts in ethics, family medicine, geriatrics, nursing, pain management, pharmacy, psychiatry, psychology, rehabilitation medicine, rheumatology and social work. Initially, more than 4122 citations were identified, with 520 full text articles obtained and summarized. Groups of panel members gave each article rankings, to judge the strength and quality of evidence to each recommendation. They ranked the quality of evidence as Level I, II or III and the strength of the evidence from A (Good evidence to support the use of a recommendation: "clinicians should do this all the time") to E (Good evidence against the use of a recommendation, which is therefore "contraindicated"). However, as the evidence-based literature was found to be very limited in sample and design for the population > 75 years of age, the panel noted that some of their final recommendations were based on clinical experience and were without existing scientific evidence. The recommendations that followed were divided into four sections: Assessment of Persistent Pain, Pharmacologic

Treatment, Nonpharmacologic Strategies and Recommendations for Health Systems That Care for Older Persons. Each of the four sections includes a list of specific recommendations for that section and provides an in-depth review for health care professionals. In an overview, the panel recommended that all health care providers approach each patient's treatment individually and create care and treatment plans that are individually tailored—particularly for pharmacotherapy. The panel also recommended that the most efficacious treatment of pain should combine nonpharmacologic and pharmacologic treatments (American Geriatric Society, 2002). This important study has been heavily referenced in other scholarly works (over 125 references have been noted).

Nonpharmacological treatments recommended by the consensus panel. As per AGS guidelines, a variety of nonpharmacologic treatments for persistent pain have been shown to work alone or in combination with appropriate pharmacologic strategies. These nonpharmacologic pain management interventions include a number of physical and psychological treatments that often require active participation by the individual with pain. The act of participation has, in itself, been shown to help build self-reliance and sense of control over pain. These interventions include: patient education, appropriate physical exercise and use of self-help techniques. The panel noted that patient education should be included in any treatment for pain—studies have shown that patient education programs alone (especially those associated with actual practice of self-management and coping strategies) significantly improve overall pain management. For many older persons, education for the caregiver is also essential (American Geriatric Society, 2002).

According to the panel, cognitive and behavioral pain coping strategies have also proven to be an effective component of pain management. Cognitive coping strategies address thoughts that include helplessness, low self-efficacy and catastrophizing which have been shown to increase pain and disability. Cognitive strategies may also include distraction methods such as: imagery; focal point concentration; counting methods; and mindfulness methods. Behavioral strategies typically teach patients to control pain by pacing themselves, increasing their involvement in pleasurable activities and using relaxation methods.

Other nonpharmacological coping strategies include: use of chiropractors and physiotherapists, applying heat and /or ice, resting, modifying certain activities / movements (Sale, Gignac & Hawker, 2006), acupuncture, massage, yoga and other exercise programs.

Pharmacological treatments recommended by the consensus panel. In 2009, AGS updated its recommendations to reflect the significant improvements in the use of pharmacological approaches to pain, and the fact that pharmaceuticals are the most common (and riskiest) approach to treating pain in the elderly. These guidelines were published in the Journal of the American Geriatrics Society under the title "Pharmacological Management of Persistent Pain in Older Persons." Panel members included experts in geriatric pain management, pharmacology, rheumatology, neurology, nursing, palliative care, and geriatric clinical practice. From an initial source of 24,000 citations, the panel reviewed more than 240 full-text articles. Data from these articles was then analyzed to determine the strength and quality of evidence. As with the 2002 study, the number of controlled studies with participants 75 years old and older remained

low, resulting in the need to produce some recommendations based on clinical experience and the consensus of the panel members. AGS noted that protection of human participants has led investigators to exclude older adults and those with compromised medical conditions from clinical trials. In one report of 83 randomized trials of nonsteroidal anti-inflammatory drugs (NSAIDS), which included nearly 10,000 participants, only 2.3% were aged 65 and over and none were aged 85 or over (American Geriatric Society, 2002).

The 2009 guideline recommends that acetaminophen be considered as initial and ongoing pharmacotherapy for patients with mild to moderate musculoskeletal pain. But in a significant departure from the 2002 document the 2009 guideline recommends that nonselective NSAIDs and COX-2 selective inhibitors be considered rarely and with caution, as their side effects include significant gastrointestinal toxicity, which appears to increase in frequency and severity with age, and cardiovascular risk in some medically compromised individuals (American Geriatric Society, 2009).

The new guideline also recommends that all patients with moderate to severe pain, pain-related functional impairment, or diminished quality of life due to pain, be considered for opioid therapy. The guidelines add that if properly managed, opioid analgesics constitute an effective and, for some, indispensable treatment as part of a multimodal strategy in the management of various types of persistent pain. However, they note that evidence of long-term opioid effectiveness for persistent noncancer pain conditions in all age groups is lacking (American Geriatric Society, 2009).

A 2008 Consensus Statement, issued by the World Health Organization also builds on the American Geriatric Society's 2002 guidelines, but focused on the use of the

six most clinically used step III opioids—buprenorphine, fentanyl, hydromorphone, methadone, morphine, and oxycodone. This consensus statement mirrors the American Geriatric Society's 2009 document and recommends the use of opioids in treating severe and refractory cancer and noncancer-related pain as well as in individuals experiencing nociceptive and neuropathic pain. WHO also cautions the use of opioids in elderly with impaired hepatic and renal function and urges physicians to monitor possible respiratory depression and immunosuppression (World Health Organization, 2008).

A number of other drugs developed for purposes other than treating pain can effectively alter, attenuate or modulate pain perception. The term 'adjuvant drug' has been used in the cancer pain literature to describe these drugs and this term is now widely accepted in noncancer pain literature (American Geriatric Society, 2009). These drugs may be used alone or in combination with non-opioid or opioid analgesics to treat many different persistent pain conditions, especially neuropathic pain. These drugs include antidepressants and anticonvulsant medications. Tricyclic antidepressants were the first antidepressants found to reduce pain from post herpetic neuralgia, but the side effects of this class of drugs often contraindicate their use in older patients. The Serotonin-Norepinephrine Reuptake Inhibitors (SNRIs) are particularly effective in the treatment of various neuropathic pain conditions and fibromyalgia, but the Selective Serotonin Reuptake Inhibitors (SSRIs) have not proven effective. Anticonvulsant drugs, including gabapentin and pregabalin, have been found to be effective in treating neuropathic pain, but with more benign side effects than older anticonvulsant and antidepressant tricyclic drugs (American Geriatric Society, 2009).

Citing anecdotal evidence and a small number of studies, AGS has listed other drugs for pain treatment, but states that use of these drugs should be a matter of clinical judgment. Corticosteroids, muscle relaxants, benzodiazepines, calcitonin, bisphosphonates, topical analgesics and cannabinoids are among the list (American Geriatric Society, 2009).

Barriers to Assessment of Pain in Older Adults

Physician perspectives. Concurrent illnesses and multiple health problems make pain evaluation in older adults difficult (American Geriatric Society 2009), as pain is experienced across physiological, psychological and social domains. Thus, discriminating which factors are most important for the purpose of treatment can be very challenging. Further complicating the assessment is the fact that pain expression (and thus the importance of specific factors) commonly varies, not only across individuals, but also over time in one individual (American Geriatric Society 2002).

Ageism is increasingly cited as a very real prejudice among physicians that contributes to less effective medical care and pain intervention. According to the Alliance for Aging Research (2003), ageism emerges during medical training as 90% of the U.S.'s medical schools offer geriatric classes as electives, but no formal training in geriatrics is required. Even as electives, only 3% of medical school students choose to take these courses. Lack of good communication with elderly patients can lead many physicians to difficult encounters, which can lead to poorer assessments and ultimately to poorer outcomes. Another example of ageism, noted by Stewart, Meredith, Brown and Galajda (2000), is that physicians may hold the assumption that an older individual neither needs nor wants to maintain a high level of physical function or independence.

Physicians may be complicit in fostering the expectation that pain should be accepted (rather than treated) by avoiding direct conversations with patients about the consequences of pain, which can add to the patient's perception that they should tough it out (Johnson, 2008).

In a summary article by Barkin et al. (2005), the authors found other impediments to assessment, such as: lack of standardized assessment tools that reflect unique concerns of the elderly, lack of consistent use of available tools, tendency to rely on subjective pain severity scales, and lack of staff education on pain impact and its ongoing assessment and evaluation.

Adding to the complexity of the problem of treating older adults with pain is the fact that pain reports appear to decrease with age. Researchers Helme and Gibson (2001), have studied pain in older adults and concluded that pain reports peak at age 65, and the older age groups—people ages 75-84 and 85 plus—are less likely to report pain. It is not assumed that this reflects lower frequency or severity of pain, but rather a number of other possible effects. Most likely, the researchers suggest, there are variations in data acquisition where healthy older adults are more likely to participate. Furthermore, the very old are less likely to be community-dwelling and are often very poor. Another hypothesis is that the very old may not focus on their pain because of other significant life events, such as death of a spouse and loss of independence.

Older adults' perspectives. In addition to the problem of ageism and lack of education in pain assessment by practitioners, pain assessment in the elderly is complicated by the fact that many elderly patients are often less willing or less able to

vocalize their pain symptoms. Following is a summary of themes that have emerged from a number of qualitative studies regarding pain reports among older individuals:

- Some individuals have learned to accept pain as part of aging and believe they have to live with it until they die (Martinez, 2010).
- Individuals with cancer, may be fearful of reporting pain as it is often a metaphor for advancing disease (Ferrell, Rhiner, Cohen & Grant, 1991).
- For some, they see others as worse off than themselves and thusly cannot justify complaining about their pain or they believe that their pain cannot be relieved (Ferrell et al., 1991).
- Many older adults are afraid of being labeled as "complainers," which could negatively impact their care (Ferrell, 1995).
- Some older adults believe that complaining of pain will lead to a loss of independence (Phillips, 2007).
- Studies of cancer pain report that patients fear that focusing their practitioner on pain will divert the practitioner's attention from addressing the underlying condition.
- Patients may consider their need for pain medications as wasteful, rash, hedonistic or selfish and their ability to forgo analgesia as stoical, patient, thrifty and selfless (Johnson, 2008).
- Some believe that enduring pain builds strength and character (Dahl & Portenoy, 2004).
- Older adults may fear diagnostic tests and accept pain and suffering as atonement for past actions (American Geriatric Society, 2002).

Additionally, conditions often associated with old age, such as dementia or Alzheimer's disease, may complicate an older adult's ability to seek and receive adequate care for his or her pain (National Pain Foundation, Pain Causes, 2010). The assessment of pain in those with cognitive impairment is a growing area of research and a variety of pain scales have been adapted and accepted for use among older adults, including with those who are experiencing mild to moderate cognitive impairment.

For the older patient, general attitudes towards working with their physician can add to the complexity of the assessment. Many elders are passive in the medical encounter, which can be particularly problematic. Rost & Frankel (1993) found that 56% of older patients failed to raise important medical issues with their physicians. Other researchers (Greene, Adelman, Charon & Friedmann, 1989) found that older patients are less likely than younger patients to agree with their physicians on the primary goal of the visit or to find consensus when reviewing symptoms, test results, medications and health management issues.

Stewart et al. (2000) published an article reviewing the importance of communication between the older patient and his / her physician. In this literature review, the authors identified seven different potential beneficial outcomes of higher quality of communication with older patients. These include: improved concordance of treatment strategy with patient expectations, more efficient and effective decision making, increased patient recall of physician advice, improved patient satisfaction, patient adherence, positive emotional health outcomes, and positive physical health outcomes. Fifty articles were referenced in this summary. The authors concluded that there was much more to be learned on this topic, particularly in the relationship between

the physical outcomes and the patient / physician communication. Unfortunately, just over half of the articles referenced in this review were from abstracts only, suggesting a review that was more comprehensive in its breadth than its depth. Regardless, this article does touch on important relationship nuances that are unique in working with older adults—that many of today's elders have been socialized to respect and defer to their physician, which creates a barrier to the elder's full participation in their care—a central goal of pain intervention and management.

Treatment Concerns

Despite the widespread presence of pain in the elderly, many older adults do not receive treatment for their pain. The National Pain Foundation website indicated that 47–80% of older adults in community settings and 16–27% of older adults living in institutionalized settings do not receive treatment for pain, and one dementia research study found that 84% of older patients with dementia and suffering from pain do not receive any treatment (Martinez, 2010).

Physician perspectives.

Due to the many challenges in assessment and the high prevalence of pain among the elderly, some researchers argue that pain should be presumed, acknowledged and treated whether or not older patients complain of it (Sofaerer, et al., 2005). However, even when pain is disclosed and discussed, it can be difficult to manage successfully, as evidenced by the levels of chronicity and impairment that occur despite good access to health care (Mossey, 2004).

Cobbs, Duthie, and Murphy found that physician attitudes and issues of ageism can affect treatment concerns, as physicians may provide less preventative treatment information and treat their medical problems less aggressively, if they believe their health

problems are the result of natural age-related process or of long-standing lifestyle choices that are difficult to change. Furthermore, physicians may dislike treating older patients because of their sometimes complex health problems, including multiple concurrent conditions, which may not be readily resolved within a single office visit (as cited in Brown, 2007).

Perhaps the most often noted area of concern for physicians treating older adults who are experiencing pain is the many age-associated differences in drug effectiveness, sensitivity and toxicity as older patients are generally at a higher risk of adverse drug reactions (American Geriatric Society, 2009). For some classes of pain-relieving medications (e.g. opioids), older patients have demonstrated greater analgesic sensitivity as physiological decline in organ function (e.g. renal or hepatic) can affect the pharmacology of analgesics and therefore, the onset of action, the rate of elimination and the half-life of drugs. Comorbidities and polypharmacy increase the possibility of drug interactions and adverse events, such as respiratory depression and dizziness, which can have serious consequences in a patient who may already be at risk for falls and fractures.

Furthermore, body fat composition changes as people age and decreased protein stores (often due to poor nutrition) will affect the protein binding capacity of certain medications. Drugs may compete for protein-binding sites, rendering one or more of the medications ineffective. Changes in sensory and cognitive perception such as sedation or confusion are also a risk for some patients due to the potential side effects of both opioid and nonopioid medications, such as antidepressants and anticonvulsants (Gandey, 2010). The side effects of opioids, such as constipation and fatigue, can prevent a person from functioning and can cause more suffering than the pain. If the end of life is near,

morphine or other opioids cannot be increased without increasing the likelihood of death (Dahl & Portenoy, 2004). The World Health Organization notes that these physiological changes lead to a narrowing of the "therapeutic window" for analgesic treatment in the elderly, resulting in increased difficulty in balancing the risk of adverse events against the need for adequate analgesia (World Health Organization, 2008). The following table summarizes some of these important side effects and physiological changes.

Table 1

Pharmacological Changes With Aging

Pharmacological Concern	Change With Normal Aging	Common Disease Effects
Gastrointestinal absorption or function	Slowing of gastrointestinal transit time may prolong effects of continuous release enteral drugs Opioid-related bowel dysmotility may be enhanced in older patients	Disorders that alter gastric pH may reduce absorption of some drugs Surgically altered anatomy may reduce absorption of some drugs
Transdermal absorption	Under most circumstances, there are few changes in absorption based on age but may related more to different patch technology used	Temperature and other specific patch technology characteristics may affect absorption
Distribution	Increased fat to lean body weight ratio may increase volume of distribution for fat-soluble drugs	Aging and obesity may result in longer effective drug half-life
Liver metabolism	Oxidation is variable and may decrease resulting in prolonged drug half-life Conjugation usually preserved First-pass effect usually unchanged Genetic enzyme polymorphisms may affect some cytochrome enzymes	Cirrhosis, hepatitis, tumors may disrupt oxidation but not usually conjugation
Renal excretion	Clomerular filtration rate decreases with advancing age in many patients, which results in decreased excretion	Chronic kidney disease may predispose further to renal toxicity
Active metabolites	Reduced renal clearance will prolong effects of metabolites	Renal disease Increase in half-life
Anticholinergic side effects	Increased confusion, constipation, incontinence, movement disorders	Enhanced by neurological disease process

Note: Adapted from "Pharmacological Management of Persistent Pain in Older Persons," by American Geriatrics Society, 2009, *Journal of the American Geriatrics Society, 57,* p. 1334. Copyright 2009 by the American Geriatrics Society.

Adding to the complexity of prescribing analgesics, older patients have been systematically excluded from clinical trials of analgesic drugs. In one report of 83 randomized trials of nonsteroidal anti-inflammatory drugs (NSAIDS), including nearly 10,000 subjects, only 2.3% were aged 65 or over and none were aged 85 and older, despite the fact that older people were more likely to experience the side effects of analgesic medications (American Geriatric Society 2002). Due to the limited number of clinical trials including older adults, recommendations for age-adjusted dosing are not available for most analgesics.

Research on the pharmacological treatment of pain suggests that another area of significant concern for physicians is the risk of addiction. While the issues of addiction are real (and popularized in our media), the likelihood of addiction is less than 1 in 200 (Weiner, 2010). Those who argue for increased patient rights in the area of opioids for severe pain note that patients may be dependent on a medication without addiction, which would be defined by drug-seeking behavior. Even though patients need ever increasing doses of opioids (because tolerance, also known as pseudo-addiction, develops rapidly to these drugs), most patients with pain severe enough to need an opioid, have no history of addiction to any drug and their risk of developing addiction is "very, very small" (Dahl & Portenoy, 2004). Some researchers view the reluctance of practitioners to prescribe these drugs as over-influenced by political and social pressures to control illicit drug use (American Geriatric Society 2002). In spite of the fact that the use of opioid analgesic drugs for persistent, non-cancer related pain remains controversial, consensus statements from major professional pain organizations endorse their use in appropriate situations.

Although opioids are more commonly accepted as pain medication for those experiencing cancer pain, their use (or lack of use) remains a major cause of the under treatment of cancer pain (Jacobsen et al., 2009). An often-cited 1994 study by Cleeland et al. found that 42% of metastic cancer patients were not given adequate analgesic therapy. This study also found that age was predictive of poor pain management, with those 70 years or older having an increased odds ratio of 2.4 for poor pain management. Although this study is 16 years old and new guidelines for the treatment of cancer-related pain have been published by the American Geriatric Society (2002 and later updated in 2009) and the World Health Organization (2008), a 2008 review of the literature found the problem still persists, with under treatment usually attributed to an inappropriate use of opioids for reasons often conceptualized in terms of barriers related to health care provider, patient, family, institution and society (Maltoni, 2007).

According to the National Cancer Institute, a number of barriers restrict the prescribing of opioids, creating additional challenges for physicians in the practice of effective pain management. In many states, local and state laws often restrict the medical use of opioids to relieve cancer pain, prescribing patterns of physicians are closely monitored, which makes them fearful for legal action. Furthermore, insurance companies may not reimburse patients for "noninvasive pain control treatments." Other challenges include limited availability of opioids in some neighborhoods or the medication being simply too costly for the patient (National Cancer Institute, 2010).

Physicians also note concerns about patient compliance. Many elderly patients suffer some type of cognitive impairment, either from pathology or medication, which is often compounded by sight and hearing impairments. These challenges can lead to

problems of compliance and difficulties in accurately describing pain and adverse events (World Health Organization, 2008), with the result that the patient may be over-treated, under-treated, may suffer adverse events or may develop tolerance. Adding support to this position, Morrell, Park and Poon (1989) found that older adults incorrectly comprehended 21% of the information on prescription labels that was written by a pharmacist. Other research suggests that some older adults have particular difficulty in understanding information that is complex or requires making inferences (Kemper, 1992, Rogers, Rousseau & Lamson, 1999).

Nonpharmacological treatment for pain has been well researched and accepted; however, many physicians and psychologists worry that older adults may not have the learning skills needed for participation in these rehabilitative therapies (Jorge, Gerard, & Revel, 2009). One of the few controlled trials examining the effectiveness of Cognitive Behavioral Techniques (CBT) in pain management for a wide range of ages found that age was unrelated to outcome. This study compared an intermediate-treatment group and a wait-list control group and compared the wait-list control group with itself (delayed treatment). Participants were randomly assigned to the treatment or wait-list control group and the distribution of ages between groups was nearly equal (27-80 and 27-79, respectively). Therapy was conducted in 10 weekly, 2-hour group sessions, which consisted of explaining stress inoculation training (SIT) (Turk, Meichenbaum & Genest, 1983 as cited in Puder, 1988), reviewing progress and problem solving. Subjects in both groups completed daily pain diaries. One-and six-month follow up assessments were done in both groups.

The primary results were that CBT was efficacious in that those in the treated group reported their chronic pain interfered less with their activities and they were better able to cope. Age did not make a significant contribution to the results. Based on these findings, the authors concluded that increased age was not a contraindication for the treatment of chronic pain using CBT techniques and is a cost effective and safe alternative (relative to drug therapy and surgery) for older adults (Puder, 1988). This study is important in that it was one of the first to evaluate and confirm the value of CBT techniques for pain management in older adults. Although it is not clear how the authors are defining older adults (55 plus? 75 plus?), this study does start to break down some of the myths regarding older adults' abilities to learn new coping skills.

Older adult perspectives. Research suggests that older adults are often reluctant to take pain medications and instead look for other ways of managing their pain. Some focus on prayer and hope (Gibson et al., 2006) while others place more emphasis on acceptance. From the perspective of the elderly, the safety, rather than effectiveness of treatments, is often a higher concern. Many older adults see pain medications as high risk; although research also suggests the elderly have limited knowledge about arthritis medication, with few individuals being able to list potential side effects (Hill & Bird, 2007).

A qualitative study by Sofaerer et al. (2005) studying the functional impairments reported by older adults with chronic pain and the strategies they use, included unstructured interviews from 63 people who ranged in age from 60 to 87 years. Two main themes emerged: (a) the desire for independence and control, and (b) adaptation to a life with chronic pain. The subjects rarely mentioned use of medication to accomplish

these goals, but instead indicated that they relied heavily on other pain management techniques. These included acceptance and non-acceptance, pacing oneself, helping other people, the use of prayer and "looking good and feeling good." Part of acceptance was learning to live with what could be done. Nonacceptance of pain—fighting the idea of having pain and trying every way possible to obtain relief—often presented a challenge in dealing with the medical system. Pacing oneself included knowing one's own limitations and carefully planning daily activities. Helping other people was described as a way to put their own pain in perspective and forced them to get out of their house, which was seen as a useful way to be both social and active. Prayer was often cited, not necessarily a way to remove the pain, but as a way to cope. For others, looking good (taking time and effort for personal grooming, wearing attractive clothing or make-up) led to feeling good.

Canadian researchers (Sale et al., 2006) using phenomenological analysis, found that despite reports of pain, older adults with osteoarthritis (n = 18) did not take their pain medications as they did other prescribed medications. Many patients will interpret "as needed" as "when desperate" or "when all else fails" while the provider intended it to mean "to improve symptoms" or "to enhance quality of life" (Johnson, 2008). In focus groups, older patients with OA saw medication as masking, rather than curing their pain (Gignac et al., 2006).

In another study looking at medication adherence, 75% of seniors in a Medicare survey report having arthritis, but only 40% of them report actively treating it. In other samples, only about half of patients who report functional impairments from pain take

any medication for it, which differs from the extent of seniors' use of treatments for other chronic medical conditions (Johnson, 2008).

In a qualitative study of 19 older adults with arthritis pain, only 4 subjects (21%) were taking pain medications as directed, whereas the remaining 79% "purposefully did not take their OA medications as prescribed" (Sale et al., 2006). Many older adults acknowledge treatment behaviors that might be considered irrational, such as filling prescriptions and then throwing the medication away, putting lower dose pills into a bottle with a higher dose on the label, and hiding nonadherence from family members (Johnson, 2008). Many patients reported fear of addiction as a key barrier to using stronger painkillers. At the same time, 95% of the participants were taking at least one herbal remedy and/or vitamin for their arthritis (Johnson, 2008).

Educating older adults and changing perceptions, habits and attitudes can be difficult. Okun & Rice (1997) found that older adults with osteoarthritis were more likely than nonarthritic older adults to misinterpret a factual text on arthritis as confirming their false beliefs about the disease when in fact it disconfirmed these erroneous beliefs. Such false beliefs may arise through reliance on folk wisdom or illusory correlations and likely have implications for participant's selection of treatments and subsequent compliance. This type of memory distortion can be particularly problematic for older adults, given their greater consumption of medical services as well as their exposure to sometimes complex and unreliable medical claims from media reports as well as drug advertisements, supermarket tabloids, websites, friends and family (Brown, 2007).

Summary and Introduction to Present Study

Chronic pain affects older adults more than any other age group and often leads to a greatly reduced quality of life. To treat pain, the American Geriatric Society recommends a combination of pharmacological and nonpharmacological treatments. However, physicians are often hesitant to recommend and/or prescribe pain medications due to patients' often declining cognitive abilities, complex medical conditions and age-associated differences in drug effectiveness, sensitivity and toxicity (American Geriatric Society, 2009). Further compounding this already complex situation are the older adults' perceptions of pain medications, and their reluctance to take them. In one study, only 21% of the subjects were taking their pain medications as directed, whereas the other 79% "purposefully did not take their OA [osteoarthritis] medications as prescribed" (Sale, Gignac, & Hawker, 2006). The reasons cited for this are varied. Some are rooted in well-acknowledged concerns about side effects (e.g. upset stomach, constipation), and others are in direct conflict with published and / or generally accepted guidelines (e.g. "I only need to take pain medications when the pain is so bad that I can't manage").

Social cognition theories of health behavior, such as the health belief model, suggest that four key elements determine an individual's adherence to treatment: threat of the illness, positive outcome expectancy, barriers to using the treatment, and intention to adhere (Riekert & Drotar, 2002). Previous qualitative research has shown how medication taking is a process where patients balance their concerns about medications (the risks) against their perceived need for the drug and its perceived benefits (Gadkari & McHorney, 2010). This process results in a cost-benefit analysis—weighing beliefs about the necessity of medications against their concerns about the potential adverse

effects of taking the drugs. This suggests that concentrating more on reassuring patients about the safety of the treatments—specifically reducing fears about long-term effects of taking medications and dependency—rather than on the benefits of treatment, is more effective for adults in general and likely much more relevant for older adults who are very often risk averse.

Further complicating the medication decision-making process, is that as we age, memories tend to become decontextualized and it has been found that older adults tend to use more automatic processing (e.g. heuristics; stereotype activation and affective reactions to stimuli) than younger adults. Older adults often think if they have heard a piece of information before (i.e. it seems vaguely familiar to them), but cannot remember the specific source of the information (i.e. who said it or where it was learned); they use the heuristic that if information seems familiar then it must be true. This type of memory distortion can be especially troublesome for older adults, given their greater use of medical services as well as their exposure to sometimes complex and unreliable medical claims from media reports as well as drug advertisements, supermarket tabloids, web sites, friends and family members (Liu & Gonzalez, 2007).

Schwarz and Clore (1996) found that in situations in which older individuals must make complex or speeded decisions, information is often encoded in terms of its emotional value to the individual rather than its actual content. However, when an emotional assessment of a situation conflicts with one's cognitive assessment, this might result in older adults' remembering only a negative impression of a treatment—for example, that it was very painful to a friend or relative—and ruling out this treatment despite there being many other factors to recommend it.

The purpose of this dissertation is to look more deeply into the factors, including the risk-aversion aspect, of the decision-making process that older adults use in determining whether to take their pain medications—in particular, the emotional heuristic process they engage for making these decisions. I recognize that heuristics can be adaptive, as noted by Gigerenzer, and are an important tool that allows individuals to simplify a complex judgment, but in some cases, the use of heuristics can lead to errors in reasoning (cited in Liu & Gonzalez, 2007). According to Peters et al., and Tversky & Kahneman, within a medical domain, the use of heuristics might lead to older adults' tendency to over- or under-estimate their likelihood of becoming ill or of suffering side effects (as cited in Liu & Gonzalez, 2007).

It was hoped that the use of semi-structured interviews would open up the participants' thought, recall, reflection and emotional processes to explore and identify major themes, processes and sources older adults use for making decisions about their pain medications.

It was for these reasons a qualitative method was chosen. Qualitative research methods enable health science researchers to delve into questions of meaning, identify barriers and facilitators to change and discover the reasons for the success or failure of interventions (Starks & Trinidad, 2007). Furthermore, qualitative methods allow for interpretation of the data in terms of the meaning people bring to them and are often used when studying participants' perceptions or experiences.

Videotaped, semi-structured interviews were conducted in the participants' homes. This approach was chosen as it would permit a more in-depth, naturalistic view of the individual's experience. This methodology also allowed me to look for and

summarize dominant ideas and themes across the participants' experiences and allowed for descriptive as well as interpretive information.

The final product of these interviews is a 30-minute DVD that was produced in the hopes of capturing the full experience of living with pain as experienced by older adults. Since it is well known that much of our communication is nonverbal, it is hoped that the film will elaborate on the phenomenon under study. In addition to completing this dissertation's work into understanding the experience of pain and use or non use of pain medication, it is intended that this DVD can be used as an educational tool for those who are working with older adults around issues of pain management.

Method

Research Design Overview

This study explored the attitudes of older adults towards pain medications—specifically the emotional heuristics they utilize in determining whether to take their pain medications. Using videotaped, semi-structured interviews, I observed, interviewed and videotaped participants who were experiencing pain, in their homes and with their pain medications at hand. It was hoped that this would allow me to capture the participant's reality of living with pain and the decision-making process they utilize for determining whether to take pain medications. In addition to identifying key thematic elements and heuristics in the decision process, the secondary purpose of the study was to create a DVD that would capture on film a lived, fuller experience of pain in older adults, providing much more information than simply transcribed words.

Conversation and observation of the participants occurred over the course of an in-home, videotaped interview that lasted approximately one hour. In addition to video

taping the conversation, I also took field notes to record my observations of the process and any other relevant data that may not come up in the interview.

A semi-structured interview was selected as it would permit an open ended, free discussion between myself and the participant, giving the participant the opportunity to talk about issues that were relevant to him / her. I also wanted to avoid guiding the subjects, and possibly suggesting ideas that they may not have been considering. During this process, I kept an ear out for key themes and ideas to explore in more depth as the participant allowed.

Procedures

Participants were recruited through agencies and through personal and professional networks. Agencies utilized for recruitment were the Center for Elder Independence (CEI) in Oakland and the Institute on Aging (IOA) in San Francisco, both of which are affiliated with adult day health centers. Management at the adult day health centers identified potential agency participants and the idea of participating in this research was proposed to them by center staff. Those that were interested were told I would contact them, which I did shortly after I received notice from management. In an initial phone interview, potential participants were screened for inclusion / exclusion criteria, and if they met the inclusion criteria, they were offered a $50 incentive for completing the in-person interview. Personal and professional networks were utilized to expand the recruitment effort beyond CEI and IOA and to add more diversity to the study. Through these networks, my contacts were asked to mention my study to friends, neighbors, and colleagues. If these individuals were interested, my contacts advised them to phone or email me directly. The original goal of this study was to interview 6

participants, although, as will be discussed later, a larger sample was recruited. No one in this study was attending a comprehensive pain management clinic.

The particular approach utilized for the interviews was documentary style, focusing on the details of the participant's everyday life that are relevant to his / her experience of pain and the decision-making process regarding whether or not, and how to take pain medications. For the final film, clips were chosen and assembled to highlight the major themes that arose during the interviews.

To minimize the confound of demand characteristics, I assured the participants that I have no affiliation with anyone providing their medical care. I attempted to make it clear that I was here only to record their experience, without judgment.

Criterion-based sampling. Criterion-based sampling was used to select participants who represented a broad cross section of older adults, who are experiencing pain but are still able to live in their own home. Broadly, the research participants were required to meet the following criteria: (a) they experienced the phenomenon under study (pain) as determined by the Brief Pain Inventory (Cleeland, 1991[1]), and (b) they were able to articulate their lived experiences and decision-making processes. As stated earlier, names and contact information for potential participants were provided from CEI and IOA as well as from personal and professional networks. I briefly interviewed the contacts by phone to determine whether they met the inclusion criteria.

Inclusion and exclusion criteria are detailed in Table 2. To meet the inclusion criteria, the older adults needed to be experiencing pain, under care of a physician who has prescribed pain medication (either OTC or prescribed) and inconsistent or not always adherent with their doctor's prescribed medication regimen. The criteria of must be

"home dwelling" and not "living in a nursing home or board and care facility" was important because these are often markers for mental competency and also for independent decision-making regarding medication.

The exclusion criteria of "not a fluent English speaker" was important because I needed to engage people as quickly as possible in a conversation about emotional decisions and my inability to speak another language (as well as inability to find translators) would prevent such a conversation.

Table 2

Inclusion and Exclusion Criteria

Inclusion criteria	Exclusion criteria
Home dwelling	Living in a nursing home or board and care facility
At least 65 years old	Not cognitively competent (difficulty understanding intention of interview, difficulty answering questions)
Cognitively competent enough to complete survey (understand questions / answer appropriately)	Frail health—not able to attend for 30– 45 minutes without stress
Healthy enough to complete an approximately 30–45 minute interview	Not a fluent English speaker
Currently experiencing daily pain (without medication) of at least mild (1-2) to moderate severity (6-7) (as determined by the Brief Pain Inventory, Cleeland, 1991)	Not currently experiencing pain
Currently taking, or recently have taken pain medications—either prescribed or OTC. Participants must also report an inconsistent or variable recent history of taking pain medications	Experiencing pain, but completely adherent with pain medications
Fluent in English	
Willing to be videotaped	
Must be under the care of a physician for treatment of pain	

Gender, work history, education and socioeconomic status were recorded but not used for inclusion / exclusion criteria.

Those individuals who met the inclusion criteria were offered an interview to be conducted in their home. This strategy was chosen to ensure the participants were comfortable and that participation was made easier for them. When I arrived, I encouraged them to avoid distractions (e.g. television off) and to meet individually. However, one participant asked to be interviewed with her husband, and I agreed to conduct the interview with them together.

Phone interviews for screening. Phone interviews for the purpose of screening were conducted with 15 people. The phone interview typically lasted about 15–20 minutes and was utilized as a chance for me to explain the project, to ascertain the individual's pain experience (using the modified BPI), to understand what pain medications they were or were not taking and also to detect any level of cognitive impairment. Of the 4 individuals who did not participate in the in-person interviews, one declined when she realized it was going to be videotaped, another had been experiencing pain several months ago, but the pain had disappeared, one had stopped taking pain medication altogether and another decided she was too busy to be interviewed.

Interview guide. Again, this was a semi-structured interview, which meant that I could use the questions as a guide, rather than a strict protocol. Generally, the interviews focused on the pain experience and their reasons for taking or not taking the medication. The first step was the introduction, where I reminded the participants that the purpose of the study was to better understand the reasons why older adults do and do not take their pain medications, and that I hoped this research would contribute to the study of how best

to manage pain in older adults. I also explained the format for the interview, which was a semi-structured interview, where I would l listen to the participant's story and give them time to talk freely, but also ask a few specific questions. I also explained that there were no right or wrong answers and that there were no pharmaceutical companies or doctors involved in this study. I reminded the participants that the interview would be videotaped. I also reviewed informed consent procedures and expectations regarding confidentiality. The actual interview guide is provided below.

Table 3

Interview Guide

Topic	Discussion Questions
Demographics	Record basic demographic information: age, sex, race, estimate of socioeconomic status, work history and educational history
Begin recording here	
Assess lifestyle	Please describe a typical day for me
Assess current pain	Begin with the open-ended question: "Are you currently experiencing any pain and how are you managing?" If the participant is currently experiencing any pain or has recently experienced a pain episode, ask him / her to rate their daily pain on a scale of 1 to 10. The researcher will also ask if they are currently taking pain medication(s) and if so, how severe their pain would be if they were not taking any pain medications. If the participant describes the pain as mild or moderate, the researcher will continue with the interview. If the participant describes the pain as severe, the researcher will assess whether or not it is ethical to continue. If the participant is not experiencing pain, or has not experienced a pain episode within the past week, the interview will end.
Assess comfort with recording.	Please tell me how it feels, so far, to be videotaped? Do you feel comfortable answering questions this way? Do you think your answers are the same as they would be without the video recorder?
Understanding broader experience of pain	Please tell me more about your experience(s) of pain.
Introduce topic	From our earlier conversation, you told me that when you experience pain, sometimes you take pain

	medication and sometimes you don't. I'd like to talk more about this.
Taking the Medication	What are the circumstances / context? How do you decide? -- Is this how you decided in the past? On a scale of 1 to 10, how big is the potential benefit of the medication? What are your thoughts / emotions when you do take your medication? How do you feel after you decide to take your pain medications, aside from pain relief?
Not taking the medication	When you decide to not take medication: What are the circumstances / context? How do you decide? -- Is this how you decided in the past? -- On a scale of 1 to 10, how important are these reasons? -- What are your thoughts / emotions when you don't take your medication? -- How do you feel after you decide to not take your pain medications? -- Were the risk of side effects or other risks part of your decision? -- If no, please explain. If yes, continue with following questions: What is/are the risk(s)? What thoughts / emotions come to mind when you consider these risks? Where/how did you get this information? Did you seek it out or was it offered to you? On a scale of 1 to 10, how real / big is this risk?
Significant others medications?	What are your thoughts / emotions when you consider this?
Pain medications	Have you ever heard or read any information that conflicts your belief about this risk? If no, continue to significant others. If yes, continue with question below:
Advice to others	What thoughts / emotions come to mind when you consider these ideas?
Experience of interviews	Do you think this interview has changed the way you think about your pain medications?

Videotaping was ended here and then I moved to closing statements, including summarizing the participant's thoughts and offering to discuss her / his experience of the interview and the videotaping. I also explained my next steps—completion of the interviews, summarizing the information and editing the film. Finally, I asked the participant if he / she had any remaining questions.

Early evaluation. In an effort to develop an iterative evaluation process, I conducted two pilot interviews and sent a DVD of these early interviews to a member of my dissertation committee and to several professionals working in the field of older adults and pain. The purpose was to assess the appropriateness of the method and the Interview Guide.

Early feedback indicated that the general recruitment criteria were appropriate as well as the Interview Guide. It was noted that these individuals tended to talk about topics not directly related to the research goals and the film would need to be edited tightly to maintain focus. Other suggestions included capturing more of an individual's emotional experience of pain and to explore more the relationship between pain, lifestyle and medications. Another commented that watching the film did in fact provide a greater understanding of older adults and their pain experience.

Filming. Filming and the in-depth interview were arranged at a day and time convenient for the participant. To conduct the filming, I used a small, consumer-grade digital video camera mounted on a tripod that was positioned next to me. To ensure sound quality, I used a microphone that was placed on a table between us. I periodically checked the camera to verify it was still capturing the audio and video and that I had a good shot of the participant. For the most part though, I ignored the camera, as I wanted

the participant to "imagine" the camera was "gone" in an effort to create a more naturalistic, relaxed atmosphere for the interview.

Editing. After completing the interviews, I had approximately 12 ½ hours of film. Before editing could commence, the film needed to be converted to an iMovie compatible file format. This was accomplished through approximately 50 hours of file conversion. This new file format allowed me to edit the film using iMovie 2007 on my MacBook. As my objective for the finished DVD was approximately 30 minutes, I needed to edit approximately 96% of what I filmed. Generally, what was edited out was content where we strayed off topic (e.g. personal history stories, details about alternatives to pain medications), and repetitive information.

While reviewing the interviews, I realized that themes started to emerge (discussed in more detail in the following section). These themes provided brackets for organizing the film and creating structure.

Results

Participant Recruitment

Initially, it was expected that the bulk of the recruitment would come from CEI and IOA. However, during the recruitment process, it was realized that both these agencies serve a population of older adults, especially in their adult day health centers, who often are cognitively impaired and thus could not participate. In the end, only 3 participants were recruited through either CEI or IOA. The remaining 8 participants were recruited through personal and professional networks.

As noted earlier, the original proposal called for 6 interviews, but I expanded to 11 in an effort to diversify the sample to be more representative of the Bay Area and to

see if different themes emerged. However, as I moved beyond my first 6 interviews, I saw that culture or race was not as great a variable as expected, except as it relates to socioeconomic status (SES). (This impact of SES is discussed in more detail under Discussion.) This final group of participants does reflect more closely a representative sample of the Bay Area population and includes 7 women and 4 men. The majority of the participants were in their late 60's and early 70's, and three were in their early to mid 80's. Of these 11, one is African American, 1 is Brazilian and her husband is Korean (he also participated on camera). Seven of this group are of high income and the remaining four are of average to low income. Among these 11, the sources of pain include: cancer, stroke, arthritis, fibromyalgia, headaches, multiple sclerosis, sciatica, stenosis, spinal injury, bursitis and neuropathy. Pain medications include: carbamazepine, baclofen, ibuprofen, naproxen sodium, aspirin, acetaminophen/aspirin/caffeine, hyrdocodone/acetaminophen, nortriptyline, acetaminophen, acetaminophen with codeine and oxycodone /acetaminophen.

Themes

The free flowing nature of a semi-structured interview yielded 11 different conversations. However, over the course of these interviews, common themes did emerge. These themes are consistent with what has previously been documented in the literature. Those mentioned most frequently are described in the following section.

Fears of addiction. This was the most frequently mentioned concern among this study's participants. Some had a personal or family experience with addictions, others had merely heard or read about the addiction.

For most, the fear of addiction was real and was immutable, regardless of their doctor's assurances regarding their own personal risk of abuse. They noted that although these assurances are given, the risks and dangers are prevalent in these participant's lives and so were salient to them. Of the 11 participants, 3 had a personal history of drug or alcohol addiction, 2 more had children who had a history of drug or alcohol addiction. Of the remaining 6, one was a retired nurse and another had a son who was a nurse. One woman did give consideration as to whether or not it would matter if she was addicted, especially in light of her age and general health (83 years old, multiple sclerosis, heart failure, osteoporosis and sciatic pain).

Too many pills. The problems of needing to take too many pills each day (irrespective of the nature of the pills) was noted by several of the participants and so was included here as its own category. In addition to the pills for pain, everyone I spoke with was also taking some other kind of medication and or supplement. Not all spontaneously mentioned the pill load, but for those who did, the concern was the practical effect and trouble of having to take so many pills as well as concerns about loading their bodies with medication. It is interesting to note that only one individual mentioned concerns around drug-to-drug interactions.

Side effects. The fear of side effects is frequently mentioned in research literature as a concern with pain medications and it did emerge in this study as well. The side effects of the drug as well as its expected efficacy are major considerations in the decision making process of whether or not to take pain medication. Those who described concerns about side effects were speaking primarily about prescription pain medications,

and were clear about what they wanted to avoid. Most common side effects mentioned were dopiness, dizziness / unsteadiness on feet, dryness, headaches and stomach troubles.

Tough choices. It became clear that each individual in this study had their own set of values or rules to live by, that they mapped all their life decisions against. This has been shown in previous qualitative research that reported medication taking as a process where patients balance their concerns about medications (the risks) against their perceived need for the drug and its perceived benefits (Gadkari & McHorney, 2010). The participants in this study often described the same process wherein they struggled to find that perfect balance between pain, the side effects of the drugs, the reduction in pain and the point where they are able to function in life—all according to their set of values.

Taking charge. Many of the participants emphasized the importance of conducting their own research into their pain and their pain medications. Research sources were books, magazines and the internet. Friends and family members as a referral source for information was mentioned three times and in two of the instances, these older adults had children who were nurses. Conducting one's own research has often been discussed in situations where the patient does not trust their physician, and while some of this study's participants did echo this, more often the participants stated that they liked and trusted their physician, but felt they were responsible for their own health and their own decision making.

Trusting the doctor. The subject of physicians naturally came up in this conversation and in fact, being under physician care for pain was one of the inclusion criteria. Most of the study's participants felt they had a positive relationship with their physicians and for those who spoke highly of their doctors noted "he / she listens to me"

as the primary reason they like and trust their doctor. In the research, this factor is often noted as predictive of medication adherence. However, this study shows that all of the participants took their pain medications on a schedule that they determined (which was actually an inclusion criteria), but it is noteworthy that it was always less than prescribed.

When it gets bad. This is the point where the participants in this study took their pain medication. As covered in more detail in the Discussion section, each individual has a threshold the pain must cross before they will take their pain medications. It is interesting to note that it is likely many of them had been advised by their doctors to take their medications (or at least some of them) prophylactically, but no one mentioned this.

More frustration. Taking the pain medications does not just bring relief from pain; for several, it also brings more frustration. For these individuals, taking the pain medications represented a failure or a breakdown in their alternative coping mechanisms and this often led to feelings of loss of control—a significant psychosocial problem for older adults.

Other interesting, but less frequently mentioned themes that have been highlighted in the DVD include:

- Discussion of the differences versus the similarities between psychological and physical pain, which one participant explained as no difference (Psychological versus Physical Pain).
- The very real psychological and physiological benefits of living with family (Family Helps).
- The greatly improved quality of life for those with financial resources to seek out alternative treatments (Having Resources).

- The value of religious faith when facing pain (Jesus).

Table 4

Summary of Themes and Sample Quotes

Thematic category	Sample quotes
Fears of addiction	"I have no desire to take something that could be addicting" "I don't want to be addicted to anything. That's my main objective, the whole cause of this liver cancer is from my past life" "I would feel…not addicted, but I just don't want to feel like I'm dependent on pain medication"
Too many pills	"You hear so often seniors having a collision course with bottles of pills" "I take so much medication anyway…I just don't want to add to the collection"
Side effects	"I've taken and stopped taking because I feel so confused, which I know in old age you can get confused anyway – I feel I'm relatively alert to what is going on in the world and I'm afraid of losing that in a way" "I feel like I'm going to throw up plus my head feels like it's going to bust"
Tough choices	"He said, taking all these pills can probably give you, he stated probably, give you a better shorter life because they might kill you earlier, would you rather have a better shorter life or a lousy longer life?" "So when I take one of these it's like I'm going against my own philosophy, but I'm at the point where I'm so exasperated with the amount of pain I'm in…what's better? Do I stay in pain and feel like shit…or do I take one of these and hope the pain gets better"
Taking charge	"I decided that this was something I had to take care of myself…I just wanted to know what was going on…I have to know what is wrong with me…plus it's just kind of a challenge" "I'm going to go over my medical history for the past say 20 years and try to pinpoint some things"
Trusting the doctor	"My primary care physician…I have great respect for her, I do listen to her, when you see her, she asks you what is going on in

	your life, what are you eating, what are you feeling?" "I think he's full of shit"
When it gets bad	"But I take Vicodin if nothing else helps" "The point is when I feel that sharp pain, then I start getting ready to think about taking it because I don't want it to go into spasm" "Sometimes when I get a bit desperate … I take Tylenol with codeine"
More frustration	"It's emotional because I get exasperated" "Dammit, I've got to take the Tylenol" "Confused, a little angry"
Psychological versus physical pain	"Psychological and real [sic] pain, it's all the same"
Family helps	"It helps living here with family and kids running around to take away the depression" "He told her, you are so worried about your daughter in the states you cannot be cured"
Having resources	"I'll go to Pilates…acupuncture…personal trainer… body work…"
Jesus	"I don't take it because no, I don't need it, I think about Jesus"

The DVD

In addition to the written work completed here, a 30-minute DVD was produced to provide a richer exploration of the experience of pain in older adults. To orient the viewer, the beginning of the film includes clips of all the participants describing their pain. This section is then followed by a majority of the participants naming their pain medications. These introductory segments are followed by the themes as outlined above.

Although a complete transcript of the film is included in the Appendix, much of the individual's experience was communicated nonverbally—through body postures, prosody of language and facial expressions. A sense of who they are as individuals can

be realized through their appearance, manners and surroundings. In several scenes, watching the participants interact with their pain medication is quite enlightening. Although being on camera is not a natural experience, all of the participants, within 15 minutes of beginning the interview, seemed to have forgotten about the camera. In all instances, the participants appeared to enjoy the interview and the process. For some they were happy to have a visitor, and even for those with active social lives, they appreciated the chance to tell their pain story.

Discussion

Emotional Heuristics

The goal of this dissertation was to understand the emotional heuristics that older adults use when choosing whether to take their pain medications. I suspected that risk aversion was the most motivating aspect for older adults in their decision-making process and that emotional heuristics were being utilized to support that position. Furthermore, I speculated that emotional heuristics, while often important, were being used in place of more rational, reality-based strategies to adequately evaluate options. It was expected that the emotional heuristics would be "rules of thumb" that were created by information gathered from various sources (some unreliable) and internalized. What was discovered was that emotional heuristics were very much in use, as they relate to fears of addiction, but not often in other aspects of pain medication taking.

In this complex evaluation process that each participant described prior to taking their pain medications, participants described asking themselves the following questions:

- How long will the pain last?
- How severe will it get?

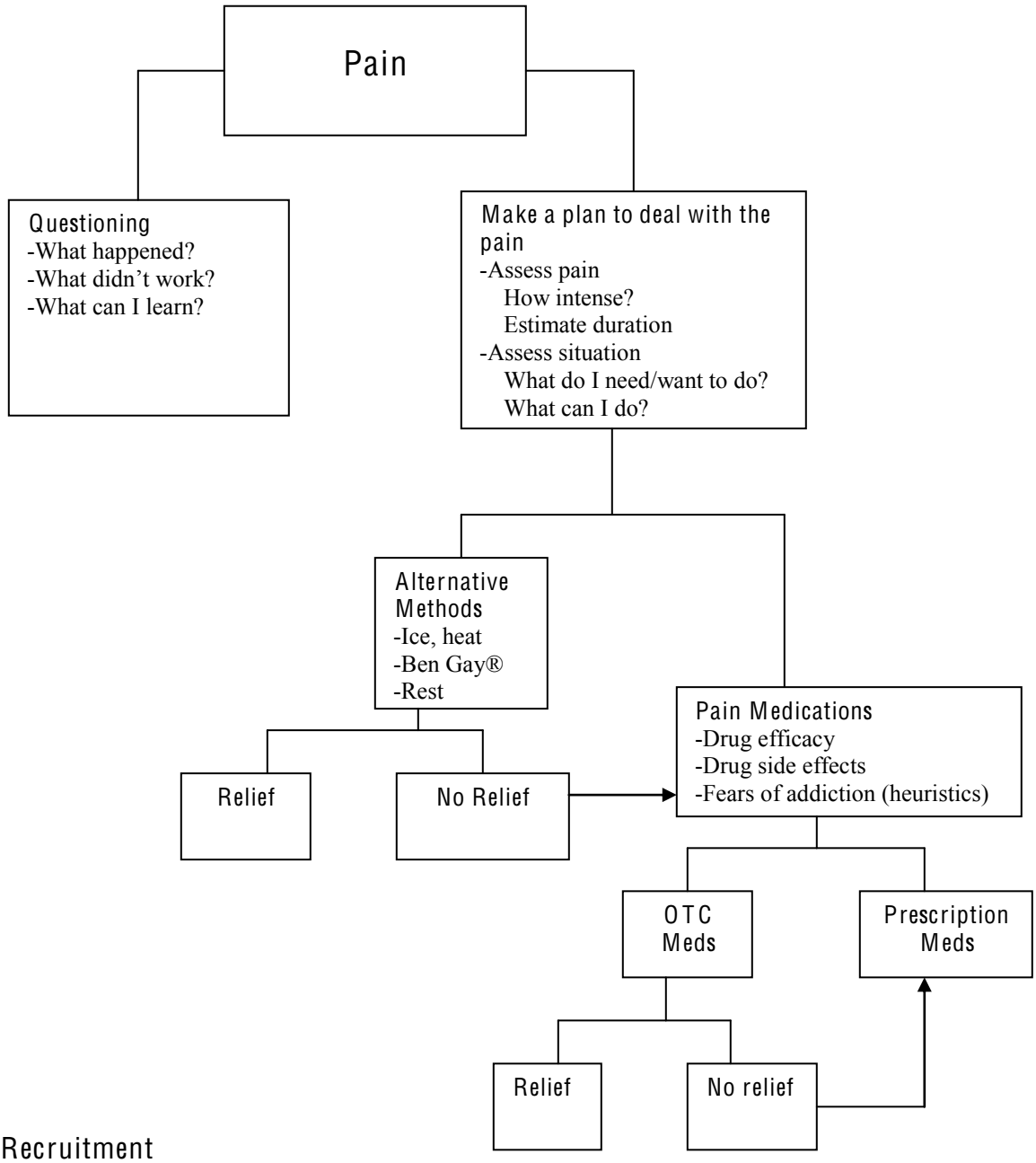
- What activities do I need to do? What activities do I want to do?
- How much will the pain be reduced if I take the medication?
- How long will the pain be reduced if I take the medication?
- What will the side effects be?
- Can I manage the side effects?

The fear of addiction is one significant aspect of the pain management process that exists in the back of the mind for these participants. This concern is always part of the equation, and is considered regardless of their answers to the above questions. As if to validate her concerns, one of the study's participants handed me an article regarding pain medication addiction among seniors.

For those older adults experiencing pain, much of life becomes about not just risk aversion, but pain aversion as well. Not only is the experience of pain uncomfortable, but also the decisions involved to treat the pain are complex, difficult and often come with a price (concerns about side effects) and long term fears (concerns about addiction).

Despite the complex nature of treating pain and the central role pain medications play, it is interesting to note that all of the participants commented that they had never spent so much time or thought so deeply about their pain medications. This suggests it may be valuable for physicians, pain management specialists and psychologists to have a dialogue with their patients specifically on pain medications, to explore in more depth the emotional heuristics connected to the pain medications, in particular, around fears of addiction. Following is a flow diagram to demonstrate this decision process and the complex, multifactorial nature of this evaluation.

Figure 2. Use of Heuristics in Pain Management in Older Adults



Recruitment

Both the difficulty and ease of recruitment was unexpected. It was expected that recruitment through CEI and IOA would be easier and yield a broader, more culturally diversified group of individuals. However, recruitment through both of these agencies was through their adult day health centers, which serve a large number of adults with

significant health problems, including dementia. Although the agencies were supportive in their efforts to identify potential subjects, they found it challenging to identify individuals who could meet this study's criteria—especially the criteria requiring home dwelling, not-cognitively impaired participants.

At the other extreme, one group I contacted, Ross Valley Seniors (a relatively affluent, mostly Caucasian group), yielded so many interested participants I could not interview everyone. In addition to the this group's health being generally better than the health of those at CEI or IOA, another factor that likely led to this group's interest in participating is that I attended one of their meetings and this gave the members a chance to see what kind of person I was and to meet me—thus reducing any potential fear they may have about allowing a stranger into their home.

Through all the recruitment efforts, it was extremely difficult to recruit non-Caucasians. At CEI and IOA, there were African Americans interested in speaking with me, but one could not schedule our meeting without the assistance of his sister, whom I was never able to connect after several attempts, and another gentleman had such a serious speech impediment that he could only offer "yes" or "no" responses. As for my personal and professional networks, I believe this speaks to the paucity of non-Caucasians living in Marin County and to my networks being limited to Marin County. When I contacted agencies serving African American and Hispanics in Marin County, the agency directors were welcoming and their members friendly, however, no one was interested in participating. When I commented on this to one of the agency directors, she said it was probably because "our people don't usually like to go outside of our community." This certainly makes sense as I was someone who was an unknown and

although I was offering $50 cash, I would be walking into his or her home and asking personal questions.

I believe that a more culturally diverse sample could have been drawn if the interviews had occurred at an outside location, such as in an office in a clinic. However, the way in which people hold and express themselves is quite different in an office versus their own home, and one of the intents of this study was to understand the experience of the older adult as lived and experienced in their home.

In the future, relying more on personal referrals may draw a more culturally diverse sample, but it would take much more time and require more extensive networking. It did appear that individuals were more open to meeting with me if they had a close friend or family member encourage them to talk with me. This third party endorsement let them know that I was the kind of person with whom they could feel safe.

Reflections on Use of Video

This study is unique in its methodology in that it adds a deeper understanding of the phenomenon being studied by using film. In discussion, the decision-making themes that arose were very often themes that have been mentioned elsewhere in the literature. However, what a transcript and summary tables cannot capture, is captured in the film. The result of this work is a presentation on the details of the themes and an opportunity for others to understand the gestalt, or the whole, of older adults' experience of living with pain.

The limitation to the filming was, of course, that I lost a participant who was not willing to be filmed, and the process of filming required a period of acclimating to the

procedure. In addition, it's possible the participants may have unwittingly behaved differently simply by the fact that they were being videotaped.

Difficulty Staying on Topic

Generally, it was very difficult to keep people on target talking about their pain medications as opposed to their pain experience in general. One benefit of the flexibility of a semi-structured interview guide was the opportunity to follow people down a particular path to help build rapport and to see what their story might yield. I believe this wandering narrative occurred because the experience of pain is so overwhelming and for many it touches on so many aspects of their lives. It is assumed that most practitioners and loved ones would not have the time or interest in airing this narrative to the same degree as permitted in my interviews. I am quite sure that all of the participants could have spent more time just talking about their pain experience. However, in spite of my gentle redirections, all the participants appeared to enjoy the interview and the process.

Emotional Pain

The most remarkable experience of this project was the frequency with which participants shared extremely painful emotional stories—"my father was also my grandfather," "my daughter died four years ago," "my son was addicted to drugs," "I haven't talked to my children in three years," "my wife died 7 years ago," "I spent my early years in a series of foster homes." This was even more surprising because in each initial conversation, I was clear that the purpose of this study was to explore their perceptions of their pain medications. However, during the course of the interviews, it became clear that a conversation about pain medications needed to include a discussion

of *pain* and a discussion about pain was fluidly, interchangeably a conversation about physiological *and* psychological pain.

Pain and Aging

For all participants, the experience of pain and their pain medications represented "old age"—a period marked by losses and diminished abilities. The mere existence of pain medications was another reminder that there were forces controlling them that were beyond their control. Thus, when individuals were faced with the dilemma of having to choose between experiencing pain or taking their pain medication, they often became frustrated, angry, and depressed. As for adaptation to life with chronic pain, all participants had accepted (some more readily than others) that chronic pain was a part of their lives. Those who more readily accepted pain as part of their lives were those who were older—in their early to mid 80s. For all, their activities and pain medication utilization was titrated to find a perfect balance between the lowest dosage of pain medications and an acceptable level of pain.

Values

Another key observation from the field was that everyone I interviewed had a set of values they used to manage their health care (and their lives in general). For some, these values were immutable, for others, there was some flexibility. From these values, they developed points of view regarding their pain and their pain medications—what it means to live with pain, how much pain they are willing to accept and what they are willing to compromise. For most, this was an evolving process that utilized a set of pros and cons (e.g. "if I take the pain medication, I'll feel better, but then I'm unsteady on my

feet"), with some feeling even more frustrated by the fact that taking their pain medications represented going against their own best interests.

Self Concept

The idea of self concept, in relation to pain medications, was mentioned by one of the study's participants. In discussing her fears of addiction, she stated, "I'm a kind of person that doesn't want to take pain medication, if I don't have to." Although this was a comment from just one of the participants, it is emblematic of a concern older adults have regarding the use of pain medications. For some, they believe that taking even OTC pain medications is representative of a kind of person that they are not. For others, taking prescription pain medications is something only "drug addicts" take and this is absolutely against their own self views.

Impact of Socioeconomic Status

Another major observation occurred around socioeconomic status (SES). Through the interviews, I talked with people across a broad spectrum of income and education. One woman I interviewed lived in East Oakland and could no longer exercise because her neighborhood had become too dangerous. Another woman lived in San Francisco with sweeping views of both bridges and had recently completed a major hike in Bhutan. One of the participants had only completed 8th grade while another was a retired lawyer. Although everyone I spoke with wanted to avoid taking their pain medication (or take a minimum amount), the striking differences were in their nonpharmacological strategies. Those of lower SES utilized ice and Ben Gay ®, while those of higher SES utilized exercise, personal trainers, acupuncture, massage, supplements, herbal remedies. Thus, those of a higher SES (at least in this sample) were

able to keep the experience of pain at a more manageable level and then, if necessary, could take OTC pain medications to manage. Those of lower SES had alternative mechanisms that did not seem to avert the pain as effectively and thus were more likely to take OTC or prescription pain medications.

Losses

For all of the older adults I interviewed, the pain never completely goes away. Taking the pain medications lessened the pain, which resulted in an increase in activities, and a greater enjoyment of life. However, these positive feelings were often muted by the frustration and anger experienced by having to take these medications. It is these feelings of having to take medication and the inability to do what one wants to do that contribute most significantly to feelings of loss—loss of pleasurable activities and loss of control.

Pain Guidelines Were Being Followed

In all cases, it appeared that participants were being treated for their pain using protocols consistent with those suggested by the American Geriatric Society (2002, 2009). This consisted of a combination of pharmacological and nonpharmacological treatments with the pharmacological treatments starting with OTC medications. For all, their pain medications were prescribed with careful consideration of other comorbid health issues.

Alternative Methods of Managing Pain

Everyone I interviewed attempted to manage their pain with other methods before taking their pain medications. As noted earlier, the range of alternative methods was broader among those participants with greater financial resources. Some of these

research participants also focused on prayer, distraction and a few utilized acceptance as a conscious strategy.

Not Taking the Medications as Prescribed

Again, this research supports earlier findings that older adults often do not take their pain medications as prescribed. Every participant admitted to taking the pain medication on a schedule that worked for him or her. Again, this schedule was created with a great amount of consideration, but it was not exactly to what the doctor had prescribed.

Implications for Treatment of Pain by Physicians

One of the major findings from this study is the unique and highly individualistic experience of managing pain. It is well known among pain professionals that each individual experiences pain differently (intensity, frequency, duration), but what may not be as well known is the complex process each individual utilizes to manage their pain.

This study suggests that patient care may be improved if physicians and pain management specialists have a conversation with their patients about their pain medications—specifically to explore the emotional heuristics connected to the pain medications, in particular, around fears of addiction. Physicians and pain management specialists may find better adherence among their patients when they focus more on reassuring their patients about the safety of the medications, rather than focusing on the benefits. Following this conversation, pain professionals should discuss the possible prophylactic effects of taking the medication on a consistent schedule, how to titrate their medications (if appropriate) and exploring the use of alternative methods, with a consideration to the individual's income and access to other services. The process of

reviewing the prescription instructions with the patient should be made explicit, ensuring that the patient understands the directions as well as understanding the importance of taking the medication at the start of a "breakthrough" of the pain. This dialogue can provide important information to the patient and can be used in their formulation for deciding whether or not to take their medications. Physicians and pain management specialists may also improve patient adherence to pain medications by encouraging their patients to call to discuss their hesitations or questions. In conjunction, patients may benefit from a flyer (that they can take home to review), which states the common fears and around pain medications and provides explanations to help alleviate the patient's fears or concerns.

Another important suggestion for professionals working with older adults who use pain medications is to understand that although there are older adults abusing pain medications, there are a greater number who are not abusing the drugs and in many instances are under treating their pain. Holding this understanding may shift views among some physicians in how they conceptualize and approach pain management in older adults.

Finally, since the experiences of pain and pain management are complex, physicians can realize improved pain management in their patients by working collaboratively with psychologists who are trained to work with issues around resistance to help their patients manage the myriad of psychosocial issues related to pain and its management.

Implications for Psychological Interventions with this Population

As noted above, psychologists can (and have) worked collaboratively with physicians and pain management specialists to help patients improve their pain management and thus changing their pain experience. There are a wide number of cognitive and behavioral interventions that have been successfully used for years, but what this study brings to light are primarily two important considerations.

The first is the value of allowing an individual to have the time and space to speak openly and honestly about their pain experiences—physical and emotional. It is clear that the two are intimately connected and the process of talk therapy will open up the individual's experiences which will be transformed just on the experience of bringing their thoughts and feelings from the unconscious to the conscious and also from the empathic witnessing by another human being. This was experienced many times by the participants in the study who frequently commented that no one had ever talked with them, in any depth, about their pain medication and their strategies for managing their pain, and it became clear that my listening validated their feelings and strategies.

The second is the importance of working with patients to help them develop a pain management strategy that supports their values and life goals. Working with a psychologist who has a knowledge of pain medications, patients can develop a pain management plan that is more closely aligned to their deeper needs within a framework that is medically sound and practical. This discussion should also include an exploration of the possible heuristics (emotional and others) the patient may be employing when considering taking their pain medications. Opening up a conversation about the interconnectedness between pain and depression and the role heuristics play in decision

making, may help patients recognize their own needs more clearly and evaluate the risks more accurately.

Use of the DVD as a Training Tool

The primary benefit of the DVD is that it provides a glimpse into the natural, in-home, lived experience of older adults, their pain and their pain medications. From this, professionals working with older adults on issues of pain and pain management can learn several important lessons. The first is the process older adults use to determine whether to take their pain medications and the emotional consequences experienced from taking their pain medications. The second is the wide variety of pain medication management / organization tools utilized. Some participants were quite organized and knowledgeable about their pain medications while others were disorganized at best with little knowledge of their medications.

Lastly, and perhaps most importantly, the DVD can be used to help stimulate thought and conversation among health care practitioners who work with older adults around issues of pain. In particular, it can be used to discuss preconceived notions and biases and help provide an emotional understanding of pain in older adults. Pain is very much an emotional experience and the more health care professionals can understand this, the more compassionate, as well as effective, they can become.

Final Conclusions

The experience of pain in older adulthood is highly prevalent and is a significant factor in decreased quality of life. Managing one's pain is no simple task. It involves a process that taxes all of one's resources—the mental challenges of understanding the

physiology of the pain, learning about pain treatment options as well as managing one's emotional state. It is understandable that older adults will use heuristics.

The most notable themes that emerged from this project were the fears of addiction and the process of balancing the side effects of pain medications with life goals and values. It is clear that each individual develops a map for how they want to live their lives and no one desires to experience pain to such an extent that it compromises the things they would like to do in life. Thus, older age involves a process of evaluating your choices and when you have to give up a choice, those who are able to age successfully are those who can find a suitable replacement. This complex process is unique to each individual, and for everyone it varies from day-to-day and even from moment-to-moment, creating a constantly flowing evaluation of options. Thus, those with the most resources (financial, social) and the greatest cognitive abilities will be more successful at navigating this terrain. Furthermore, it suggests that nonadherence is more than a simple story about whether someone is a good or bad patient, but rather is a highly unique and evolving story.

Although this research is limited in it is breadth of cultural diversity and number of participants, preliminary hypotheses can be drawn around race and ethnicity, as they tend to follow SES. The possibility of this correlation can be found in Delaney, Biggs, Kronmal and Psaty's 2010 study that suggests that OTC aspirin may be utilized differently in some sub-populations or among different ethnic groups and that some behavioral factors, such as higher levels of intentional exercise and rates of health insurance coverage were higher among OTC non steroidal anti-inflammatory drugs NSAID users as compared to prescription NSAID users. Prescription NSAID use also

correlated with higher uses of prescription medications and with less than high school education and low income (Delaney et al., 2010).

In conclusion, although this study did not identify new themes around medication use, it does bring these themes to life, expands on them and highlights the tough choices older adults face and the emotional heuristics they use. As researchers it is often easy to read statistics and draw conclusions, but what became apparent when reviewing the film, was that there is so much more to learn by understanding the emotional experience of being an older adult, experiencing pain and taking (or not taking) pain medication.

Suggestions for Further Research

In conducting a new, updated literature review, almost two years after my proposal was approved, it was remarkable to witness the increase of articles on the subjects of "pain" and "older adults." For example, conducting a PsychInfo search on "older adults" and "pain," appearing in the title, for *all the years* prior to July 2010, yielded 146 articles. A similar search for the period of July 2010 to 2012 yielded 65 articles, nearly half the amount in less than two years. This reflects a growing interest and awareness of the pain experiences of older adults and the complexities with treating them.

Among this recent research, there was nothing that would challenge this report's findings. Rather, the research supported the phenomenological findings of this study and provided more detailed understanding of these phenomena. For example, the Pokela, Bell, Lihavainen, Sulkava, and Hartikainen (2010) article on analgesic use, focused on older adults aged 75 years and older, acknowledging the differences between "younger" older adults and "older" older adults.

In a similar vein, the process of completing this research has opened up several questions that may be worth further exploration in an effort to better understand (and ultimately to treat) pain in older adults. One such area is the intersection between emotional pain and physical pain, which is often difficult for many individuals to differentiate. Certainly both pain experiences are processed through the same brain centers and do impact one another, but it may be worthwhile to research more deeply if there are advantages or disadvantages to distinguishing between emotional pain and physical pain.

Another area of research that deserves consideration is the validity and cost effectiveness of providing custom pain management assessment and treatment programs. This research found that each individual not only has a unique pain experience, but they also have their own perspective on how they would like to manage their pain. Although there are obvious cost implications for our health care system, it may be possible to develop such a program cost-effectively by incorporating psychological interventions into in a primary care setting.

Building on this study's work, a broader, larger study of older adults' perspectives on pain medications may be valuable to understand the larger societal and health care impacts. To underscore the importance of this understanding, every participant in this study mentioned that they had never spent so much time thinking or talking about their pain medications, yet acknowledged that their pain and their pain medications had a significant impact on their lives.

Lastly, I believe it would be beneficial to develop a comprehensive pain management program for lower-income older adults. Having access to the benefits from

nonpharmacological interventions (e.g. exercise, physical therapy, acupuncture, massage) that wealthier, older adults were able to utilize may help lower-income older adults manage their pain more effectively.

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Footnotes

[1]

Appendix A

Brief Pain Inventory – Short Form

Modified Brief Pain Inventory

Date: ____ /_____ / _____ Name:_____

Phone Administration

1. Please rate your pain by assigning a number that best describes your pain at its worst in the last 24 hours.

0 1 2 3 4 5 6 7 8 9 10
No Pain Pain as bad as you can imagine

2. Please rate your pain by assigning a number that best describes your pain at its least in the last 24 hours.

0 1 2 3 4 5 6 7 8 9 10
No Pain Pain as bad as you can imagine

3. Please rate your pain by assigning a number that best describes your pain on the average.

0 1 2 3 4 5 6 7 8 9 10
No Pain Pain as bad as you can imagine

4. Please rate your pain by assigning a number that tells how much pain you have right now.

0 1 2 3 4 5 6 7 8 9 10
No Pain Pain as bad as you can imagine

5. Please indicate the number that describes how, during the past 24 hours, pain has interfered with your:

A. General Activity

0 1 2 3 4 5 6 7 8 9 10
Does not Completely
Interfere Interferes

B. Mood

0 1 2 3 4 5 6 7 8 9 10
Does not Completely
Interfere Interferes

C. Walking Ability

0	1	2	3	4	5	6	7	8	9	10
Does not Interfere										Completely Interferes

D. Normal Work (includes both work outside the home and housework)

0	1	2	3	4	5	6	7	8	9	10
Does not Interfere										Completely Interferes

E. Relations with other people

0	1	2	3	4	5	6	7	8	9	10
Does not Interfere										Completely Interferes

F. Sleep

0	1	2	3	4	5	6	7	8	9	10
Does not Interfere										Completely Interferes

G. Enjoyment of life

0	1	2	3	4	5	6	7	8	9	10
Does not Interfere										Completely Interferes

Appendix B

Consent Form

You are invited to participate in a study conducted by Deborah Nelson as part of her degree requirements. Through my research, I hope to gain a better understanding of older adults and their pain experience, and ultimately to contribute to searching for better and more effective treatments. You were selected as a possible participant in this study because you met our initial criteria and indicated an interest in participating when speaking with Ms. Nelson. Please read this form carefully and ask any questions you may have.

If you decide to participate, Ms. Nelson will outline the format for the interview prior to beginning. The interview is expected to last about 1 hour and all efforts, including taking breaks if you wish, effort will be made to ensure your comfort. If, at any time, you choose to withdraw from this research, you may do so simply by stating your desire to withdraw. Your decision whether or not to participate will not prejudice your future relations with your doctor, nurses or any other medical / care provider, including [Center for Elders Independence or Institute on Aging].

There may be risks associated with your participation. The most likely risk is an increased emotional or physical response to your pain. If this is your experience, you will be referred to a licensed therapist for a single consultation at no cost to you. There are also possible benefits which include: feelings of well-being that may come from sharing your experience of pain as well as an increased awareness and understanding of your own pain experience.

By signing this consent form, you are also agreeing to have the interview videotaped. Although you may be recognizable from your image, your name and address will not be revealed and will be kept confidential. Any information that is obtained in connection with this study and can be identified with you will remain confidential and will be disclosed only with your permission or as required by law – specifically if it is determined that you may be at risk of harming yourself and / or others and / or if there are signs of neglect or elder abuse.

You will receive token of appreciation of $50 if you participate fully in the interview and sign this release. There are not costs to you for participating in this research.

If you have any questions, please feel free to ask Ms. Nelson at (415) 419-1159 or her research advisor Diane Zelman, PhD at 415-955-2123 or contact Alliant International University's Institutional Review Board at 1 Beach Street, Suite 100, San Francisco, CA 94133; irb-sf@alliant.edu; or (415) 955-2151.

This consent form will be kept by Ms. Nelson for at least three years beyond the end of the study and was approved by Alliant International University's Institutional Review Board on April 26, 2011.

YOU ARE MAKING A DECISION WHETHER OR NOT TO PARTICIPATE. YOUR SIGNATURE INDICATES THAT YOU HAVE DECIDED TO PARTICIPATE, HAVING READ THE INFORMATION PROVIDED ABOVE.

Statement of Consent: I have read the above information, and have received answers to any questions I asked. I consent to take part in the study.

_____ I have received a copy of this consent form for my records.

_____ I would like to receive a letter summarizing the findings of this research once it is complete.

_____ _____

Signature Date

_____

Printed Name

Appendix C

Film Transcript

OLDER ADULT VERSUS PAIN MEDICATIONS

THE PAIN

M4: well, my pain, it has to do with uh uh my liver, I have uh tumors in the liver

F2: I couldn't even pick up my arm, bursitis

DN: oh yeah

F2: it was like I could not move my arm at all, it was like a frozen piece of meat, you touch it like that and it was painful all the way to the back

F1: right now you know its just when I move a little bit, so I'll say a 2, you know

F6: my head is heavy I cannot think clearly I think because the headache is like this -- because she is suffering for such a long time, the normal situation is with some pain and it is very depressing especially because we here are in this strange country and then, it becomes worse

F6: I have bone spurs on the right side of my lower spine and bone spurs on the right side of my neck, a certain motion, like that and it will be like, like a cattle prod and it will be just a shocking pain right there where the inflammation was and so that's when I know I'll have to be careful but then I'm always stiff, I have osteoarthritis, you can see that in my hands, I've had that for 30, 30 years

F4: probably the chief reason for taking is sciatic which I have now, it goes down my right leg, it gets, without moving around a bit it gets worse

M1: See I had an accident in 1972, at work, I was flipped off the top of a freight car and when I landed down on my feet, my spine went like this and I was paralyzed from the waist down

DN: So, you've been experiencing pain since 1972?

M1: Oh yes ma'm

F5: I would be very depressed if I had to go on in the kind of pain and the pain was not anything I'd ever heard of before, I really had the feeling like I was being crushed like between two doors -- shocks from the base of your neck, head, down through your spine and then radiates through your body, it's really quite -- unlivable

M3: It's called a death causing syndrome because without medication people were killing themselves -- I mean it can get really nasty – where I wouldn't want to spend a day

F3: the hip, the knee, I feel like I need some kind of brace, an elastic something around here, its just those areas, the joints, it's the arthritis probably, he said it is coming from the back, and so the back is always just a little bit, um sore

M2: well anyway I have all these things that cause pain anyway, arthritis and stenosis, and you know, I'm shorter than I used to be when I was younger by about 2 inches

DN: oh that's quite a bit -- and then you have sciatic, right?

M2: well, then I started noticing that this leg, you know my butt and my leg is really really painful and the pain isn't just the sciatic, it is really pretty much on my left side, this hand, like even right now its uncomfortable, my feet are really sensitive to cold

THE PAIN MEDICATIONS

F2: this is the way they bring the medication

DN: and is that a week's worth?

F2: A week. They used to bring it in every Thursday, they used to have in on Friday, but I guess they have their own rules. This is what you have to start on. I start tomorrow,

Friday, and I take the night time that's for the pain, that's the one I take, because I only get one a day for the pain

DN: and that's the Vicodin?

F2: yes

DN: OK, so you take the Vicodin every night?

F2: No, no, no. I do not take the Vicodin unless I really need it

F4: That is when, not every night, but probably most nights and I do end up taking Tylenol w/codeine -- and that is really the only regular pain medication I ever take

M4: I take ibuprofen and Aleve, I'm weaning myself off the main pain pills that the doctor gave me

DN: and what were those?

M4: um, that was, geez, a form of uh, I don't really wanna, just throw out a name at you, but it's a mild pain pill sedative that they gave me

DN: do you still have it?

M4: yeah

DN: did the Endocet take away all the pain?

M4: well, it never takes all of it

F5: During the worst times I would take like 6 of these a day (Excedrin), and I'm down to maybe like 1, maybe a half, occasionally none, and this is an arthritis thing (Aleve)

M2: OK, I don't like to take Tylenol if I've had anything to drink, any alcohol

DN: because of?

M2: because of the synergistic effects of the alcohol with an NSAID, so I have these aspirins, I think that the research or the jury is still out on aspirin on how much is good

for you, but clearly a little bit is good for everybody, you read 81 mgs, whatever it is, so I'll take this like if I get up in the morning and I had a bad night sleeping and I'm sitting here and I'm drinking coffee and I'm just like, you know, it's not going away so I'll take this (aspirin) and I've also noticed that instead of taking the aspirin, that once in awhile I'll take this (Aleve) during the day, one, not two and not days in a row and I've noticed that it is pretty effective after a couple of hours

M2: so that's when he gave me this nortirptiline

F3: Vicodin?

DN: how many mgs do you know? Usually it says

F3: they all do, yeah, predinosone for flair ups -- I never took medicine before -- methotrexate , we did that one, where is the Vicodin? Here it is

M3: I'm a walking commercial for Kaiser

DN: Well I'm glad you had such a positive experience, for sure

M3: Well people say they have problems…well they do have problems with everything, OK

M1: then the pain is gone, so I have no need for it, but I have a few more tablets in there just in case of I needed them, because you know when the medication is ordered for you it takes a couple of weeks before you get 'em, usually they say 5 to 7 days, for me it's 7 to 10 days

DN: this is through the VA system?

M1: yeah

DN: So what if it's something, if you're in excruciating pain right at that moment, do you have to wait 2 weeks to get something?

M1: oh yeah

MAJOR THEMES

FEARS OF ADDICTION

F4: so I don't know, I'm just the kind of person I don't want to take pain medication if I don't have to, for some reason because I just don't want to make a habit of it

DN: because if you made a habit of it, it would mean ?

F4: I would feel, like I said, not addicted, I just don't want to feel like I'm dependent on pain medication, if I can avoid it

DN: what would it mean to you if you were dependent on pain medication?

F4: I just, I don't know why, I suppose would it matter if I were dependent on it? I just feel that I'm better off trying to find an alternative way of getting rid of the pain, if I can. I don't know why, what would it matter if I were addicted, really?

F6: I have no desire to take something that I think could be addictive

F5: but I don't really want to get started on anything that might, I've never had that problem, so I don't even want to get started on that if I don't have to, I think maybe once I took some codeine for when I had a tooth pulled, oh its just, it just that I hear on the radio about Rush Limbaugh and all these people who have all the power to have all they want and

M4: because I don't wanna take these for any length of time (pointing at the Endocet)

DN: because?

M4: because I don't want to be addicted to anything. That's my main objective ah, the whole cause of this liver cancer is from my past life and I've had a colorful past

DN: OK – you've lived a full life

M4: yes, so I know all about what pain pills is all about and I don't wanna take these too long -- I would rather live with the ibuprofen and the Aleve

F2: I read so much about it and saw so many people that are addicted to to medication, even older people, they get

DN: Do you know people who have gotten addicted?

F2: Yes I've heard of some people, I know some who I've talked to and they get up in the morning and say I've got a headache, I'm gonna take my Vicodin, my feet are hurting, I'm gonna take some Vicodin, it seems like they're looking for different parts of pain for the Vicodin

F3: and I knew Vicodin was something that you could be addicted to and I've been told very carefully, or very seriously that I don't have that problem and I'm telling you the truth I don't have that problem, but my son has gotten into drugs and alcohol

M1: well then I had to go to the hospital and I got the Vicodin, but like I told you before I don't like to get involved with that too much, I don't want to get used to it

DN: what do you mean get used to it?

M1: well it's narcotic

TOO MANY PILLS

M3: well is that it? Tegretol, baclofen, yeah, that's it, now see when I first stated I was taking 6, 10, 16 a day, and now I've got in down to, not counting the warfarin, now I got it town to 2, 4, 10 I take the baclofen 3 times a day and I'm going to start cutting that down

F4: I take so much medication anyway which is mostly related to my heart, beta blockers and various things, that I just don't want to add to the collection

F6: I'm close to being 69 years old I don't want to start having these meds, I take so many supplements, I have to take these meds for the heart, I don't want to add anything to that

DN: so there's two things, one of which is the fear of addiction and the other is just the pill load

F6: yeah, yeah, I mean you hear so often seniors having a collision course with the bottles of pills

SIDE EFFECTS

M2: well because I was having so many side effects especially the dryness you know and the headaches um that I started tapering off

F4: I felt more confused, of which I know in old age you get confused anyway but I feel like I'm relatively alert to what is going on in the world but I'm afraid of losing that, in a way

F2: its my whole body, but it really, I feel like, like I try to eat something very lightly because I feel like I'm going to throw up plus my head feels like it's just going to bust

DN: from the Vicodin?

F2: yes

F6: I take as little Tylenol as possible because its hard on your stomach

TOUGH CHOICES

F5: if I had to, I would do that , that's more important than upholding any kind of morality or whatever it is, no the first thing is that you gotta be a real person and if that does it, then I would hope then to never, you know, over do it, but taking the pain medication would be something I would do if it were necessary

DN: to support your larger values?

F5: yes, absolutely

M4: I know that my whole concept with taking this was that I take half a dose which is one pill, I take one in the morning and one in the evening and that's gotta work

DN: because?

M4: because I wanna stay in my right frame of mind. I want to be able to deal with life on life's terms, through the day, I don't want to be in no dopy you know, lay down state where I can't move, I don't wanna get up, I don't want nobody to talk to me because that's what that will do to you

DN: well you know, to play the devil's advocate, you would save a lot of time if you just took the Vicodin

F5: well I know but then I would probably trip

M2: so when I take one of these, it's like I'm going against my own philosophy, but I'm at the point where I'm so exasperated with the amount of pain I'm in, it's like OK, well alright, what's better? Do I stay in pain and feel like shit, excuse me, or do I take one of these and hope the pain gets better and then hope also that I'm watching other parts of my health sufficiently that whatever bad, negative impacts it has, I'm off setting with healthy ones

F4: well sometimes it's I've got something very important to do tomorrow, I've got to be in better shape, I've got to get some sleep, it's mostly to help me to sleep, and then I'll take some because I know I've got to get going tomorrow -- some appointment or something

M3: so the doctor at the health club I work out with, he said well taking all these pills, can give you probably a better, he stated probably, a better shorter life because they might kill you -- but you have a better shorter life than a lousy longer life

TAKING CHARGE

F5: I decided that this was something I had to take care of myself, that's when I got Doctor Pelligrino's book, it was just by accident, I went on the internet and said these are my symptoms what is this and little by little, I got down to exactly what I got and I then I ordered this book and he really saved my life

DN: Did you go to the doctor right away?

F5: I think about, no I didn't, I wanted to research it myself, I wanted to know what was going on and you know doctors can give you a lot of tests and they can't come up with any answers and I can't blame them if they can't tell me what's wrong with me, I have to know what's wrong with me, I mean, I take responsibility for what is wrong with me because they didn't cause it I did, so I want to find out, you know back track, find out where it all started, plus its all kind of a challenge

F3: I go seeking out answers and I'm trying to find out

F2: whenever I get any new medication

DN: oh you're very serious about getting your own information, good for you

F2: see this is all for prescription drugs, that I read, this comes back to the Vicodin, all of these are drugs that are good in one way and bad in another (shows "The Pill Book" and "PDR: Pocket Guide to Prescription Drugs")

M3: from my reading and that, my research that, I mean putting a pill like this in your body, is definitely not a natural thing

M2: I'm going to go over my medical history for the past say 20 years and kind of pinpoint some things

TRUSTING THE DOCTOR

F7: but I'm scared to go to doctor because it is a bothering for him, but I feel if I have a doctor who is so friendly and concerned, I think very nice

F6: my primary care physician, she's a woman and I have great respect for her, she's, I do listen to her, when you see her she asks you what is going on in your life, what are you eating? What are you feeling?

M4: when we first met I initiated our relationship on a first name basis -- he's somewhat of a friend of mine now

F2: I trust him that much I know, but I do want for my own

F5: her struggle with her doctor I finally changed doctors because he was an idiot, he would give her six pain pills for the month and she would break them into little pieces, so that, I mean she's 86 what's she gonna do, rob a bank?

M1: if the doctor gives you OK to take that, go ahead, but I wouldn't, I wouldn't take anything on my own, that's what doctors are for you know. If you're ill, you go see a doctor, right?

M2: with me to see him, I'm gonna say look what's the deal and I'm gonna want him to show me studies, some kind of academic, you know basis for his use of this

F3: I would listen to, I will do what the doctor tells me, obviously

M3: I think he's full of shit…

WHEN IT GETS BAD

F6: well the point is when I feel that, like that sharp pain, then I start getting ready to think about taking it because I don't want it to go into spasm

F4: its usually an hour or two, sometimes three hours before I've gone to sleep and that's sometimes when I get a bit desperate and I take a Tylenol with codeine because it does have the effect of helping me to sleep as well as making you more comfortable, I think

F5: I was taking this and I noticed that it helped a lot (Aleve) so if I look like I'm going to have a really bad night and I've already got aches going and a busy day, I'll take one of these and I'll sleep through the night

M1: no, I don't take nothing if nobody's here

DN: oh, OK, so you won't even take an Aleve?

M1: No. Aleve, I enjoy taking them, well I shouldn't say I enjoy taking them, it was surprising to think that it's relieving a little pain for me

F2: but I take Vicodin if nothing else helps

F3: if it's really hurting then I take one Vicodin and um then I go lay down on my wedge and that really helps and I usually take a little nap

F1: well that time I was feeling you know the pain was uncomfortable, so I decided OK, I'm gonna take that, it was two pills about every four hours, so, you know I went along with that, but when the pain decreased, I said no, I can get by without, and so just this medicine I take because its for anxiety, nerves and -- that

MORE FRUSTRATION

F6: damnit I've got to take the Tylenol

DN: what's the goddammit about?

F6: well yeah, it's about whether I exercised or did the Pilates that day, or the day before it's like dammit, it should have held longer, the fix should have held longer

F4: I'm just desperate to go to sleep, emotionally I get fed up being wide awake

M2: it is emotional because I get exasperated and while I know that the Western medical, well at least the American medical profession is really about selling medications more than anything else, by and large, I don't think I've ever had a conversation with an internist who said, you know, get out and walk

F2: confused, a little angry I think but I think more confused , because I can't go back to doing what I'm doing, I'm always, I think for everyone who is getting older, you're always thinking, it helped today I don't know if its going to be worse tomorrow.

OTHER PERSPECTIVES

PSYCHOLOGICAL VERSUS PHYSICAL PAIN

DN: does the experience of pain impact your ability to be present?

M4: it does, it takes you away from being real because all your mind is on, is on the pain, that's what I used to do in my old days was we took stuff to not be real, to get rid of the pain of the world

DN: psychological pain or physical pain?

M4: psychological and real pain, its the same, it's the same

DN: it is, yes

M4: we took stuff like this to get rid of the pain, so I don't need a whole lot of that to get rid of the physical pain you know, I know that its real and it's OK, it's alright to hurt a little bit you know

FAMILY HELPS

F6: because in the 3rd world the family life system is quite different, is so close and very free to have close contact, but here it, very isolate -- in Brazil she was having stomach ulcer for a long time and the specialists for the stomach, was a very close friend and he told her you are so worried about your daughter in the states you cannot be cured

F4: pain and fatigue bring on depression I think you know, is it worth it sort of thing? what am I doing this for?

DN: is what worth it?

F4: hmmm?

DN: is what worth it?

F4: is life worth it really? But it helps living here with family and kids running around to take away the depression, but I can't say I don't get depressed because I do sometimes mostly because the inability to be doing the things I like to do and I used to do

HAVING RESOURCES

F6: Tylenol and then I'll go do the stretches, I'll go to Pilates or I go to acupuncture, the acupuncturist does a lot of work on the spine to get the blood circulation there and the articulation so its sort of this combination I rotate through all of these – personal trainer who does everything according to how you would do in Pilates too, except it's weight bearing and you're dealing with strength and um flexibility, and then the Pilates which is really the inner, inner core and the posture work, so they're all the combination and they're all supporting sort of the same goal and approaching it from different aspects and for some reason doing all of them helps and then you go to get body work too, I go for body work every month or so

JESUS

F1: Jesus, Jesus he went through so much pain, nailed, crucified to the cross, so the pain times and some times I feel lonely I think about Jesus cuz he was crucified, he was lonely so I think about him and my pain and I take the medicine when I need it, but when I don't need it I don't take it, because no, I don't need it, I think about Jesus or I do something

DN: what is it when you think about Jesus that brings you some peace with your pain?

F1: because he's my friend

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Deborah K. Nelson

Appendix D:

Summary Highlight of Participants' Data

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Participant	Age	Pain Meds	Alter. Method	SES	Pain on Avg.	Pain Impact on General Activity	Pain Impact on Mood	Pain Impact on Enjoying Life
F7	75	OTC	A	High	3/4	10	9/10	8/9
F3	71	OTC/V	B/C	High	3/4	3	0	1
F6	69	OTC	B	Very high	4/5	0	5	2/3
F1	71	OTC	C	Very low	4	2	0	3
F2	85	OTC/V	C	Low	5	6	2	6
M1	86	OTC/V	A	Avg	5/6	5	0	0
M2	67	OTC/N	B	High	8	9	9/10	10
M3	71	OTC/H	B	High	3	1	½	0/1
F5	78	OTC	B	High	3	4	2	2
M4	63	OTC/E	B	High	3	4	2	2
F4	83	TYLw/C	A	High	3-5	2	½	1

Pain meds:
OTC = over the counter
OTC/V = over the counter and Vicodin
OTC/N = over the counter and nortriptyline
OTC/H = over the counter and hydrocodone/acetaminophen
OTC/E = over the counter and Endocet
TYLw/C = Tylenol with Codeine

SES = socioeconomic status

Alter. Method = Alternative methods for coping with pain
A = distraction – reading, watching movies, watching television, hobbies
B = walking, exercise, supplements, herbal remedies
C = ice, Ben Gay®