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# The Experiences Of Black American Older Adults Managing Pain: A Nursing Ethnography

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# THE EXPERIENCES OF BLACK AMERICAN OLDER ADULTS MANAGING PAIN: A NURSING ETHNOGRAPHY

by

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# DEDICATION

I dedicate this work as tribute to my elders.

Because they were, I am.

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I am forever grateful and indebted to my village of supporters, advisors, cheerleaders, and shoulders:

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# CHAPTER 1

## The Problem with Pain

Pain is a problem that affects more than 116 million American adults and costs an estimated $560-635 billion dollars a year in health care expenses and lost work productivity (Gaskin & Richard, 2012; Institute of Medicine of the National Academies, 2011). The full impact of pain however goes far beyond the numbers. For many, having pain means learning to successfully manage it or face overall disability, depression, social isolation, and even death (American Geriatrics Society, 2009; Clark, 1999; Fine, 2011; Roy, 2009; Sofaer et al., 2005). Pain is a challenging stressor that can affect every facet of a person's life and significantly diminish their quality of life (Borge, Wahl, & Moum, 2011; Dorit, 2011; Garrison, Overcash, & McMillan, 2011; R. A. Moore et al., 2010; Torvik, Kaasa, Kirkevold, & Rustøen, 2010). Those at greatest risk for diminished quality of life secondary to pain are older adults.

Older adults have an increased likelihood to have chronic end-stage diseases that cause pain. Some studies have noted that as many as 70-90% of individuals with advanced chronic diseases, such as chronic obstructive pulmonary disease (COPD), chronic heart failure (CHF), and cancer, experience moderate to severe pain (Berry & Paice, 2010; Walke, Byers, McCorkle, & Fried, 2006). Additionally, other chronic diseases such as osteoarthritis, rheumatoid arthritis, and peripheral neuropathies help to account for the 67-80% pain prevalence noted amongst adults over the age of 65 (Davis & Srivastava, 2003; Horgas, Yoon, & Grall, 2012). Unfortunately, the management of pain amongst the older adult population has been consistently poor (Herr, 2011; McDonald & Walsh, 2012). In fact, the U.S. Department of Health and Human Services estimates that more than half (57%) of adults, age 65 and older, have pain that has lasted for more than a year (National Center for Health Statistics, 2006). Of particular concern within the older adult and chronically ill populations are Black Americans.

Black American older adults, represent a disparate population that has been shown to consistently have unmet pain needs (Shavers, Bakos, & Sheppard, 2010). These adults are less likely to report pain to healthcare providers (National Center for Health Statistics, 2006) and generally receive poorer quality of care with less access to services as compared to White Americans (Agency for Healthcare Research and Quality, 2010). Furthermore, when Black American older adults do report pain, they are more likely to report higher levels of pain, suffering and depressive symptoms as compared to White Americans (Limaye & Katz, 2006). Such disparity in the management of pain amongst Black Americans increases the likelihood that many Black American older adults experience pain at levels that diminish quality of life—a problem warranting further investigation by professionals concerned with the optimization of health and the reduction suffering.

The effective management of pain, like other issues affecting quality of life, is an important issue to nursing. Nurses develop and encourage actions that will protect, promote, and optimize individuals', families', and communities' ability to feel integrated and whole. These interventions are developed by understanding the relationship between human responses, or behavior, and health. Understanding how Black American older adults manage pain can provide important information about how the phenomenon of health is conceptualized by the Black American older adult community and shed light on the relationship between self-perceived health and the behaviors involved in pain management. Furthermore, this information may aid nurses in helping this population to optimize their health and thereby improve their quality of life. Very few studies have examined the management of pain amongst Black American older adults—especially by studying the pain management experiences and behaviors of Black American elders from their own perspective and within their own environment. This nursing research proposal, will examine the experiences of Black American older adults managing pain, especially their goals, expectations of, and concerns with pain management—and elicit their ideas for improving pain management nursing practice. Chapter 2 provides a review of the literature about pain management, particularly for Black American older adults, and further focuses the rationale underpinning this research.

# CHAPTER 2

## Review of the Literature

Chronic pain is a significant problem that affects the quality of life of Black elders. Ample research has been completed over the past ten years that links chronic pain to psychological distress and overall patient declines, yet adequate pain control seems to remain problematic for these elders. The constancy of inadequate pain management for Black American elders points to a lack of appropriate problem identification—namely understanding the relationship between pain and health. The following chapter not only describes the linkage between pain and health, but also provides a social context for the plight of the Black American elder with pain. Futhermore, literature is noted that ties pain to emotion and the management of pain to quality of life. Additional evidence is provided to qualify pain as a stressor that requires human adaptation for coping and survival. Finally, ethnograpy is presented as the most appropriate methodololgy for studying the concept of pain management within the context of Roy's adaption model.

### Pain in the Black American Community

Black Americans make up nearly 14% (42 million) of the US population (U.S. Census Bureau, 2010) and about 8% (about 3.2 million) of adults aged 65 and older (Meyer, 2001; Pirkl, 2009). This diverse group of people whose ancestors came primarily from Africa, the Caribbean, and Central and South America, have a common history of enslavement, acculturation, and racial oppression which distinguishes the group from other cultural groups and influences their behavior, values, lifestyles, and creative expressions (Scott, 2005). It is widely recognized in the literature that cultural and ethnic affiliation directly impacts health experiences as well as the identification and selection of appropriate care (Conner et al., 2010; Griffith, Allen, & Gunter, 2011; Jackson, 2010; Marshall, 1990). Additionally, researchers have noted that severe life events, such as previous painful experiences and beliefs about symptoms can intensify pain experiences (Bass, 2009). One author, Palanker, detailed how public health responses to pain have intensified its impact within the Black American community.

According to Palanker (2008), imbedded mistrust in the health care system precipitates how and when Black Americans choose to access health treatment. She noted that this distrust dates back before the Tuskegee Syphilis Experiment to slavery era times during which medical experimentation such as pain studies, smallpox vaccine development, and experimental surgeries (sans anesthesia) were tested on involuntary subjects. Despite radical changes in science and healthcare, Black Americans remained excluded from mainstream health institutions for the first 65 years of the 20th century until the passage of Medicare Act. This Act required hospitals to desegregate in order to receive federal funding. Although the Medicare Act caused almost immediate hospital integration, Black Americans receiving benefits under Medicare, Medicaid, or the Veterans Administration fund continued to receive poorer quality of care as compared to White Americans. The author noted that this may be related to the preference of managed care organizations (MCOs) to work with prescribers who provide fewer services, prescriptions, and referrals—a problem for a population with a high incidence of poor health. Continued disparities, in the quality of health care between Black Americans and White Americans, further impact the health-related behaviors of Black Americans (Kosoko-Lasaki et al., 2009).

Shavers, Bakos, and Sheppard (2010), for instance, completed an extensive review of literature from 1990 to 2008 on racial and ethnic patterns impacting pain management. The authors specifically identified cultural influences on healthcare by searching articles that described traits of various racial and ethnic groups. An evaluation of over 187 articles and other sources of information found “consistent evidence that racial/ ethnic minorities suffer disproportionately from unrelieved pain compared with Whites" (p.179). For example, minority patients were more likely to receive lower doses of pain medications and experienced longer wait times to receive those medications despite higher pain scores as compared to White Americans. Additionally, minorities had more difficulty than Whites did in effectively communicating pain needs to clinicians in ways that were clearly understood and believed. While the authors noted that culture could mediate individual pain responses, they were also clear in expressing that cultural attitudes and beliefs about pain can affect how the pain of others is both perceived and responded to. Of course, the degree to which culture influences pain is relative to amount the individual identifies with their cultural or ethnic group. Other mediators can include age, socio-economic status and place of residence.

Interestingly, Black American elders residing in nursing homes have also reported higher levels of pain intensity and more psychological cofactors than their White American counterparts (Limaye & Katz, 2006). They are not receiving the same pain management and treatment options (Bonham, 2001; Sengupta, Bercovitz, & Harris-Kojetin, 2010; U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, & National Center for Health Statistics, 2009). This is especially unfortunate as older adults in general already represent a group that has unmet pain needs as compared to their younger counterparts.

For example, a study by Hwang and colleagues (2010) evaluated over 1,000 medical records of adults visiting emergency rooms with a chief complaint of a painful condition. The authors found that older adults (aged 65-84) had more unresolved pain upon discharge than younger adults (18-64) and older adults were less likely than younger adults to be prescribed recommended opioid analgesics for moderate to severe pain. Furthermore, data presented by Albert and colleagues (2008) noted that Black American men and women had increased severity of osteoarthritis symptoms compared to White Americans. This is not surprizing as researchers have found that people of African descent have increased physiological sensitivity to pain as compared to non-Hispanic Whites.

For instance, Cambell and colleagues (2008) recorded electromyographic (EMG) activity of the left bicep femoris muscle of 58 healthy young Black and non-Hispanic White adults while electrical stimulation was applied. This was done in order to measure the nociceptive flexion reflex (NFR). Recall that the nociceptive flexion reflex is a withdrawal reflex in response to pain. The researchers also collected psychological measures such as the Pain Catastrophizing Scale, The Kohn Reactivity Scale, The Frid Scale, and the Visual Analog Mood Scale to help identify the effect psychological factors had on NFR and/ or group differences. The scientists found that there were significant differences in NFR thresholds between racial groups when age, sex, body mass index, blood pressure, and the noted psychological barriers were accounted for.

Another study by Grewen, Light, Mechlin, and Girdler (2008) looked at the relationship between peptide oxytocin (OT), a brain neuromodulator, and pain. Participants in this study consisted of 48 women, 25 Black Americans and 23 non-Hispanic White Americans—a subsample of volunteers from a larger study evaluating mediating factors of stress-induced pain perceptions. Archival plasma was tested for oxytocin assay and compared to pain testing outcomes. Each participant expierenced three seperate pain tests, ischemic, thermal heat, and cold pressor, and were evaluted for pain threshold, tolerance, subjective intensity, and unpleasantness. Additional questionaires included the Beck Depression Inventory and the Spielberger State and Trait Anxiety Inventory. The Black American women of the study had significantly lower baseline levels of plasma OT concentrations and expierenced significantly lower pain tolerance. Other factors such as caffeine and alcohol consumption, smoking, contraceptive use, education, age, blood pressure, depressed mood, anxiety, serum estradiol, cortisol, and ACTH were accounted for. Similar findings related to pain tolerence were noted in a larger study (n= 206) by Rahim-Williams and colleages (2007).

Laboratory induced pain is of course different from the type of pain expierenced by individuals afflicted with various medical conditions, however these studies provide some understanding of how diverse populations respond to pain and the results do not seem to vary within comparitive studies of patients expierencing pain secondary to pathophysiologal conditions.

For example, a recent study by Hooten and colleagues (2012) compared Black Americans (n=40) matched to 3 White Americans (n=120) on age, sex and treatment dates over the course of a three week outpatient multidisplinary pain rehabiliatation program at the Mayo Clinic. In addition to lower percentages of Black Americans completing the program (78% compared to 89% Caucasian), at the conclusion of the intervention, Black American participants reported significantly more pain intensity, depression, distress, and pain catastrophizing, as well as diminished health and functional status. As the researchers of this study noted, additional research initiatives are needed to better understand the complex array of clinical and biological factors that influence the disparity of pain control within the Black American population. As it relates to osteoathritic pain specifically, Albert and colleagues (2008) noted that the differences in pain intensity might be explained by ineffective treatments such as increased use of topical pain agents and over-the-counter medications versus perscription osteoarthritis medication.

Palanker (2008) suggests that the decreased use of opioids within the Black American community may be due, in part, to the federal government’s war on drugs that largely depicted typical drug abusers in ways that stigmatized Black Americans and led to unconsious racial bias in prescribers. Differences in treatment options may also be related to access. Poor access to healthcare services is associated with an increased utiliztion of complementary and alternative therapies (Barner, Bohman, Brown, & Richards, 2010). Specifically, Barner and associates (2010) found that prayer was one of the predominant forms of complementary therapy used by Black Americans. This supported previous work by Dunn and Horgas (2004) that noted older adults, specifically women and minorities, reported religious coping strategies to manage pain more frequently than White men.

A study by Jones and collegues (2008) described an increased use of prayer among Black Americans with osteoarthritic knee or hip pain. The vast majority of Black Americans enrolled in the Jones study found prayer to be helpful in diminishing pain. Additionally, the authors noted a correlation from a previous study in which patients who perceived prayer as being helpful in reducing their pain were less likely to consider more invasive types of treatments such as total joint anthroplasty (TJA). Interestingly, in a comparitive study of religion and health, Franzini, Ribble and Wingfield (2005) found that while increased religiosity was noted amonst Black Americans as compared to White Americans and Latinos, Blacks still reported the lowest levels of self-rated health. This may be related to the increased likelihood that individuals with fewer social supports and greater perceptions of victimization and racisim will use non-organizational religiosity such as personal devotion to manage stress (Franzini et al., 2005). Appropriate social supports are of course associated with effective coping (Evers et al., 2003).

Despite increased perception of pain, Black American elders are still less likely to report pain to providers than White Americans which makes effective treatment even more difficult (Herr, 2002; Sengupta et al., 2010). This is particularly an issue when coupled with other recognized barriers to pain control such as age-related expectations, relationships with health care providers, knowledge deficits, lack of access and emotional distress (Davis, Hiemenz, & White, 2002). To be proactive about pain management means acknowledging and understanding the differences in cultural responses to pain (Briggs, 2008).

Culture may be defined as the learned patterns of behavior, beliefs, and values shared by individuals of particular social groups (Marshall, 1990). Culture influences what is most important to individuals and allows humans to cope with the concrete, specific problems [such as changes in health] that arise during the course of life (Malinowski, 1944). The values, beliefs, and social relationships shared by groups of people impact both how decisions are made and how life is experienced in relation to these decisions. Not only does culture helps to frame the health-seeking behaviors of humans (Kosoko-Lasaki, Cook, & O'Brein, 2009; Rew, 2003) but it may also explain the emotions associated with particular experiences such as pain. Effective pain management mandates grasping the culturally rooted relationship between pain and emotion.

## Pain and Emotion

The relationship between pain and emotion has been discussed in the literature for centuries. Early philosophers Plato and Aristotle referenced pain as a negative emotion that was simply part of the normal human experience (Aristotle, 350 B.C.E.; Plato, 360 B.C.E). In Judeo-Christian society, it has been taught that pain and suffering are the consequences of sin (Genesis 1-3). It was actually not until 1644 A.D. when the lectures of French philosopher Rene Descartes were published that the view of pain shifted from an emotional, and perhaps spiritual experience, to a physical sensation that was perceived by the mind and influenced by one’s previous life events (Descartes, 1664). Today, it is recognized that physical pain is related to the activation of sensory receptors called nociceptors by various types of noxious stimuli (Godfrey, 2005; Helms & Barone, 2008; Oberg, 2011). The existential components of pain (emotions, spirituality, sociability), or those non-physical components that contribute to suffering (Boston, Bruce, & Schreiber, 2011;

Gudmannsdottir & Halldorsdottir, 2009; Strang, Strang, Hultborn, & Arnér, 2004) have been recognized and supported by literature for decades.

In 1959 hospice innovator Cicely Saunders coined the phrase “total pain” to describe the experience of pain because “much of our total pain experience is [comprised] of our mental reaction…” (as cited in Clark, 1979, p. 732) and limiting pain to only a physical symptom does not acknowledge the mental distress, social concerns and emotional problems that compose the total pain experience. The gate control theory proposed by Melzack and Wall (1965) follows this logic by asserting that affective variables such as attention, fear, and expectations impact how pain messages are transmitted to the brain. Research studies that followed Melzack and Wall began to verify this theory and new conceptualization of pain.

For example, a series of small laboratory controlled studies were published in 1976 (Lanzetta, Cartwright-Smith, & Eleck) that verified the impact of emotional responses to the pain experience, specifically pain intensity. Lanzetta and colleagues (1976) completed 3 studies with 47 participants ($n_1 = 18$, $n_2 = 9$, $n_3 = 20$) that induced pain caused by electrical shock. The authors found that by modifying expressive behaviors, specifically having the participants alter their facial expression in anticipation of shocks, changes were induced in both the ability of the skin to conduct electricity as well as the subjective reporting of pain intensity. Similarly, a study by Carney, Cuddy, and Yap (2010) found that altering body posturing caused neuroendocrine changes in testosterone and cortisol which in turn facilitated adaptive behavioral changes. Interestingly, cortisol, a steroid hormone produced by the adrenal gland of the kidneys and controlled by the hypothalamus of the brain, may be found in lower levels within chronic pain patients (Mork, Westgaard, et al., 2012, 2010; Edwards, Heyman, & Swidan, 2011; Riva, FibGalli, Gaab, Ettlin, et al., 2009; Sudhausa, Frickeb, Stachonc, et al., 2009). While the small nature of the studies completed by Lanzetta and colleagues limits generalizations to larger populations, the study challenged other prevailing theories of the time that suggested a causal relationship between pain and emotion rather than simply one of correlation. Furthermore, this work supported the propositions of Lazarus and colleagues (1964) that stress responses could be manipulated by altering the perception of the participant to the stressful event. This idea that pain, a stressor, was subjectively perceived and expressed was reiterated in the nursing definition of pain presented by Margo McCaffery (1968), “pain is whatever the experiencing person says it is, existing whenever the person says it does” (p.8), and led to more research that considered the linkage between pain and emotion.

Leventhal, Brown, Schacham and Engquist (1979) completed a larger study that was similar to that of Lanzetta and colleagues described above. Unlike the Lanzetta study, Leventhal aimed to determine the role of stimulus interpretation in distress reduction. In three experiments, 194 males ($n_1 = 50$, $n_2 = 68$, $n_3 = 76$) were subjected to laboratory induced pain caused by cold water. The studies found that sensation information provided prior to the event along with distraction were effective means of reducing distress; however pain warnings actually significantly increased pain distress. These results led the authors to believe that humans process pain information both objectively and subjectively, or emotionally. While the objective information helped to determine the immediate meaning of pain, it was the subjective interpretation of the pain experience that determined the threat value. This information is interpreted individually, based upon both current threat and previous pain experiences, and leads to the initiation of behavioral coping responses.

The view of pain as more than just a physical experience created a definite shift in the pain paradigm that opened up the study of pain by a variety of disciplines which called for standardization in terminology used to discuss pain. To meet this aim the International Association for the Study of Pain began to publish a taxonomy list. Within this list, pain was defined as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage" (The International Association for the Study of Pain, 1986, p. S217)—a definition still used today. The IASP provided a detailed explanation for using this particular definition, which recognized that pain is always a subjective experience that is influenced by previous painful history. The authors stated that pain is "unquestionably a sensation in a part or parts of the body, but it is also always unpleasant and therefore also an emotional experience" (p.S217).

A few years following the publication of the pain taxonomy listing, Fernandez and Turk (1992) wrote a synthesis paper about the sensory and affective components of pain. The authors noted that pain intensity, which they referred to as arousal, and qualitative emotions contributed to the affective components of pain. The extensive review of the literature completed by Fernandez and Turk concluded that the sensory and affective components of pain could be separated despite collinearity demonstrated through multivariate statistical analysis. The authors believed that a reciprocal relationship between pain sensation and emotional distress accounted for interdependence between the variables but future research using innovative methods could further distinguish between the sensory and affective components of pain.

A decade after Fernandez and Turk, it was widely accepted amongst both clinicians and researchers that pain is both a physical as well as an emotional state. The American Geriatrics Society (AGS) Panel on Persistent Pain in Older Persons (2002; American Geriatrics Society, 2009) went so far as to note that while pain was derived from either sensory stimuli or neurological injury, the pain phenomenon was modified by subjective experiences such as individual memories and emotions. This idea was substantiated by a study completed by Nicolson and colleagues (2010) that found increased cortisol levels (stress hormone) in study participants with chronic pain who had experienced maltreatment as children. In fact, the more severe the reported maltreatment was, the higher the cortisol levels were. High cortisol levels are associated with increased pain intensity.

The AGS panel also recognized that persistent pain might not be associated with a noted disease process and the frequent occurrence of other symptoms, such as anxiety and depression (also associated with high cortisol levels), made pain difficult to assess and treat. However, based upon the premise that pain is physical and emotional; pharmacological, and nonpharmacological guidelines for the treatments for pain in older adults were published. Nonpharmacological treatments included physical and psychological modalities as well as the development of cognitive and behavioral coping strategies.

As new pain assessment tools began to be both developed and validated, affective domains such emotion were included within the assessment. For example, Clifford and Cipher (2005) developed the Geriatric Multidimensional Pain and Illness Inventory (GMPI) to "assess pain and associated limitations in the ambulatory elderly who may be experiencing multiple medical problems" (p. 47). Similar to other scientists, the authors believed that the complex and subjective nature of pain required a survey instrument that would measure the participants' perception of the impact on pain to daily activities as well as emotional functioning. Using a sample of 401 residents in 16 long term care facilities, the GMPI evaluated emotional distress by looking specifically at loneliness because of pain, irritability due to pain, anxiousness due to pain and residents self-rated ability to cope with problems. The study validated the use of the GMPI and found significant differences in how patients with pain rated assessment items on loneliness, irritability, anxiousness, and coping as compared to patients without pain. While this study reiterated that pain is a concern that causes existential problems, it did not provide further insights into the self-management of pain by the older adult population.

Vlaeyen, Crombez and Goubert (2007) also evaluated the psychological impacts of pain, but unlike others, they began discussion on how the meaning of pain could influence pain responses. The authors, who discussed theoretically grounded treatment implications for chronic pain, maintained that the phenomenon of pain contains both psychological and emotional variables as well as social ones. They believed that these mixed variables explained why individuals with the same injury oftentimes had different pain experiences. The authors noted that psychophysiological responses to pain such as changes in heart rate, respiratory status, and muscle tension could further exasperate and intensify the immediate perception of pain. However, these responses "cannot be separated from the context in which the individual is situated and its meaning" (p. 182). This argument allowed the authors to lay an effective foundation for the use of cognitive behavioral therapy in the management of chronic pain as this type of therapy addresses the pain experience, as well as mood, affect, and coping. The argument also points to the very subjective nature of the pain experience, which is culturally rooted and influenced by the environment.

The convergence of data pointing to both sensory and affective components of pain continues to lead to further conceptualizations of how pain is both understood and treated. Researchers and practitioners alike have begun to accept a biopsychosocial model of pain (see Figure 1) that recognizes the impact of psychosocial factors such anxiety on not only how pain is experienced, but also how it is reported, the progression of the disease causing pain, and the most effective treatments. This understanding has also lead to the separation of how disease, the objective disruption of normal biological functioning, is viewed in comparison to illness, the subjective response to disease (Gatchel, Peng, Fuchs, Peters, & Turk, 2007). Today, research has begun to evaluate some of the individual domains of the pain experience.

Ruzicka and colleagues (2007) surveyed 150 cognitively intact elders aged 65 and older with chronic pain using a variety of instruments validated to measure various aspects of the pain experience including the physiological, sensory, affective, cognitive, behavioral, sociocultural, and spiritual dimensions. Although the majority of these dimensions were selected because they had been adopted by the National Nursing Research Agenda in 1994, spirituality was added as a dimension due to its significance in the literature (Ruzicka et al., 2007). Data analysis of the elder surveys by the authors found that unique pain experiences are comprised of a mix of belief systems, past experiences, behavior patterns, cognitive abilities, emotional frameworks, and spiritual development—further validation of the multidimensional nature of the pain experience proposed by researchers over a decade. Today it is generally accepted that pain can negatively impact all dimensions of a person's life and may lead to suffering (Gudmannsdottir & Halldorsdottir, 2009). Both the study and effective management of pain requires that researchers and clinicians alike recognize pain as a complex and uniquely subjective experience that can significantly reduce quality of life.

## Pain Management and Quality of Life

Pain management refers to the manner in which pain is handled. The methodology used in managing pain can vary significantly depending upon one's knowledge, beliefs, values, and resources. As it relates to the clinician, pain management is "the systematic study of clinical and basic science and its application for the reduction of pain and suffering" (Leavitt & Kersta-Wilson, 2010). While the scientific consideration of pain may not be on the agenda of most older adults, it stands to reason that most patients who experience pain are interested in reducing or eliminating pain and employ methods to do so (AGS Panel on Persistent Pain in Older Persons, 2002; American Geriatrics Society, 2009).

When pain is not appropriately managed, it can lead to several other health problems such as: declines in socialization, sleep disturbances, depression, anxiety, appetite changes, cognitive declines (Institute of Medicine of the National Academies, 2011; St.Marie, 2010) and feelings of hopelessness, despair, abandonment, and even punishment (Puchalski, 2006). These negative health outcomes cause stress and diminish quality of life, which has been defined by the World Health Organization (WHO) (1998) as “an individual’s perceptions of their position in life in the context of culture and value system where they live, and in relation to their goals, expectations, standards, and concerns” (p. 17). Clearly, quality of life is a subjective experience that is often mediated by one’s physical health. In fact, the term health-related quality of life (HRQOL) is frequently referenced in the literature. HRQOL is used to specify the aspects of an individual’s life that are impacted by disease or health conditions and their treatment. Tools such as the SF-36 (Ware, 2010) were developed to measure HRQOL and the generally accepted domains of HRQOL—physical health and functioning, emotional health, cognitive functioning health, role performance, work productivity, sexual functioning and life satisfaction. As a subjective experience that is influenced heavily by culture, it is not surprising that there are noted differences in the relevant domains of quality of life depending upon the culture of the population under study.

For instance, residential health facilities for elders, such as nursing homes, help assure that quality of life is maintained for older adults who live in these facilities long term through regulatory requirements that mandate individualized plans of care, meaningful activity, a homelike environment and maintenance of personal resident rights (Centers for Medicare & Medicaid Services, 2007). Researchers Kane, Kling, Bershadsky and colleagues (2003) were able to evaluate domains of quality of life that made a significant difference for older adults in nursing homes. The specific components of quality of life used by the authors were identified by a review of the literature, expert opinion, and focus groups. Following a survey of 1,988 residents in 40 nursing homes within five states, factor analysis confirmed 10 specific quality of life domains for older adults. The identified quality of life domains included comfort, meaningful activities, security, functional competence, privacy, autonomy, spirituality, well-being, dignity, enjoyment, and relationships.

Interestingly, pain has the ability to affect every noted quality of life domain. The resident voice however is what is most essential in understanding the impact of pain to quality of life, as defined by the person. As one author concluded, “the resident voice must be sought in reaching operational definitions for quality of life” (Kane, 2003, p. 28). The voice of the individual is best heard through qualitative study.

Qualitative study is a way of understanding the world from the perspective of the participants. One author succinctly described qualitative research as “the systematic study of phenomena with rigorous adherence to design, the data of which comprises oral, written, or artistic descriptions of human experiences, and for which there are no digital findings” (Parse, 2001, p. xxiii). This study of human experiences, as expressed by humans in their natural settings, provides scientists with the opportunity to understand phenomena in relation to the meanings people bring them (Denzin & Lincoln, 2011). Qualitative study not only allows scientists the ability to study phenomena as it is experienced, but also to understand the context of these experiences and the role that this context plays in reactive behavioral responses often referred to as coping. This is particularly important in the study of how pain is managed, as qualitative study can help researchers to understand how specific interventions for pain are experienced and valued. Using a qualitative methodology, **the first research question to be answered by this study is: How do Black American older adults experience pain and pain management operationally, emotionally, and qualitatively (the defining attributes).** It is projected that through this study, we can also more fully understand the important role of coping to the pain experience as well as the relationships between pain, stress, and the self-perceived health of the person.

### Pain and Coping

Pain is a stressor—a stimulus that affects the development and behavior of the human adaptive system (Roy, 2009). Like other stressors, humans adapt to pain by employing behavioral strategies, called coping mechanisms or coping strategies, that will allow for the reduction of negative health outcomes and facilitate improved quality of life (Dunn, 2004; Lemyre & Lalande-Markon, 2009, Roy, 2009). Lazarus and Folkman (1984) defined coping as "the constantly changing cognitive and behavioral efforts [used] to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (p. 141). Coping is closely related to adaptation, which is the ability to make modifications that will allow for continued existence within one's environment (Merriam-Webster, 2012). *The Roy Adaptation Model* (Roy, 2009) further expands the concept of adaptation describing it as "the process and outcome whereby thinking and feeling people, as individuals or in groups, use conscious awareness and choice to create human and environmental integration" (p.29). Adaptation therefore is the anticipated outcome of effective coping. Unsurprisingly, coping strategies are more predictive of pain and adjustment to pain than disease processes (Bass, 2009; Keefe, Abernethy, & Campbell, 2005).

Humans adapt to stressors biologically through automatic chemical, neurological, and hormonal adjustments, or culturally based upon cognition and emotion (L. G. Moore, Arsdale, Glittenberg, & Aldrich, 1987). The cultural component of adaptation is the foundation of coping processes. The actual responsive behaviors, or coping strategies, which are culturally derived, help to mediate the regulatory activities of the body physically, emotionally, socially, and physiologically (Roy, 2009). Sister Callista Roy (1970) uses a conceptual model to describe how humans use adaptation to respond to environmental stressors and maintain health.

### The Roy Adaptation Model.

The Roy Adaptation Model (RAM) (Roy, 2009) is based upon the premise that humans are holistic adaptive systems in constant interaction with their internal and external environments. Stimuli from these environments, such as pain, will illicit responses that the system must respond and adapt to in order for the individual to maintain functionality. According to Roy (2009), how effectively humans deal with stimuli, or cope, influences their health.

The ability of humans to effectively manage stressors, or adapt, may be objectively assessed based upon the level of response needed to restore or maintain functionality. Adaptation may be described as integrated, compensatory, or compromised. When little response is needed, as all structures and processes are working together to maintain optimal functionality, the adaptation level is considered integrated. The adaptation level reduces to compensatory when it becomes necessary for the body to activate other internal systems to maintain a level of homeostasis. Finally, the adaptation level will diminish to a compromised state when there are problems with the system that do not allow the body to be restored to homeostasis and adaptation does not take place as anticipated.

The current adaptation level of the individual determines how positively he or she will respond to further stimuli. Furthermore, the type of stimuli that the individual is exposed to influences the adaptive response. Essentially, the RAM describes a reciprocal interactive change process. Change is the result of multiple preexisting factors, such as culture, beliefs, and values that influence behavior. The major construct of the Roy Adaptation Model is coping. Roy described three different types of stimuli and two modes of coping.

### *Stimuli.*

Roy (2009) categorized stimuli, or that which provokes a response, as focal, contextual or residual. A focal stimulus is one in which a primary stress response process is initiated from either internal or external stressors. A focal stimulus demands the immediate attention of the individual. All of the other identifiable factors present in the environment that contribute to the effect of the focal stimuli are referred to as contextual stimuli. Finally, residual stimuli are the factors whose effects in the current situation are not apparent. Oftentimes, residual stimuli are rooted in the previous experiences of the individual and therefore the effects on the current situation are not clear. When residual stimuli are recognized, they typically become the main problem to be addressed—focal stimuli—or a contributor to the problem—contextual stimuli (Fawcett, 2009).

Interestingly, although the concept of coping clearly emerges as a the central construct in the RAM and coping has been identified as one of the most important factors in understanding the relationship between stress and health (Aldwin & Werner, 2007), this concept is not specifically defined by Roy. However, the definition of coping provided by Lazarus and Folkman (1984), "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (p. 141), is appropriate and in congruence with Roy's use of the phrase "coping processes" which describe how individuals respond to environmental stressors. Additionally, Lazurus' (2006) updated view of coping as a consistent part of the dynamic emotion process is further in alignment with Roy's view of coping as a multidimensional and transactional process (Roy, 2011).

### *Coping processes.*

Coping processes, as defined by Roy (2009), are the “innate or acquired ways of interacting with, that is, responding to and influencing the changing environment” (p. 41). Roy (2009) classified coping responses as either automatic, and part of the “regulator subsystem,” or cognitive, and part of the “cognator subsystem.” Both systems are dynamic and interrelated. The systems are triggered when various stimuli from the environment causes a level of stress to the human system that necessitates adaptation in order for functionality to be maintained.

The RAM was initially developed based upon a content analysis of 500 samples of patient behavior (Roy, 1970). These behaviors were grouped into four categories that provided clues about how individuals handle stimuli from the environment and areas where further assistance was needed to achieve adaptation. The categories of behaviors, which Roy refers to as adaptive modes, include: physiologic, self-concept, role function, and interdependence (Roy, 2011).

### *The adaptive modes.*

Each of the modes designated by Roy (2009) provides a framework for assessment that assists nurses in determining necessary care. Each mode describes a category of concern evident by behaviors the individual is displaying. Within the physiologic mode for example, the main goal of the individual is to restore the integrity of the physical body both internally and externally through appropriate oxygenation, nutrition, elimination, activity, rest and protection. The complex physiological processes that are frequently problematic within this mode include fluid, electrolyte, and acid-base balance; neurologic and endocrine function; and functionality of the five senses (touch, taste, smell, sight, hearing). When the behavioral focus of adaptation is directed toward how an individual feels about themselves, their bodies, and their own abilities, the individual is considered to be functioning within the self concept mode. Role function, like its name implies, is a mode that envelopes behaviors related to societal positions and interpersonal interactions. Similarly, the final mode, interdependence, focuses on interpersonal relationships and how needs such as love and respect are offered and received. As with most complex systems, there is a great deal of overlap between the modes which at times makes it difficult to distinguish the primary mode an individual is functioning in from the other modes. Furthermore, the constantly changing nature of the environment and the changing nature of stimuli from that environment can further complicate the ability of observers to appropriately assess primary adaptive modes.

Pain is an interesting phenomenon in that it is caused by an environmental stimuli and functions as a stressor—causing stress to the individual focally, contextually, and/or residually. It can affect every domain of health (see Figure 1). Furthermore, due to the multidimensional nature of pain, it can also cause an individual to initiate adaptive responses in every adaptive mode. Therefore, the conceptual model presented by Roy provides an appropriate framework for understanding the relationships between stress, coping, and quality of life.

#### Pain posited within the Roy Adaptation Model.

Pain is initiated in the body by a noxious stimulus, or a stressor that is damaging, or potentially damaging, to cellular tissue (McCaffery & Pasero, 1999). Through a process called nociception, the regulator subsystem described by Roy (2009) initiates the release of hormones, chemicals, and neurotransmitters from the pain site, to the spinal cord and brain where pain information is processed and further coping responses initiated (Godfrey, 2005; Pasero, Paice, & McCaffery, 1999). At some point during this process, it is postulated that the hypothalamus (part of the brain) triggers the release of the stress hormone cortisol from the adrenal gland (part of the kidney). When individuals are experiencing severe acute pain, at some time during this process the sympathetic nervous system becomes activated and sends out additional chemicals and hormones that cause a series of reactions that have come to be known as the *flight or fight* response of the body.

In this instinctive response, the pupils dilate, the body becomes diaphoretic, and the body temperature rises. Additionally, both heart rate and blood pressure increase as blood moves toward the large muscle groups and organs to supply oxygen, while decreasing energy to non-essential functions like intestinal peristalsis which can result in constipation and other gastrointestinal or stomach symptoms. Most patients experiencing severe acute pain will display some or all of these symptoms. Further evidence of pain may be noted in facial expressions displaying discomfort, such as the brow furrow and verbal responses such as crying, yelling, screaming, or swearing—further manifestations of the autonomic nervous system working and the conscious experience of pain.

Generally, when pain is acute, or acutely severe, as is often the case with breakthrough pain, or pain above the usual pain intensity for the individual, it typically becomes a primary or focal stimulus. When pain is a focal stimulus, individuals most frequently cope with pain from within the physiologic mode where restoration of homeostasis is the primary goal. Through adaptive responses, alteration of the physiological reactions takes place. Oftentimes this restoration of homeostasis is accomplished through pharmacological interventions that mediate pain responses.

Chronic pain has historically been accepted to be pain lasting longer than 3 months, however recent work by Von Korff and Dunn (2008), has noted that defining chronic pain simply in terms of duration provides an inaccurate picture of the total burden of chronic pain across pain types. Rather, a multidimensional view of chronic pain increases the likelihood of evidence-based assessment and classification that could lead to improved treatment outcomes. Chronic pain differs from acute pain not only in its duration, but also in its manifestation.

Pain disrupts the integration of the body system. As the goal of the body is to maintain functionality and a state of homeostasis, when a person is experiencing pain, body systems such as the regulator subsystem described by Roy (2009), must take over and assist the individual in adapting to the painful stimulus. Specifically, the parasympathetic nervous system takes over and assists the body in returning to a normal functional state. It is for this reason that patients with chronic pain may still experience severe levels of discomfort that impact normal activities of daily living (ADL) and quality of life, yet observable evidence of pain is not as apparent as with acute pain.

Generally, patients experiencing chronic pain display cognitive and related behavioral symptoms that indicate activation of cognator (cognitive) responses. These responses most often affect the spiritual and psychosocial domains of health. Within these domains, self-concept, role function and interdependence are the adaptive modes described by Roy (2009) that are most disturbed when patients experience chronic pain. The correlation between chronic pain and negative impacts on spiritual, social and emotional well-being is well supported in the literature (Gudmannsdottir & Halldorsdottir, 2009; Higgins, Madjar, & Walton, 2004; Morone et al., 2009; Sorkin, Rudy, Hanlon, Turk, & Stieg, 1990; Weschules & Reifsnyder., 2006; Won et al., 2004).

When physical pain is the primary focus of concern for the individual, it is considered a focal stimuli. However, as the individual becomes accustomed to living with pain, as happens in the case of chronic pain, the focus of attention shifts from the focal stimulus, the physical pain itself, to other issues pain may be causing in the person’s life such as changes in mobility and other ADL impacts. For example, a person that is consumed with their inability to maintain profitable work due to pain may have great emotional anguish. While physical pain may be the causative factor, it is no longer the primary focus of the attention--the focal problem that causes a lack of integration in the body system is the person's sense of powerlessness, or what may also be referred to as emotional pain. While the physical pain is still a stimulus (and the origin of the problem), it becomes a contextual (background) stimulus. The implication for patient care is that the new focal stimulus, powerlessness, becomes the primary focus of care. The idea is that if there is integration at the cognator level, effective adaptation may take place that facilitates overall survival.

In some instances, pain may not be recognized as a stimulus at all. This is a common occurrence in older adults—particularly those with dementia. Behavioral manifestations of pain such as social withdrawal or calling out are commonly misdiagnosed as depression or symptoms of advanced dementia. An unrecognized stimulus is referred to as a residual stimulus. More and more research is beginning to take a closer look at how previous pain encounters and patient, family, and provider beliefs about pain influences adaptive coping responses (Dawson et al., 2005; Evers, Kraaimaat, Geenen, Jacobs, & Bijlsma, 2003; Johansson, Linton, Rosenblad, Bergkvist, & Nilsson, 2010). Once a stimulus is recognized it is no longer residual, but rather becomes the focus of attention, a focal stimulus or a contextual stimulus.

Within the adaptation model presented by Roy, pain is viewed as a biopsychosocial process in which complex interactions between the environment and the person initiate adaptive coping responses and influence quality of life outcomes. Several authors have noted that adaptive coping responses influence both the experience of pain and commonly linked cofactors such as depression, mood, anxiety, and functional ability (Bass, 2009; Evers et al., 2003; Gyeong-Ae, Chang, Lee, Lee, & Shin, 2006; Lopez-Martinez, Esteve-Zarazanga, & Ramirez-Maestre, 2008; Vallerand, 1995).

In addition to adaptive coping strategies effecting health outcomes and quality of life, so too does self-efficacy, or one's perception of their own ability to accomplish a particular level of performance. Self-efficacy has been linked to the types of adaptive coping strategies individuals choose to utilize (Turner, Ersek, & Kemp, 2005). Although self-efficacy is not noted as a concept within the RAM, the similar concept of self-ideal, defined as "the aspect of the personal self-component that relates to what the person would like to be or is capable of doing" is closely related to self-efficacy and a primary factor in the adaptive mode of self-concept (Roy, 2009, p. 323). This interesting relationship between pain, adaptive coping strategies and health begs the **second research question: How do Black American older adults cope with pain, particularly, what are the relationships between pain management and health related quality of life (HRQOL) and what does this tell us about the extent to which the Roy Adaptation Model resonates with these participants' lives?** The exploration of experiences managing pain is necessary to identify both effective and ineffective coping strategies within the Black American older adult population.

Through qualitative discourse and analysis, nurses can learn valuable information regarding the pain experience and the effects of stress on quality of life. Nurses may also learn more about the specific care areas in which they may make a difference—the latter of which may be identified by **the third research question: Given their experiences with pain, pain management, and coping strategies, what advice might older Black American adults give to improve pain management in nursing practice.** The Roy Adaptation Model provides an explicit, holistic framework for research that is compatible with the key outcome of improved quality of life. Pain management may be improved in the Black American older adult community by increasing provider understanding of the relationship between stress, Black American older adult pain management practices, and quality of life (see Figure 2). This study is guided by the Roy

Adaptation Model (RAM) (Roy, 2009) and is based on a critical theory perspective. The findings will provide a commentary on, or revisions of the Roy Adaptation Model. While some scholars believe that qualitative research is atheoretical, it is important to note that a priori theories help to conceptualize phenomena and appropriate methods of inquiry (Sandelowski, 1993). The most appropriate method of inquiry for this study is ethnography.

## Ethnography

Ethnography is a comprehensive research methodology rooted in human science that uses inductive logic to uncover meaning (Robinson, 2013a). Human science, or the study of human experiences, evaluates the purposeful acts of people in various situations to gain an understanding of meaning and pattern in life (Van Manen, 1990). Long the preferred methodology of cultural anthropologists and sociologists, ethnography allows for the studying of everyday life as it happens. As a qualitative method of inquiry, ethnography provides a systematic process of recognizing behavioral patterns and understanding the meaning of these patterns within certain contexts. More specifically, ethnography reveals the meaning of human behaviors within the context of culture and from the perspective of the native (Creswell, 2007; LeCompte & Schensul, 1999; Malinowski, 1944; Spradley, 1979, 1980). As Spradley (1979) noted, “every culture, and every cultural scene, is more than a jumble of parts. It consists of a system of meaning that is integrated into some kind of larger pattern” (p.186). Ethnography depends on three data collection strategies, observational field notes, interviews and artifacts to identify patterning.

### Observational Data

The ethnographic research process begins with gathering descriptions of lived experiences, termed field notes, which provide detailed accountings of human behavior. To collect this initial data the researcher will observe the cultural group under study within social settings. More specifically, he or she will make observations and document the activities taking place, the people present, the things being made and used (artifacts), and the physical aspects of the environment (Spradley, 1980). These detailed accountings of everyday life provide a foundation for identifying patterning. Key areas to consider during participant observation include: 1) how space is used, 2) where objects are located, 3) who is present, 4) what activities are taking place, 5) what events occur, 6) the timing of happenings, 7) the acts that occur, 8) the identified goals, and 9) the feelings involved (Spradley, 1980). These observed behaviors may be clarified by informed members of the cultural group under study, who are referred to as informants, through ethnographic interviews with the aim of eliciting meaning (Spradley, 1979).

## Interviews

The ethnographic interview is also used to gather in-depth information on selected topics, learn of personal histories, discover cultural knowledge and beliefs, and gather participant accounts of events (LeCompte & Schensul, 1999). Ethnographic interviews vary from other types of interviews in both the intent and the types of questions used. The ethnographic interview informs the researcher about how reality is constructed from the view of the participant (Atkinson, Delamont, & Housley, 2008; Spradley, 1979). Specifically, the manner in which members of a particular cultural group utilize language helps to inform researchers about how life experiences are categorized by that group. Interviews not only encourage the use of language by the members of the cultural group, but also provide an opportunity for the researcher to clarify his or her interpretations of behaviors (Schensul, Schensul, & LeCompte, 1999; Spradley, 1979). The intent of ethnographic interviews therefore, is to assist the researcher in learning how members of a cultural group assign meaning (Atkinson et al., 2008). To meet this aim, the researcher asks questions that will help them clarify how language is used to describe experiences and how concepts are both interrelated and different (Spradley, 1979, 1980). Specific questions are asked within the context of both formal and informal interviews.

**Informal interviews.**

Informal interviews, also referred to as unstructured interviews, allow the researcher to clarify information that arises during the course of participant observation. The informality allows conversations to take place easily with any participant willing to communicate and gives the researcher the opportunity to gather information on domain terms using open-ended questions early in the research process (Spradley, 1980). These questions facilitate communication by allowing the researcher to ask a participant about a particular topic in a way that leaves the response open to the discretion of the participant. The freedom of response in open-ended interviews provides the participant with an opportunity to speak freely about a certain topic and gives the researcher a chance to gather additional information rooted in cultural descriptions about the phenomena they are investigating.

The most difficult tasks of unstructured interviews, according to Schensul and colleagues (1999), are remaining focused on the topic of discussion, and paying attention to how the topic both relates to and illuminates the phenomena of interest. Furthermore, the researcher has the added tasks of recognizing the logical connections between ideas presented by the participant during the interview and identifying when these ideas need to be further expounded. Finally, it is oftentimes through informal interviews that key informants are identified who may be willing to participate in a more structured interview at a later time.

**Formal interviews.**

Formal, or semi-structured interviews, provide the researcher with opportunities to further clarify central domains and factors in the study as well as operationalize the identified factors into variables that will eventually become part of a theoretical model (Schensul et al., 1999). Similar to informal interviews, the researcher is able to clarify central domains and factors by asking descriptive questions about various dimensions of social situations such as: what individuals are typically present, what they usually do, what the anticipated outcomes of interactions are, and how the informant feels about all of this information (Spradley, 1980). The primary difference between the informal interview and the formal interview is that the researcher has a better conceptualization of how factors might be related at the time of the formal interview and has developed specific questions that probe deeper to illuminate the components of the relationships. Both formal and informal ethnographic interviews are more focused than just friendly conversations and serve a different purpose than traditional journalistic interviews where the intent may be simply to entertain and/or inform.

The gathering of data to describe behaviors provides the researcher with facts that help them to understand a lived experience and develop theoretical explanations for these experiences. Typically, the fieldwork data collection process is long enough to participate in a full cycle of activities amongst the cultural group and the work is wide enough to be present where key activities occur. The observations and interviews may directly impact practical nursing care by alerting the researcher to specific practice concerns that are negatively impacting the experiences of the participants. However, once data are collected, the researcher is still left with the challenge of deciphering meaning and finding trends in experiences amongst individuals of the same cultural group.

### Interpretation

Interpretation is the way that symbols, such as language, are used to describe behavior. For the researcher, a theoretical perspective guides interpretation. Famed ethnographer Malinowski

(1944) noted, “there is no such thing as description completely devoid of theory” (p.7). Theory, or ideas about how concepts are related to explain phenomena, is rooted in one’s disciplinary perspective (Robinson, 2013b). This perspective, or worldview, is determined by the concepts most valued by that individual. Therefore, in the process of obtaining descriptive accounts of experiences from participants, the researcher learns of the relationship between values and behaviors. Furthermore, the theoretical perspective of the researcher aids him or her in both recognizing patterning and determining relevancy of noted patterns for further inquiry. As Malinowski (1944) further noted, theory verifies the relevancy of facts to specific courses of events. Therefore, while the meaning of cultural behaviors is explicated by the research participants, the researcher determines how these individual behaviors are connected to a larger pattern of behaviors.

The obvious problem that can arise in interpretation is that the researcher can unintentionally inform meaning in a study by integrating his or her own beliefs and values. The scientific method of ethnography postulates that the discovery of human actions, and the rationales for those actions, must precede both professional and academic interpretations of those actions (LeCompte & Schensul, 1999). As Spradley (1980) noted, “Any explanation of behavior which excludes what the [participants] themselves know, how they define their actions, remains a partial explanation that distorts the human situation” (p.16), and as such introduces research bias. Ethnography prevents this distortion of reality through its data collection process in which participant informed interpretations of behavior are noted along with the behaviors themselves (LeCompte & Schensul, 1999; Spradley, 1980). Furthermore, the processes of collecting multiple data sources helps to establish the truth value and consistency famed qualitative researchers Lincoln and Guba (1985) described when discussing research trustworthiness. Additionally, the researcher remains conscientious of their own feelings and ideas about the phenomena they are studying, the data they have collected, and the personal consequences of study involvement by recording introspective thoughts in a journal throughout the study (Creswell, 2007; LeCompte & Schensul, 1999; Schensul et al., 1999; Spradley, 1980; Van Manen, 1990). The thoughts and ideas in this journal are particularly important as they help to maintain the neutrality of the researcher. This journal also becomes central during the analysis process as it helps the researcher identify patterning, advance emerging theory, and keep their own biases about such matters at bay.

## Data Analysis

Unlike solely quantitative research, data analysis in ethnography does not take place following the completion of data collection; rather, it happens concurrently to data collection using a recursive, or repeated process of analysis, until patterning becomes apparent (LeCompte & Schensul, 1999; Spradley, 1980). Spradley (1980) described a widely accepted data analysis plan that is separated into three stages of analysis including domain analysis, taxonomic analysis, and componential analysis. Each stage is repeated as necessary until the relationships between and among the behaviors described within the field notes become clear.

### Domain analysis.

The process described by Spradley (1980) begins with what he calls a domain analysis, or patterns of sameness. After a few initial observations of human behavior and perhaps a few interviews with key informants, the researcher reviews the individual elements of a social situation and attempts to determine how they are logically related. For example, a researcher at a flu clinic may record a behavior observed as pulling away a bit and frowning following an injection. This behavior may then be described in a participant interviews as a wince. After reviewing field notes, or the written accounts of data that were collected through observations and interviews, the researcher may determine from domain analysis that a wince describes a type of pain response. This process of describing the semantic relationship between the cultural meaning and the lived experiences continues until uncertainties arise; at which point the researcher collects further observational or interview data to clarify.

### Taxonomic analysis.

Following domain analysis, taxonomic analysis, or the process of determining the organization of cultural domains, is completed (Spradley, 1980). Taxonomic analysis involves finding the patterns between different categories of behavior using both contrast and comparison. Whereas domain analysis connects cultural meaning to individual behaviors, taxonomic analysis evaluates the connectedness of groups of behavior. In continuing with the previous example of the flu clinic, taxonomic analysis might find that several behaviors, such as wincing, frowning, sucking air, gritting teeth, and shutting eyes tight, all fall under the category of pain response. It is often during taxonomic analysis that the researcher finds that some domains are part of a larger domain. Ultimately, taxonomic analysis shows "the relationship among all the included terms in a domain" (Spradley, 1980, p. 113). Again, uncertainties in classification are clarified through further observation and interviewing of participants as necessary. The final stage of analysis is that of componential.

### Componential analysis.

Spradley (1980) described componential analysis as a "systematic search for attributes (components of meaning) associated with cultural categories" (p.131). The attributes of a cultural category are its unique characteristics that are consistently present. These attributes are clearly separated by nuanced variations from other categories and thus create patterns of contrast. For instance, an attribute of a flu clinic is that the only service provided is the administration of the influenza vaccine. In comparison to other types of clinics, such as a sports physical clinic, or a TB clinic, it becomes apparent that the central term clinic refers to a type event in which behavior focuses on the provision of one service for a limited time. The anticipated outcome of componential analysis is to find differences in attributes and determine how they are connected to a theoretical framework. Again, as in the previous stages of analysis, information is further clarified by participants through observation and interviews. Completion of all three stages of ethnographic analysis, to the point where patterning is apparent, yields theory that is grounded in research findings or better known as grounded theory (Glaser & Strauss, 1967).

## Theory Development

As was previously noted, research begins with ideas about how concepts are related. These formative theories inform the research question and methodology—the logical process for affirming and connecting facts (Carter & Little, 2007; Malinowski, 1944). Grounded theory arises in ethnographic research from the constant comparison of concepts that takes place during the course of a study. The behavioral patterning that becomes apparent at the conclusion of the study leads to modifications of the formative theory that initiated the research. Eventually, these modifications result in a complete theoretical model (Schensul et al., 1999). Theory is the anticipated outcome of science and accomplished by connecting concepts to build hypothetical structures that explain facts relevant to a particular discipline (Jacobs & Huether, 1978).

Ethnography has its roots in the discipline of cultural anthropology. In cultural anthropology, the practical activities for finding facts have focused on observations and descriptions of social behavior with the aim of discerning cultural patterning (Wolcott, 1999) in order to solve human problems (American Anthropological Association, 2011). Similarly, nursing, or the study of humans participative experiences with health (Parse, 1998), uses observations and descriptions of behaviors, within the context of health, in order to understand how culture, the widest context of human behavior (Malinowski, 1944), impacts health decisions and influences quality of life. Information discovered by cultural anthropologists, using ethnographic methods, helps to build the discipline of anthropology by generating various social theories that explain behavior. Similarly, information discovered by nurses using ethnographic methods can help to build the discipline of nursing through the development of various nursing theories that explain behaviors. Additionally, the information discovered by nurses using ethnographic methods, assists them in intervening with humans to optimize health and diminish suffering. Though the disciplinary perspectives may vary a bit, both nursing and anthropology are essentially concerned with improving the human condition.

## Improving the Human Condition through Critical Ethnography

Fundamentally, nursing practice revolves around improving the human condition. Similarly, research about improving nursing practice explicitly commits to improving the lives of those nurses care for. In fact, certain research traditions also explicitly target improving the lives of research participants, or using their experiences as a guide to improve the lives of the community's participants represent. This is the case for qualitative research methods, such as ethnography, that aim to empower humans through social action—especially when based on a critical theory perspective (Creswell, 2007).

While most ethnographies are interpretivist and anticipate that social interactions serve as the site where cultural and social life is produced and changed, increasingly, ethnographies are taking a critical theory approach to identifying inequities and righting wrongs. Critical theory posits that scientists are expected to function as both intellectual advocates and activists (LeCompte & Schensul, 1999). Within a critical theory framework, a phenomenon is investigated with the understanding that there is something in need of repair. Research efforts are not just focused on the effort to understand, but "to understand what is wrong, and link the problem to some greater wrong operating at some grander level" (Wolcott, 1999, p. 181). As philosopher Karl Marx noted, "Why should we be content to understand the world instead of trying to change it" (as cited in Wolcott, 1999, p.182). Change is made possible through the identification of meaningful relationships (between external forces and participant experiences for instance) during the ethnographic research process.

During a research process, the distribution of power amongst social groups may become apparent. The researcher may be able to effect a shift in power and empower individuals by assisting them in recognizing their own power. Empowerment may be as simple as allowing a participant to share their story and have their voice heard in the research process (Creswell, 2007) or as complicated as assisting participants in accessing social and economic resources that allow them to become activists in shaping their own future (LeCompte & Schensul, 1999). The scientists using critical theory to guide their work "accept an added research task of raising their voice to speak to an audience on behalf of their [participants]" (Wolcott, 1999, p. 183). Empowerment is essentially the practical work of nursing.

Understanding how culture influences health and healthcare provides nurses with important knowledge to effectively assist patients in achieving optimal well-being and a high quality of life. As the essence of nursing practice is the prevention and alleviation of suffering through the diagnoses and treatment of human responses to both actual and potential health problems (American Nurses Association, 2010), quality of life is also an important concept to nursing as it reflects the overall human response to changes in health.

Nurses help individuals to find quality of life in the midst of life happening and at every point along the health continuum (Robinson, 2013b). The nursing work of advocating, protecting, promoting, and optimizing health through the facilitation of adaption provides a unique research perspective with an important utility when used in ethnographic research. In essence, ethnography affords nurses the uncommon ability to simultaneously advance both the science and practice of nursing, and to effect changes that improve people's lives.

## Ethnography in Nursing Research

Despite the seemingly natural fit between nursing and ethnography, ethnography in nursing research occurs far less often than other types of qualitative methods such as phenomenology and grounded theory. The less frequent use of ethnography as a research method may be related to assumptions regarding how the term "culture" is commonly used to reference individuals belonging to the same racial, or geographic location, rather than referencing the more complex conception of culture wherein a group shares knowledge or meaning-filled understandings, attitudes, customs, and beliefs that distinguish one group of people from another (Hirsch, Kett, & Trefil, 2002). Additionally, discord continues amongst nurses who use qualitative methods regarding how qualitative data should be used.

Mitchell and Cody (1992) for example argued, "knowledge is not used or applied to the person, but rather knowledge enhances understanding" (p.58). This statement is based on the view that the role of research is primarily to advance theory and it is only theory that directs nursing actions (Parse, 1998). While this point of view allows for research data to expand theory, it does not allow for research findings to directly impact care delivery as new information is discovered or investigations of phenomena begin with an aim of identifying problems and assisting with their resolution. Furthermore, regarding the use of ethnography in nursing, Mitchell and Cody (1993) noted, that while the goal of ethnography is "to uncover the shared meanings of a cultural group" the findings in ethnography "have more relevance for other disciplines or maintaining the status quo of biomedical nursing" (p.173). Ethnography provides a trustworthy means of systematic qualitative inquiry within the discipline of nursing that both expands nursing knowledge and has the potential of directly impacting care. Not only does ethnography provide a means of scientific inquiry and nursing disciplinary advancement, but ethnographic methods are also successfully used to strengthen and evaluate intervention programs, influence public policy, and enhance public programming (Schensul et al., 1999). Interestingly, rather than using traditional ethnography to advance nursing practice and science, at least one nurse, Madeleine Leininger, has developed a transcultural theoretical framework and methodology, rooted in anthropology, for research centered on the provision of culturally-congruent nursing care separate from the long-established methods in ethnography.

#### Transcultural nursing.

Transcultural nursing is a concept developed by Madeleine Leininger (1991) in the late 1950s with the aim of using science as a means for developing more culturally congruent care for nursing practice (Welch, 2002). Leininger, who was formally trained in both anthropology and nursing, readily saw the commonalities between the two disciplines and believed that the study of cultural meanings, values, beliefs and symbolic referents of care, could be used to help cultures by promoting health, healing, well-being and ultimately quality of life (Leininger, 2007). The theory of culture care diversity and universality is based on two premises: that caring is the essence of nursing practice and that discovering patterns of caring amongst humans will lead to new knowledge that will transform the provision of healthcare services (Leininger, 2007). The ethnonursing research method was developed by Leininger to provide a means of gathering data and completing data analysis within the theoretical framework of culture care (Welch, 2002).

While the provision of a caring relationship that facilitates health and healing is one of the primary features of the profession of nursing (American Nurses Association, 2010), the phenomenon of caring in itself is not unique to nursing (Fawcett, 2005) or human kind (Dienske, van Veeswijk, & Koning, 1980). Rather, the phenomena of health, as it relates to the process by which humans use specific behaviors to attain optimal well-being, is the central phenomena of concern to nursing (Barrett, 2002; Carper, 1978; Donaldson & Crowley, 1978; Parse, 1998; Schlotfeldt, 1988). Leininger (2007) further noted that the knowledge of culture and care practices is essential in understanding why people and cultures have survived through time; a circumstance where adaption proves an important factor of cultural survival. Observing patterning in human behaviors can reveal to nurses and other health professionals how certain actions maximize health. Furthermore, this information may be used to help humans to reach integration, or a state in which the "structures and functions of life processes are working as a whole to meet human needs" (Roy, 2009, p. 27). More often than not, nurses do not complete full-fledged ethnographies in which an entire cultural group is studied and described. Rather, nurses tend to focus on distinct health-related problems within specific contexts and amongst small groups of people (Roper & Shapira, 2000). Such ethnographic methods within this context are often referred to as focused ethnographies, miniethnographies, or microethnographies.

#### Focused ethnographies.

According to Roper and Shapira (2000), focused ethnographies are used by nurses to study specific health practices amongst certain populations. Because the research concentration is very specific, these types of ethnographies may be completed in a shorter amount of time and the information gathered is expected to be useful and have practical application for health care professionals. Although the scope of a focused ethnography is smaller than that of a traditional ethnography, the authors suggested that focused ethnographies maintain the characteristics of traditional ethnographic inquiries and therefore still allow for understanding of “the complexities of common situations” and advance theory (Roper & Shapira, 2000, p. 9). It is the position of this writer however, that within the context of critical ethnography, a priori knowledge may be used to isolate specific health-related concerns and the in-depth analysis described by Spradley (1979) may continue focusing on only a few cultural domains. Preliminary informal interviews may take place near the start of the study to ensure that the chosen domains are in fact culturally rooted and appropriate for continued study. Additionally, as this method is suggested for use within a nursing perspective, reference works using the method as a “nursing ethnography” sufficiently identifies the ethnography as being rooted in nursing and primarily concerned with the phenomena of health within the context of culture. Any further delineation is unnecessary.

The following chapter provides the methods for performing a nursing ethnography of Black American older adult experiences with pain and pain management with an eye to improve nursing practice and comment on the adequacy of the Roy Adaptation Model to represent the participants’ world.

# CHAPTER 3

# METHODS

The following chapter provides further detail on the study to be carried out. While ethnography and its linkages to nursing science and practice were outlined in Chapter 2, Chapter 3 describes operationally and procedurally how ethnography will be used to answer the research questions raised. Research tools such as questionnaires, interview guides and data analysis software are described. The setting and participants to be included in the study are specified along with ethical considerations for informed consent and research trustworthiness. At the conclusion of Chapter 3, the reader will have a clear picture of how this researcher will study the experiences of Black American older adults managing pain within the context of a nursing ethnography.

## Study Design

The proposed qualitative study will use an ethnographic methodology as outlined by Spradley (1979, 1980) and LeCompte & Schensul (1999) to answer the following research questions:

1. How do Black American older adults experience pain and pain management operationally, emotionally, and qualitatively (the defining attributes)?
2. How do Black American older adults cope with pain, particularly, what are the relationships between pain management and health related quality of life (HRQOL) and what does this tell us about the extent to which the Roy Adaptation Model resonates with these participants' lives?
3. Given their experiences with pain, pain management, and coping strategies, what advice might older Black American adults give to improve pain management in nursing practice.

Like other contemporary ethnographic works, descriptive qualitative data along with participant informed quantitative data will be used to better understand population demographics and participant behavior. Following appropriate notification, initial observations of the population within common areas of the facility will take place. These observations will be recorded within the field notes as condensed accounts then developed further into expanded accounts. After scheduled informational meetings, the researcher will begin to administer sample surveys to 120 willing residents, who have passed the Animal Naming Test (see Appendix B) for cognition and completed necessary consents (see Appendix C). As there is a total sample of approximately 470 residents living at the research site, a sample size of 120 provides around 30 percent variability.

The surveys completed by the residents will provide a better understanding of the characteristics of the population such as current levels of stress, health related quality of life, the presence of pain, current health conditions, and other demographic data. This demographic material will be summarized in SPSS using descriptive statistics (mean, median, mode, and standard deviation). Copies of all survey tools used are provided in Appendices A – H and described in further detail within the Measures section.

Throughout the study, behavioral observations will continue to be made and documented within the field notes. While collecting survey data, the researcher will also engage in informal interviews with participants. The aim of the informal interview is to clarify observed behaviors and information noted on survey tools. These conversations will also provide an opportunity to shed further light on typical daily living within the residential center.

One of the survey tools to be used is the Brief Pain Inventory (see Appendix E). Out of the 120 residents completing survey data, 20 who identify as being positive for pain will be asked to complete formal recorded interviews with the researcher in the privacy of their apartment or other location of their choosing. A copy of the formal interview prompts are provided in Appendix H. Recorded interviews will be transcribed and uploaded into NVIVO for analysis as described by Spradley (1980) and noted within Chapter 2. Ultimately, all data will be framed within the context of health. Applicability to the Roy Adaptation Model will be considered. Following data analysis, secondary confirmatory interviews will take place with available residents who completed a first interview to determine if analysis is in congruence with residents expressed thoughts and ideas.

## The Participants

The population of interest is composed of individuals self-identifying as Black American who reside in a senior housing complex within metro Detroit. Approximately 470, predominately Black American elders currently reside in the independent living housing complex chosen (described further in the “Setting” section). Unlike participants living in more restrictive settings such assisted living or adult foster care, these residents are capable of living independently and making their own choices regarding daily life. The only criterion for residency is age 55 and older. 55 is generally considered the cut off for middle-aged adults and the beginning of the “young-old” adults (Richeson & Shelton, 2006). Elders may be observed in common areas of the facility, or while completing survey tools/ interviews with researcher. As previously noted, 120 elders will complete survey tools to provide an adequate description of the population residing in the facility. Additionally, 20 elders will complete formal interviews with the aim of reaching data saturation, or evidenced repeated themes occurring.

### Accessibility.

The community dwelling Black America older adult population is moderately accessible with primary barriers being direct accessibility to the senior housing complex which is gated. The researcher currently has access to the population.

*Inclusion criteria* for participation in the study are as follows: 1) Resident of senior housing complex, 2) Age 55 and greater, 3) Able to speak and understand English, 4) Self-identified as Black American (Black, African-American, Caribbean-American, etc.), 5) A score of 14 or higher on the Animal Naming Test (see Appendix B), and for participation in the formal ethnographic interview portion of the study 6) Presence of pain in the past week or regularly taking pain medication to manage pain. Patient's self-report and nursing assessment will determine all inclusion criteria.

*Exclusion criterion* for the study is limited to patients unable to speak and understand English as determined by nursing assessment and those who do not meet the other inclusion criteria. The total number of participants as well as those, meeting inclusion criteria but declining to participate will be documented within the field notes.

### Recruitment.

The researcher will appropriately introduce herself to the community of older adults as a student researcher who is making observations and interviewing individuals about their health and pain management practices. There will be several flyers (see Appendix A) circulated throughout the facility with details of the study prior to the collection of observational data. There will also be a few informational meetings scheduled for the building to answer questions and allow interested residents to complete the consent process. Recruitment will therefore be directly through the researcher using targeted recruitment strategies that include facility informational meetings, regular recruitment days and recruitment flyers and posters. Through these techniques, potential participants will have a variety of ways to contact the researcher and note interest in study participation.

### The setting.

The setting for the proposed study is a senior housing complex within Southeastern Michigan. This high rise senior residence has approximately 470 community dwelling elders who live in one or two bedroom apartments that range in cost between $600 and $725. All utilities are included in the price of the rent. Only housing in provided in the residence, however, many outside agencies provide a variety of other services. For example, health care services such as bathing assistance and nursing visits are provided by home care agencies individually contracted by the residents. Meals on wheels and other organizations supply lunch time meals in a common area free of charge. A mobile library unit comes to visit several times a month, and university programs provide computer training and some health education events. As such, the setting chosen is an active residential community for residents. A letter of support from River Towers has been included in this proposal and may be noted in Appendix H.

## The Data Collection Tools

A variety of data will be collected from within the setting described above to answer the research questions and describe the population. The data sources will include researcher observations and field notes, recorded and transcribed elder interviews see (Appendix H), and three survey tools—the Brief Pain Inventory (BPI) (Appendix E), the PROMIS Global Health Scale (Appendix F), and the Psychological Stress Measure (PSM-9) (Appendix G). Additionally, all participants will complete a demographic questionnaire (Appendix D) and be prescreened for participation using the Animal Naming Test (Appendix B). While participant observation and interviews will suffice in answering each research question, the additional data tools listed will serve to provide descriptive information about the population (see Table 1).

The total data collected will describe the participant population and identify similarities, differences, and barriers in the management of pain as well as conceptualizations about health-related quality of life. The non-observational data collection tools to be used are described in further detail in the following section. Each tool provides an additional means of understanding the characteristics the population under study and will aid the researcher in evaluating behavioral patterning and understanding how meaning is assigned to health behaviors in the management of pain amongst Black American older adults who reside in a senior housing complex.

### Animal Naming Test.

The Animal Naming test is a brief screening tool used to identify individuals with cognitive impairment. Specifically, the test evaluates semantic verbal fluency. Semantic memory is a component of long term memory that allows the recall of knowledge of objects, facts, words and their meaning (Hodges, Patterson, Oxbury, & Funnell, 1992). An early indicator of cognitive decline is the inability to recall the names of several examples of a category such as names of animals, things you buy at the grocery store, types of fruits, etc. (Tombaugh, Kozak, & Rees, 1999). The Animal naming test (Hermann, LaRue, & Woodard, 2006) in particular is frequently used in both clinical and research settings to screen for dementia. Essentially, participants are asked to name as many animals as they can within 1 minute. Naming less than 14 items in a minute indicates cognitive impairment may be present.

### Demographic questionnaire.

A demographic questionnaire will be administered to residents of the senior housing complex to aid in further understanding the population being studied. Questions of interest include information regarding age, marital status, cohabitants, religious affiliation, financial coverage for health benefits such as physician visits and prescription medication.

### Brief Pain Inventory (BPI).

The Brief Pain Inventory is a 9-item tool that rates pain severity and interference of pain in seven key areas of function often correlated with quality of life. While the BPI was initially developed to evaluate pain in cancer patients, it has been validated in non-cancer patients with a coefficient alpha reliability rating above 0.70 (Tan, Jensen, Thornby, & Shanti, 2004). The use of the tool within the study will provide detailed information regarding pain and the influence of pain on daily living for the population subset participating in ethnographic interviews.

### PROMIS Global Health Scale.

The Patient Reported Outcomes Measurement Information System (PROMIS) is a system of reliable survey tools designed to measure patient reported health within the major quality of life domains physical, mental, and social well-being (National Institutes of Health, 2013). Pain is addressed within the PROMIS questionnaire. This tool was developed with the intention of standardizing the measurement of patient-reported health data for use in medical research to help measure the impact of treatments (Fryback, 2010). The PROMIS Global Health Scale short form is a 10-item instrument that will provide overall information on the self-reported health of the population residing in the senior housing complex.

### Psychological Stress Measure (PSM-9).

The PSM-9 is a nine-item survey tool designed to measure psychological stress, or states of psychological tension caused by events and circumstances that increase the psychosocial and/ or physical demands of the person (Lemyre & Lalande-Markon 2009, Lemyre & Tessier 2003). Again pain is addressed within the PSM-9 as in the PROMIS. The tool is based on a stress and coping model similar to the Roy Adaptation Model with the primary difference being a focus on measuring stress rather than recognizing adaptation. Additionally, stress is viewed as a construct of adaptation. The PSM-9 was initially developed based upon stress descriptors derived from focus groups then abridged for practical use within public service and clinical health settings. Validity, reliability, and internal consistency (.89) have been established (Lemyre & Tessier 2003) and the tool is appropriate for this study.

As noted, the measures described will provide helpful descriptive data to the researcher that will be beneficial in clarifying the characteristics of Black American older adults residing in an elder housing community in Southeastern Michigan. Additionally, the use of multiple data sources creates redundancy which allows for confirmation and corroboration of data along with triangulation—the cross checking of data between sources (LeCompte & Schensul, 1999). Observations, interviews, and collection of survey data will not only assist the researcher in answering the research questions, but ultimately will help to identify the relationship between stress, quality of life, and coping amongst community dwelling Black elders. The following section describes the explicit procedures for this research.

**The Procedure**

1. An informational flyer (see Appendix A) will be distributed throughout the facility. Each resident will receive a copy of the flyer via the resident newsletter. Additionally, flyers will be posted in common areas, and distributed during meetings and social events in the facility.
2. The researcher will begin taking field notes, documenting the setting, experiences, interactions, and observed behaviors. Documentation in field notes will continue throughout the data collection phase of the study. The initial writings will be condensed accountings of observations and will be lengthened into expanded accounts noting greater detail and reflection.

3. Informational meetings will take place on three different occasions within the facility to allow for further explanation of the study in detail to residents and staff as well as answer any questions that might arise.
4. Residents receiving flyers or attending the meeting that would like to participate in the study may complete the screening process (the Animal Naming Test see Appendix B), provide written consent (Appendix C), and complete a questionnaire packet that includes the Demographic Questionnaire (Appendix D), the Brief Pain Inventory (BPI) (Appendix E), the PROMIS Global Health Scale (Appendix F), and the Psychological Stress Measure (PSM-9) (Appendix G).
5. The researcher will conduct informal interviews with residents while they complete questionnaires to clarify observed behaviors, information about the site, happenings at the site, and information collected on the questionnaires.
6. Participants completing the questionnaires will be compensated $5 for their time and inconvenience.
7. Participants who scored positive on the Brief Pain Inventory (BPI), and meeting inclusion criteria will be asked to complete a formal interview (see Appendix H) which will be recorded, transcribed, and entered into NVIVO for analysis.
8. Participants completing formal recorded interviews will be compensated $20 for their time and inconvenience.
9. As field notes and interviews are being completed the researcher will continue to make observations and look for patterning. This will allow for the completion of domain, taxonomic, and componential analysis.
10. All questionnaire data will be entered into SPSS and frequency data generated.

11. PROMIS data will be entered into the secure PROMIS web-based data site for analysis.
12. Following the analysis of all data, the researcher will check back with interested participants to determine if findings are congruent with participant beliefs.
13. Participants completing secondary interviews will be compensated $20 for their time and inconvenience.

## Protection of Human Subjects

Prior to the initiation of any research activities, the researcher will obtain appropriate approvals from the Wayne State University Institutional Review Board (IRB) Human Investigative Committee (HIC) as well as obtain the appropriate letter of support from community housing manager at the data collection site. All residents and staff of the research site will be made aware of the study and the fact that observational data will be collected through the distribution of flyers and informational meetings. Anyone may notify the researcher of their desire to opt out of the study and not have their actions or behaviors documented. This information is provided on the Informational Flyer (Appendix A) and will be reiterated at the informational meetings. During ethnographic interviews, participants will be reminded that they can request the recorder be turned off at any time if there is something that they would like to share but do not want recorded. Additionally, all participants will be reminded that they do not have to respond to questions that they are not comfortable with and may stop the interview or discontinue the survey at any time. They will also be notified that information regarding child/ elder abuse, reportable communicable diseases, and illegal activities may be reported to appropriate authorizes if disclosed.

All persons wishing to participate in this study by providing questionnaire data or completing interviews with the researcher will compete an Informed Consent Form (see Appendix C) which outlines the study's purpose, procedures, confidentiality, voluntary nature, risks, and benefits. The only personally identifiable data to be collected will be on the consent forms. These forms will be kept separate from other research data and maintained in a locked file. Finally, participants will be informed that services provided at the residence will in no way be impacted by participation or lack of participation in the study.

If a participant voices discomfort during the interview at any time the interview will be stopped. If a participant becomes emotionally distressed during the interview, appropriate referrals will be made, with the participant's permission, to the building manager who assists in the coordination of care and can connect the resident with the appropriate case manager or social worker.

All recordings will be kept in a lock box located in the researcher's home when not in use. Transcripts will be maintained electronically on a password-protected computer and within a password protected file. All identifiable information will be removed from transcripts and all electronic data will be password protected with access available only to the researcher and the dissertation chair. Pseudonyms will be used to identify interview participants. Finally, per the Wayne State University Division of Research, all transcripts, and tapes will be kept for a minimum of five years and then destroyed by file shredding and electronic file deletion.

### Compensation

To provide compensation for time and inconvenience, participants will be given $10 for the completion of the population survey tools and $20 for participating in formal interviews.

### Innovation

Very few studies have examined how the Black American community dwelling older adult manages pain and the meaning of pain experiences for these older adults. The delineation of the pain experience for Black American older adults may also further explain the role of coping variables in the management of pain. Therefore, the proposed research project will improve scientific knowledge by increasing understanding of adaptive human responses that influence health outcomes. This important information may then be used in future research to test specific adaptive coping stratagies used by the Black American older adult population and to better understand the correlations of those coping variables to pain intensity and quality of life. Furthermore, it is anticipated that work from this study will result in a clarification of the Roy Adaptation Model and provide a framework for grounded theory that will inform both nursing science and practice. Understanding the relationship between pain management and health moves nursing science forward and promotes health. Additionally, the proposed project is likely to improve clinical practice by generating information for providers on patient centered approaches that help elders to improve self-management of chronic pain.

# CHAPTER 4

## Findings

The general aim of this work was to develop an increased understanding of what it is like to experience pain as a Black American older adult. It was anticipated that by evaluating the pain management experiences and behaviors of Black American elders from their own perspective and within their own environment, ideas for improving pain management nursing practice might be elicited. Nearly one year was spent observing, interviewing, and interacting with residents and staff of a community based elder housing establishment.

One hundred six of the residents completed a questionnaire packet that asked a variety of demographic questions such as their age range, marital status, and religious affiliation (see Appendix D). They also self-identified diseases and other medical conditions from a listing of common illness effecting Black elders (see Appendix D). Additional assessment information collected within the questionnaires included: data on pain—specifically the number of pain sites, pain severity, and how pain effected common daily activities (see Appendix E), self-reported outcome measures of quality of life—within both the mental and physical health domains (see Appendix F), and an evaluation of stress (see Appendix G). All residents completing the questionnaire were a random convenience sample recruited directly by the researcher with some snowball recruitment taking place as residents referred their neighbors and friends residing in the building.

When a resident completing the questionnaire self-identified as having pain and they were determined to be a good reporter by the researcher, they were invited to complete a more formal, which was recorded and followed an interview guide (See Appendix H). A total of 20 residents completed formal recorded interviews and follow-up interviews with the researcher. These interviews provided greater detail on what it was like for them to live with pain.

Additionally, numerous informal interactions with and observations of the residents of the facility took place over the course of 10 months. These observations and interactions were mostly completed in common areas of the facility, but also took place in individual apartments as invited. As per study protocol, whenever observations were being made in a common area of the facility residents, visitors, and staff were reminded that interactions were being observed and documented. Furthermore, all participants completing formal interviews were provided the opportunity to meet privately in their home, however many preferred to meet in common areas of the facility. Privacy was still assured by meeting at times of the day with low traffic in the area and in locations that allowed for more intimate conversations. The researcher also consistently wore photo identification from Wayne State University that was easily visible and identified her as research staff. After several weeks at the site, both residents and facility staff began to recognize the researcher, make appropriate greetings, and at times provide introductions to other staff and visitors. Numerous opportunities were available, and of course used, to informally interview residents and staff regarding normal daily activities, to clarify observations, and to expand upon topics gathered from the more in-depth formal interviews. These observations, informal interactions, and researcher notes were maintained within a field work journal.

The culmination of these data revealed that these urban Black American older adults were able to maintain community engagement despite moderate to severe pain that often limited their functional ability. Pain and its management had profound effects to the physical, mental, social and even spiritual health of these elders. However, they keenly managed their pain, with medications, home remedies, prayers and social supports despite an underlying fear of dependence.

The following chapter provides details of the study findings within the context of the research questions.

## The Black Elder Pain Experience

The first research question this study considered was how do Black American older adults experience pain and pain management operationally, emotionally, and qualitatively (the defining attributes)? This question was answered by means participant observation, interviews, demographic data, and the Brief Pain Inventory. In addition to providing information on how the surveyed population experienced pain, the data collected provided facts about the general characteristics of the participants.

### Participant characteristics.

The participants of the study represented a diverse group of men and women. Approximately 60 percent (62.3%) of the participants were female, while 40 percent (37.7%) were male. Ages ranged from 55 to over 90 with the most common age range being between 60 and 64 (see Table 2). Additionally, while many participants listed themselves as being currently single (38.7%), more than half were either currently separated, divorced, or widowed (52.8%) (see Table 3). Interestingly, 83 percent of the elders surveyed lived alone, while only 17 percent lived with someone—generally a spouse or child (field notes). Religious affiliations covered everything from Catholicism to Mormonism with the majority of participants being affiliated with the Baptist church (50.9%) (see Table 4). On the questionnaire that was completed, participants were asked to circle medical conditions that they had been diagnosed with. The most common conditions included hypertension (hypertension 68.9%), osteoarthritis (58.5%), diabetes (36.8%), and depression (25.5%) (see Table 5). It is probable that the participants' health conditions affected how they experienced pain.

### Pain severity and interference.

The Brief Pain Inventory – Short Form (BPI) was used as a means of understanding how Black American older adults experience and react to pain. Specifically, the BPI subjectively evaluates pain within the sensory domain, how badly it hurts (severity), and within the reactive domain, or how much it interferes with usual daily activities (interference). In completing the BPI, participants described the total number of pain locations on the body, their least, worst, average, current pain intensities, and the medications commonly taken for pain along with their effectiveness. Furthermore, the BPI evaluates how pain effects common activities of daily living such as sleeping, walking, working and getting along with others. According to questionnaire responses, about 86 percent (n=91, 85.8%) of the surveyed population experienced pain in an average of 5 pain sites. However, it should be noted that most the frequently recorded number of pain sites, or mode, was 2. When asked to rate the worst pain experienced in the past 24 hours on a 0 to 10 scale with 0 indicating no pain and 10 indicating pain as bad as you can imagine, the mean score recorded by participants was 7 with the most frequently recorded score being 10. The average pain score for the group was also rated as 7 (see Table 6). Pain severity, which is calculated by determining the average, or the composite score, of the least, worst, average, and now pain, on the same 0-10 scale described above, was about 5 (5.49). It was expected that the higher reported levels of pain severity would correspond to pain interference scores.

Pain interference, or the measure of how much pain has inhibited usual daily activities is scored by calculating the average scores of the seven interference domains: general activity, mood, walking, work, relationships, sleep, and life enjoyment. Interestingly, although the group only reported average pain interference of about 4 (4.23), on a 0 to 10 scale, with 0 indicating no interference and 10 indicating complete interference, scores were over 5 within the specific domains of general activity (5.59), walking (5.73) and normal work (5.7). The lower interference score of 4 is accounted for by lower participant scores in the areas of relations with other people (3.38) and enjoyment of life (4.09) (see Table 6). Although generally, increased medication usage and increased use of opioid analgesics might be expected amongst a population reporting moderate to severe daily pain, this was not the case with this particular population.

### Medication usage.

Despite the benefits of prescription pain relievers, participants often found pain medications not to be very effective in the reduction of pain. According to participant survey responses, the average pain relief from pain medication was only 65%. Only about 20 percent of the population experienced 100% pain relief from pain medications. Although most of the surveyed population reported severe pain, the most commonly prescribed pain medications were medications commonly prescribed for mild to moderate pain: hydrocodone with acetaminophen (29%), acetaminophen with codeine (12%), tramadol (10%), and ibuprofen (6%) (see Table 7). About 17 percent of the population surveyed who were experiencing pain took no medications at all.

### *Treatment preferences.*

Many participants had a preference for natural non-pharmacological treatments and home remedies for pain management (BPI, field notes). This preference, often arose out of concerns about medication side effects such as nausea, constipation, fatigue, dizziness, and mental fogginess (9 sources, field notes). In fact, during formal interviews, about half of the elders interviewed, discussed concerns they had about side effects (9 sources). Additional elders discussed these same concerns informally as they completed their questionnaires (field notes). As one resident Esther[1]

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[1] All names and other personally identifiable information have been changed to protect anonymity.

related, “I read every one of my scripts; it had all the same side effects. If you’ve got four scripts with the same side effects, what kind of condition are you going to be in?” Esther’s concern resulted in her not taking any of those four prescription medications (Esther). In fact, six other participants specifically discussed not taking their medications, because they were either concerned about side effects or they did not feel as though the medications were helpful. Laura also avoided taking her prescription medication due to concerns about side effects. She noted, “When I have pain in my legs, I just go in the bath room and put some warm water on it, because he gave me some medicine for them, and I don't take it because it makes me sick.” Naomi was very clear that she would not take medications if she believed that there were too many bothersome side effects listed. “I don't take medications that have a lot of side effects,” she said.

Rather than using prescription medications, some participants chose to use natural home remedies. These remedies ranged from simple treatments like aroma therapy, hot water soaks or baths, often with Epsom salts or vinegar, to more complicated concoctions (field notes). For example, a few participants described using red alcohol for pain (Lois, Daphene, Yvette, field notes). The red alcohol, commonly sold under the brand name Dr. Fred Summit’s Penetrating Arthritis & Sport Rub™ was readily available at local dollar stores (neighborhood stores with many low priced items that generally start at $1) (field notes). The red alcohol is a thin liquid salve that contains isopropyl alcohol, Epsom salts, and capsicum. Daphene described it as smelling like, “a lemon in the sun” however the researcher thought it smelled more like menthol (Daphene, field notes). It may be applied directly to skin for pain treatment or added to water for soaking (field notes). A couple of participants described making a new salve from the alcohol. The new salve was created by filling a glass jar with “a neck that is big and wide,” like a mason jar, with moth balls, pouring the red alcohol on top of the moth balls then allowing the mixture to sit for about 3 weeks (Yvette, field notes). This new remedy was reported to have a strong cooling affect and similar to the original preparation, it was placed directly on the skin or added to water for soaking.

Other types of rubs, creams, and ointments, often referred to as liniment, were also used by participants. One resident described making homemade capsaicin ointment. She stated, “That’s just cayenne pepper. Basically; it’s real pepper. So I will use the oil, it was peanut oil, and I will put that on there [the cayenne pepper], you know, to see if it would help and it--sometimes it did” (Theresa). Residents who preferred to stick to store bought treatments, had a preferences for things such as green alcohol (isopropyl alcohol with wintergreen oil (methyl salicylate)), Icy Hot®, RingMaster’s Oil®, Tiger Balm®, BioFreeze®, and other generic variations of common topical pain relievers (12 sources 23 references, field notes). The most commonly prescribed topical pain reliever noted by participants was lidocaine (6 sources 18 references, field notes).

Natural remedies, creams, and ointments seemed to be perceived as being safer than prescribed medications by some participants (field notes). A few participants, such as Macy, were more general in how they discussed concerns about prescription medications, specifically opioid analgesics. Macy said simply in reference to opioid analgesics, “I don’t want that in my body” (Macy). Other participants were clearer that they were concerned about the harmful effects medications might have on their organs (9 sources). Paul for example when asked if he had any concerns regarding medications noted, “I don’t want to burn out my kidneys or nothin’ messin with them pills you know” (Paul). What participants did seem to be consistently clear was the concern expressed regarding addiction (field notes).

***Addiction.***

During formal interviews the topic of addiction came up rather frequently as it related to medication usage. In fact, there were 28 references to addiction, becoming an addict or a “junky,” or “getting high” noted by 14 different sources. For example, as Zora discussed the stress and anxiety that she was experiencing, she mentioned that the doctor had recommended medication for anxiety but she was not going to take it. As she noted, “They want to give me [a] stress pill. I ain't gettin no stress pills. I know what I'm going through. "But it relaxes you" (stated sarcastically). No, gone get me high. I want to know what I'm doing every day.” Similarly, when talking about medications with Zena, she indicated that she did not take a pill every time that she hurt because “you know, you're trading in the one problem for another.” When asked to clarify what she meant by that, she went on to say, that she was concerned about the medications—“some being habit forming, or just becoming dependent on them.” To deal with this concern she got in the habit of watching the clock and waiting as long as she could between doses, with the goal of having more medication left over each month when it was time for her refill (Zena). Sometimes, the concerns about addiction were due to more personal connections of witnessing addiction, having the feeling of being high, or struggling personally with substance abuse (field notes).

Theresa, who was quite knowledgeable about herbal treatments and natural remedies for ailments, while not opposed to medications, preferred the natural route whenever possible. She related struggling with severe menstrual cramps as a young girl, around 11 years old, and being prescribed Darvon®, propoxyphene hydrochloride, for pain. As she recalled, “I was taking one every four hours because the pain was so severe, and I was just almost crazy.” In addition to taking medications at a young age, watching others seemingly addictive behaviors with pain medications dissuaded her from using them. In one example she recalled a man begging of pain medication:

> I was in the emergency one time with these knees, and the guy next to me was begging the doctor for some. And evidently, he had been there several times, you know, because it was a lady doctor he was talking to and she said, “I can’t give you any more.” And what she

> did, instead of her comeback, she sent a man doctor and he said, “I’m only going to give you ten, and after that you will not get anymore” you know, and I thought uh-uh (negative).

In addition to concerns about addiction, participants also expressed concerns about the related concept of tolerance, or the adaptive state in which the body becomes accustomed to certain substances and more of the substance is required to achieve the same effect. Monica mentioned practicing the same habit that the participant Zena discussed of trying increase the time between doses of her pain medication. When asked what her concern was with the medication, she noted “You can get immune to a lot of pain pills. You can get immune to-- I don't care how many times you’re going to took it, after a while it ain't going to work because your body been gotten immune to it.”

Another participant, John, was dealing with tolerance due to unmet pain needs and struggling with active addiction. John had been “clean,” or drug free, for 22 years. As he stated, “I used to be a dope fiend...and it still...it still...it takes a lot to make me feel alright.” His history of heroin use created a tolerance to many of the medications commonly used to treat pain. John indicated that he had never spoken to his doctor about his drug addiction. He stated, “No I ain't never shared it with him. You know I just leave it like it is. Cause once they feel like you a dope fiend they don't want to be bothered too much.” John had diabetic foot ulcers on both of his feet which were wrapped in gauze, neuropathy in the fingertips of one hand, and persistent back pain (John, field notes). He often had to walk on the heels of his feet along with the assistance of a walker (John, field notes). Despite this daily pain, John was incredibly active, and was almost always seen walking about (field notes). When asked what motivated him to keep going, John echoed the sentiments of other residents—the fear of dependence. As he stated, “I don't want to be lazy and be a big fat nothing (hits hand on the table)--cause it's too many of them in here and they depend on somebody to help them." John went on to talk about others he had observed that in his opinion had allowed themselves to become dependent on others. He became almost irate, slamming his hand on the table, raising his voice, and cursing as he reflected on people that he did not feel were trying—folks that had let themselves go (John, field notes). All John wanted was to be like a normal person. As he stated, "I'd try anything just to relieve the pain where I could feel alright to where I could be like a normal person. Sometimes I'm like a normal person….I have a hell of a lot more energy. I clean up. I do this and do that. I'm alright."

Although John's comfort level with the researcher allowed him to openly discuss his drug use, generally, personal drug use was not openly conversed about by participants. However, three other participants did admit to using substances such as heroin and cocaine for the management of pain on the Brief Pain Inventory. Within the medical establishment, addiction is treated as a chronic, neurobiological disease and it was treated as such within this study.

**Living with pain.**

The elders that participated in this study lived with moderate to severe pain daily. Pain was described as being so bad that "you got to holler sometime" (James). Pain that "when it grabs you it holds you...all you can do is just oh, just walk and scream" (Jane). Similar sentiments and examples of the difficulties of living with pain were echoed by 15 other participants during formal interviews within 49 different references. Some participants had to take medications just to be able to attempt to sleep at night but still awoke unable to easily move due to excruciating pain (5 sources, field notes). Esther described waking up one night with pain so severe pain that it limited the use of her hands. She recalls, "I woke up one night, screaming. My mother thought somebody had broke in the house." She also had spasms in her legs that were so severe that she felt forced to go to the emergency room in an attempt seek some relief. Relief came from being "jabbed" with a needle in the arm (Esther). Another participant had to keep her head positioned in a certain way and occasionally massage her throat just to be able to converse (Daphene, field notes). This daily hurting seemed to affect nearly every aspect of the lives of the elders who were encountered. Their greatest voiced concerns were the changes pain caused to their mobility and other activities of daily living (BPI, field notes).

### ***Daily pain problems.***

Activities of daily living are the regular types of movements that are required in everyday life. These activities include the movements required for eating, bathing, toileting, walking, dressing, and transferring. While the BPI noted moderate interference to general activities, walking, and the ability to work, participant observations and interviews clarified the multifaceted ways in which pain effected living. Participants reported difficulties with bathing and grooming, house work, cooking, driving, working, shopping, sleeping, concentrating, walking, and even sex secondary to pain (BPI, field notes, 17 sources 68 references). For example, when Esther was asked about the ways in which she thought pain affected her life, she said,

> In some ways, I can’t move around. Sometimes it has some effect on my thinking, or trying to remember… I’m just depressed that I can’t do the things like I used to do; just get up and go, and come back home and do whatever I’ve got to do. Now, if I’m having trouble with my joints or whatever, I can’t get up and run and do what I have to do and come back.

Esther went on to note that pain even affected how she bathed. She was no longer able to take a bath because she could not get out of the tub by herself. When Janine was asked the same question—how she thought pain affected her life, she noted:

> Well, let's see. It keeps me from going where I want to go, because like I said, I don't tell nobody. Whenever my friends said, "Let's go to the river walk," I always find an excuse,

> or something, because I know that I don't want to get so far, and tell them to bring me back. So it have affected me, yeah. Kept me from doing things that I want to do.

Other participants made similar statements regarding how they avoided certain social activities with friends and family in order to not have to worry about not being able to complete the activity, needing assistive devices, or simply being the focus of pity (5 sources, field notes). In addition to affecting social relationships, changes in functional status caused by pain often affected the ability of the participants to earn the income they were accustomed to.

#### ***Changes in income.***

Changes in income due to pain and decreased functional status created an additional, and at times unexpected, burden that many participants were not really prepared for (field notes). For some, these changes in income meant that participants had to leave their homes in the community and move to more affordable, though perhaps less desirable, housing, ride busses instead of driving costly cars that required maintenance, and even participate in activities differently (field notes). Both men and women spoke about how pain stopped them from working (BPI, field notes, 4 sources 6 references).

Abraham, who was a carpenter by trade, spoke in detail about the physical requirements of his job and how he was no longer able to meet those requirements due to pain. He was asked how long ago he had begun to experience pain and what he noticed first. He said the pain had begun 7 or 8 years ago and that he noticed that his knees were simply not bending in the ways in which he expected them to bend. As he related:

> Anything you can do with your knees, I did it during my job. Finishing concrete for instance or laying a tile floor, you’re on your knees constantly. I can’t do that anymore [chuckles]. And as a carpenter, you carry a lot of heavy loads, a lot of lumber. And it gets heavy, and

> you can’t do that with your creaking knees. The knees really complain about that. And I guess, the occasional pain in my back is probably the beginning of the arthritis in my back. So, the construction trades were all out. They’re completely out. About the only thing I can think of that I could probably do is hanging wallpaper, and I never really liked that [laughter] (Abraham).

Lois, who suffered from nerve pain secondary to a stroke along with carpal tunnel in both wrists was no longer able to earn a living as a hair dresser due to pain. When she was asked how her pain affected her daily living, and what it prevented her from doing she noted:

> Well, it prevents me from working. I could never work with this. No, I'll never work again because I've tried. I mean, working on myself is ... That's why I wear wigs. …
>
> I do my hair, but after a while, my thumb gave out. And, I was saying the other day, I was just saying to myself, because I was trying to curl up my hair and it was starting to hurt. And I was like, I shook my head, I said, "Hair dressers just don't know. They don't buy into insurance. They don't pay their taxes. And, when they get, when that thumb give out, and the curling iron, the curling thumb give out, you're gone. You're done. You are done. When that wrist gives out, you are done. When those, um-rotor cuff, rotor cuff tears, tear up, you're done. You're done." They don't understand. (Lois)

Lois shook her head and looked off into the distance as she spoke (field notes). Changes to usual daily activities and functional status was distressing to these participants and caused an underlying fear (field notes). The fear that came with pain was the fear of becoming dependent. For the participants of this study, maintaining independence was of the utmost importance.

### *Fear of dependence.*

Within the apartment complex, and on the local grounds, residents were observed using a variety of assistive devices: canes, walkers, wheelchairs, and motorized scooters (field notes). These devices were necessary to maintain some functional ability and independence. John, mentioned earlier, recounted a time that he left for an appointment to the hospital and forgot to take his walker with him:

John: My back. It kill me. If you notice I'm okay standing up. Walk for a few minutes then the next thing you know (demonstrating hand falling forward) like that. Then the more I be walking it really get to me. I can't...(shakes head). One day, I was in the hospital. Like you were saying and I didn't have that with me (points at his walker)—

Sheria: - Your walker? (John shakes head yes)

John: And man I was struggling to get a bus stop to catch a bus and get home. And I was…oh man I was in misery.

While the walker John was using did allow for increased autonomy, he was dependent upon it for his mobility. Although he was able to walk without it at times, not using meant he was would experience increased pain later that worsened his mobility for a period of time (John). John was a frequent walker and visitor of the researcher. He regularly stopped by to say hello wearing his typical outfit of gym shoes and a jogging suit and of course pushing his walker along (field notes). Like John, many participants were dependent upon walkers, canes and electronic scooters for their mobility (9 sources, field notes).

It was not uncommon for participants to have medical devices such as canes and walkers ordered, but not in use (field notes). Upon visiting several residents' homes to either complete questionnaires or interviews, assistive devices were frequently noted in the home, usually near the front door or in the corner of a common area, not in use (field notes). When asked about the devices, the most common response was that the devices were only used when they were really needed, or when they were "absolutely necessary" (field notes). As residents were conversed with both formally during interviews and informally during visits, it became apparent that there was actually a fear of dependence in not being able to function without the device if they submitted to it. In speaking to one resident, Adam, about the use of his cane, which he did not like using, he mentioned that he received an offer to get a motorized chair but that he did not want it. When he was asked what concerned him about using the motorized chair he stated:

> Adam: I think that you get dependent upon that thing and you not using your muscles and limbs and things like that. They become dormant if you're not using them. I think you need to exercise by walking. So that's the problem. I see people around all the time here with those things and their always in them.
>
> Sheria: - And you don't want to fall into that?
>
> Adam: - No. No I do want to do that. As long as I can walk Lord I thank you and I want to walk. Now if I can't then I thank God for that. But at this point I don't see that it's necessary to do so. Just cause they say I'm eligible--I don't want it.

Adam's concern about becoming dependent by using something simply because it was available and not because it was absolutely necessary echoed the concerns of residents that did not want to take pain medications due to concerns about addiction and tolerance.

In thinking about the first research question, how do Black American older experience pain and pain management operationally, emotionally, and qualitatively (the defining attributes), it was found that the participants of this study experienced pain physically—it severely hurt when they compared their usual pain to the worst pain they could imagine. At times, the pain caused them to audibly cry out. Their pain diminished their mobility, forced the use of some assistive devices, and caused difficulty in all of the usual activities of daily living, including the ability to do normal work. Pain was experienced socially—it negatively affected the relationships they had with others. Pain was also emotionally distressful—it decreased life enjoyment for the participants. Despite the multitude of negative effects caused by pain, participants' fears about addiction and dependence, along with concerns about medication side effects, lead many to use more opioid-free analgesics and nonpharmacological treatments for pain management. One would anticipate that the negative effects of pain within nearly every domain of self—physical, social, and emotional—would ultimately diminish quality of life.

## Pain, Coping and Quality of Life

The second research question that was considered within this study was, how do Black American older adults cope with pain, particularly, what are the relationships between pain management and health related quality of life (HRQOL) and what does this tell us about the extent to which the Roy Adaptation Model resonates with these participants' lives? The Patient-Reported Outcomes Measurement Information System (PROMIS) provided a means of further assessing health-related quality of life (HRQOL), specifically through the global health items or the PROMIS Global Health short form. Additionally, the Psychological Stress Measure (PSM-9) allowed for the measurement of stress and tension. Finally, participant observation and interviews provided clarification to items on both of these measurement tools and gave additional information on how coping was achieved.

### Mental and physical health.

At times, the resilience of the elders over-shadowed the difficulty that they had with day-to-day activities. It was by no means easy living with daily pain and making the necessary life adjustments to effectively cope with pain (field notes). This daily coping effected participants' quality of life. The PROMIS Global Health short form (PROMIS) used in this study was a means of measuring patient reported outcomes within the health-related quality of life domains of physical, mental, and social well-being. The 10-item PROMIS tool asks patients to rate their overall health, quality of life, mood, physical health, and social relationships using mostly five-point scales that range from excellent (5) to poor (1) or completely (5) to not at all (1). One question on the form asked specifically about pain and uses a typical 10 point scale that ranges from no pain (0) to worst imaginable pain (10). Ultimately, scores could be used to calculate participant determined global, or overall, physical health (GPH) and global mental health (GMH). T-scores allow the sample results to be compared to an estimate of population norms. The estimated US population norms for adults, or T-Scores, for GPH and GMH were 50 with a standard deviation of 10 (Hays, Bjorner, Revicki, Spritzer, & Cella, 2009). To date there are no noted average population scores specific to older adults or Black American older adults.

The average Global Physical Health (GPH) scores for the participants in this study experiencing pain (n=91) was 36 (see Table 8). This score indicates that in comparison to an estimate of the US population, these participants rated their quality of life, within the physical health domain, as being 28% lower (about 2 standard deviations) than the population average. Table 9 provides further details of the specific item responses on the PROMIS Global Health tool. Of note, is that the average pain reported on the PROMIS was about 7 which matches scores reported in the Brief Pain Inventory (see Table 9) and that the only area that averaged a rating of "fair" (2) was physical health.

Although the sample size of participants not experiencing pain was much smaller (n=15), there was a great contrast in the self-rated GPH. Participants were identified as not having pain if they selected "no" (choice 2) on item number 1 on the brief pain inventory which asks if pain is experienced. These patients had an average GPH of 52 which means that their average self-rated physical health was on par with, or about 4%, higher than estimated population averages (see Table 10).

Interestingly, the Global Mental Health (GMH) scores generally improved for the pain population. Participants experiencing pain had an average GMH score of 44. Again, in comparison to estimated population average scores of 50, these participants were only about one half of a standard deviation away from population norms (about 12% less) (see Table 8). Quality of life within the mental health domain for patients without pain remained above average. These participants reported an average GMH score of 51 which remains on par with the general population, or about 2% higher than population averages (see Table 10). In addition to providing information regarding how they self-rated various dimensions of quality of life, participants completing the questionnaire provided important information about how they were able to manage stress.

**Stress.**

The Psychological Stress Measure short form, the PSM-9, was used to measure psychological stress on an 8 point Likert scale. Participants ranked 9 stress variables over the past 4-5 days from 1 (not all) to 8 (extremely). Examples of items included: "I feel rushed; I do not have enough time," "I feel preoccupied, tormented, or worried," and "I feel a great weight on my shoulders.” item responses on the tool were developed from descriptors of stress gleaned from focus groups (Lemyre & Lalande-Markon, 2009). Higher scores indicate higher levels of stress. The 15 participants not reporting pain, reported an average PSM-9 score of 19 with the most common score being 20 (see Table 11). Participants that did have pain and completed the form (n=86) reported higher PSM-9 scores of 36 with most commonly reported score being 48 (see Table 12). Though range of responses was quite variable (SD = 14), Table 13 provides further details on the specific item responses used in the calculation of the score. The participant scores in the PSM-9 could range anywhere from 9 to 72, therefore their scores of 19 and 36 indicated that they were only mildly to moderately stressed. This data coincides well with the higher self-rated global mental health (GMH) scores the participants had in comparison to their global physical health (GPH) scores. Participant observations and interviews provided great insight into the specific means in which elders with pain used positive coping to maintain their mental health and stress levels despite physical challenges. These coping strategies included things such as maintaining a positive mindset, relying on faith to provide motivation and hope, regular exercise, and community engagement with opportunities to earn an income.

### Maintaining a positive mindset.

The ability to maintain a positive frame of mind, despite adversity, was perhaps one of the strongest themes of the study. 19 different sources referenced remaining positive as a means of dealing with life’s various stressors—including pain. Positivity seemed to increase self-confidence and provide motivation for continued movement and engagement despite pain (field notes). When asked what motivated her, one participant Janine said her own self-confidence is what motivated her. She indicated that her self-confidence was actually something that she had lost and that she was trying to regain it again. When the researcher asked her what was motivating her now to be more confident, she replied:

> “I had to live with myself, and I usually have doubt in myself, so I go to the mirror every day and think, "You are going to be okay. You are a beautiful woman, you are going to be okay." And that helps me to motivate myself every morning. And then I want to come out and live like I still do (Janine).

Janine was not immune to the difficulties of living with pain, but she was determined to not allow those difficulties to define how she viewed herself or how she chose to live her life. Another participant, Jane, was also determined to not let things get to her nor allow negativity to affect how she chose to live her life.

Field notes revealed that Jane was incredibly active within the facility. She almost always could be found in the basement of the apartment building where most of the activities took place. She was either a participant in the activity or one of the volunteers working to see that the activity ran smoothly (field notes). She did everything from participate in the exercise group to pop the popcorn for movie night, and set tables up for the daily lunch (field notes). Jane also lived with moderate to severe daily pain due to arthritis. What was most striking about Jane though was that she was always smiling, laughing and engaging with others when she was observed (field notes). The researcher asked Jane why, unlike some others, she remained so engaged and ready to assist as needed despite her pain. Jane promptly responded, “Because I am concerned and compassionate.” She went on to reveal that it was not uncommon for people to ask her “Oh why are you always smiling?” or “Oh, why do you want to do this? Why do you want to help this person?” She felt as though people questioned her intentions of being helpful in order to try to “get [her] down.” It was insinuated that perhaps she was doing too much for others unnecessarily (field notes). She went on, “I gotta not let it get to me though, you know.” (Jane). Jane was not dissuaded and remained determined to stay positive and continue doing as she pleased. As she stated, she remained engaged, “Because I want to” (Jane).

Macy, another participant, also wanted to remain active and engaged. Like Jane, Macy was quite mobile despite having moderate to severe daily pain that she described as being all over her body (Macy, field notes). In fact, one interview with Macy had to be rescheduled due to severe pain that confined her to bed (field notes). Besides continuing work in tax preparation, Macy participated with a walking group as much as she could, and engaged in religious service activities that frequently required her to walk and interact with others (Macy, field notes). To remain as active as she was, she frequently had to make accommodations for herself. For example, she could only sit for a few hours at a time so she was limited in the number of hours that she could work in tax preparation (field notes). She also had to take frequent breaks when walking, so she generally went to the walking site alone (Macy). And though the arthritis in her hands made it difficult for her to knit in the same way that she was accustomed, she found that with larger needles she could still participate in the craft, though her projects might vary from things that she might ordinarily do (Macy, field notes). What was surprising about Macy, was that in her formal interview when asked how pain changed things for her, she responded:

Macy: Um, it hasn't slowed me down, for one.

Sheria: You say it has not?

Macy: No.

Sheria: Mm-hmm (affirmative).

Macy: Because I refuse to slow down.

Sheria: You're gonna move anyway.

Macy: I have to move. Yeah.

Sheria: Mm-hmm (affirmative).

Macy: But I just got that attitude, "If you don't use it, you're gonna lose it."

Sheria: Mm-hmm (affirmative).

Macy: So I just like to keep busy.

Though of course continued movement, and the fear of dependence were also central themes in Macy's motivation, her positive outlook allowed her to continue to reframe the ways in which pain limited her mobility and changed how she performed her usual activities of daily living (field notes). As Macy stated, "I wanna live as long as I can, and I, I have to help myself. I have to, I have to make it happen" (Macy). Helping herself was managing her mind in the same way that she managed her body.

In general, the participants tried not to allow many things to upset them. Abraham spoke about having his car stolen from the parking lot of the facility which significantly limited his ability to be as mobile as he preferred, he said, "No point in crying about it, because nothing I can do about it anyway." He went on to say, "I just quit worrying about anything, I just say the hell with all of it… No, I just decided whatever it is, it isn't worth it. If I can take care of it I will, if I can't then I won't, but I'm not going to worry about it." When he was asked by the researcher, about how he got to this space, where he did not allow worry to consume him, he responded:

> Oh I had so many problems, I wasn't making enough money, my wife was-- I don't know. She a strange lady to get along with, but it wasn't her fault. I mean it was just something that-- nothing monumental occurred. It's just that I woke up one morning and I decided I'm not worrying about anything more, or I'm not going to let anything worry me. I used to worry that I didn't buy enough material for the job or that my material is going to be stolen

> while I'm away from the job, or that my beat up truck won't start tomorrow when I get ready to go into work, or the tools will break or something like that. So I decided I'm not concerned with all this. If it breaks it breaks, if it doesn't, I'll get on with it. If it breaks I'll buy a new one [chuckles]. But I decide I wasn't going to worry about anything and I don't. I haven't since then.

Abraham, like many of the other participants, had come to an understanding that there are some things in life that you just couldn't control, but what you could control was how you responded to the changes life brought you (field notes). Pain was believed to be one of those changes that was uncontrollable (field notes).

Esther, another participant who has lived with chronic pain most of her life had become accustomed to developing what she called "creative solutions" to managing changes in her functional status due to pain (field notes). As she noted, "I have to figure out ways to get around where I wouldn't hurt myself or anything" (Esther). She did not believe that there was anything that could really be done to completely rid a person from pain and so individuals had to simply learn to live with pain (Esther). She stated:

> I've been having pain over three quarters of my life. I don't think there's too much they can do…. I've learned to live with it. I don't think it's that easy to manage a person's pain like they want to. It's almost impossible. I'm a realist about certain things. It's almost impossible. I don't worry about it anymore. At first, it was depressing. Now I find, "I'm 74 years I've accomplished quite a bit.

One of Esther's greatest accomplishments was completing a degree in creative studies at the age of 60 (Esther). As an artist she was able to regularly engage in creative pursuits that made her happy. Continuing to engage in creative works, such as her current hobby of jewelry making, seemed to provide some distraction and help her to maintain a positive mood (field notes).

James summed up the approach of many of the elders encountered in this study as it relates to maintaining a positive mindset in dealing with pain. He said very simply, “I do what I have to do” (James) Most participants however did not work in isolation to stay motivated. Family and friends provided a good source of support and encouragement.

**A community of support.**

Family and friends were most often the individuals the elders of this study noted they spoke to about their pain (17 sources). Not only did these support system provide the service of simply listening, but they also provided good motivation to the elders to get up and keep going each day. Many participants found joy in those relationships (17 sources). Additionally, family and friends provided opportunities for socialization and meaningful distraction from pain (15 sources).

Immediate family often provided the most direct source of support for the residents (field notes). For example, when Abraham was hospitalized for an appendectomy, or removal of his appendix, they found an embolism. After his surgeries he was in a much weakened state and required the use of a wheelchair. His wife, whom he referenced as the person that motivated him, threw the wheelchair out and said he needed to get up. He did (Abraham). Esther spoke about her mother and her son being great supports to her as she struggled with the challenges of pain and limitations to her mobility (Esther). Jeanine felt that her grandkids were her motivation to keep going. She loved to spend time with so she would get up, take her medicine, and get herself together to do just that (Jeanine). Others found motivation in their family’s resiliency in dealing with changes in health (James, Zora, field notes).

Zora specifically spoke about the several members of her family that had been afflicted with cancer and their ability to keep going despite the disease. She recalled, “You know everybody had cancer. My grandmother and all of them, they traveled all over the world. I mean they were sick, but they said I'm not a sit up there and pity myself….When I grew up I didn't even know they were sick.” Although, these relatives were no longer even living, she still found motivation in recalling how they handled illness (Zora, field notes).

For those that did not have family to motivate them, they relied upon friends. The facility provided elders with a variety of opportunities to make new connections and friendships as well as be engaged member of the community (Adam, James, Jane, field notes).

### Community engagement.

The need to be an engaged member of the local and wider community was an important, and often natural task of many of the residents (8 sources, field notes). Perhaps this was related to the fact that most of the elders in the sample lived alone (83%). It was expressed that being connected “filled a void” by giving people something to do (Abraham, field notes). As Abraham explained when asked about why people often gathered in groups in the basement:

> People need something to do. They really need something to do, and most people are not content to read as I am. And I guess most of them get tired of watching television after a while, so I think we do need something. And let's face it, none of us are young anymore, so we all need something to do, to occupy ourselves…. No, I don't want to live my life sitting, even though this is pleasant out here. I can't sit here forever.

Laura echoed his thoughts. She noted that “…it can be boring up there in your apartment, because how much TV and cleaning and all that other stuff can you do?” Jane indicated that various activities that allowed for engagement with others were a welcome distraction. She stated:

> [When] you get involved in something, you kind of get your mind off of your own problems. Keeps your mind, keep your pains, any hurts, kind of uh, out of your mind. Keep you from thinking. When you're involved into something you kind of just lose your mind into it, and you don't feel [the pain] that well, that much."

Another resident who not able to be as engaged as she wanted to be due to pain agreed. When asked how pain changed what she would like to be doing Liz stated, "I would like to help others. Now to me that's important. It keeps you going--helping others. And it keeps your mind off of what's going on with you."

Community engagement took place in a variety of ways. Some assisted with setting up the community room for the lunch service during the week while others volunteered as floor captains, or communication liaisons between the management and each floor (Adam, Jane, Peter, field notes). Many were actively involved in churches and participated in related ministries, or opportunities to demonstrate faith through action (field notes). These elders did things such as visit hospitals and nursing homes to offer prayer and encouragement to the sick and shut-in (those unable to leave the confines of their residence), running small bible study groups, or leading choirs (Adam, Peter, field notes). They volunteered at schools to assist with tutoring and provide extra supervision. They gave rides, helped with groceries, and even handed out handmade jewelry just to initiate conversation (field notes). There was even a formal club for helping others at the facility.

The Sunshine Club was a formal group of mostly women who lived in the building and had the sole mission of bringing happiness, or sunshine into the lives of others (field notes). They kept track of who was ill, or in need, and did their best to fill those voids. They took pride in their membership and even had t-shirts that identified themselves as members of this elite group (field notes)! Still, those not participating in this club would look in on neighbors and provide assistance as they could. If we saw cans in the laundry room, a resident would call a friend that collected cans for extra income and tell them that there were a few there (field notes). If someone was collecting scraps of left-over food to feed a dog, there would be knocks at the door of people bringing by bags of bones and scraps for the dog (field notes). People would support one another in a variety of different ways.

Acquaintances in the building would motivate one another to exercise, share information and provide recommendations regarding health practices, and simply listen when an ear was needed (field notes). Being actively engaged within the community provided a variety of opportunities to be active and participate in meaningful activities. Interestingly, despite multiple interactions with other residents that also had pain, the residents were pretty hesitant to talk about their pain—even amongst their peers—with the exception perhaps of treatments recommendations and discussions (field notes). There was very little discussion regarding actually being in pain and when this discussion did take place, it was generally positively framed (field notes).

#### The taboo of discussing pain.

Amongst the elders there seemed to be an unwritten rule that pain was just not something that you talked about (field notes). Adam explained:

> I don't talk about it a lot because I believe that words have a lot of power. And you have to be careful what you speak out into existence. And sometimes "Oh I'm just hurting so bad, I'm just hurting so bad" and sometimes it's so mental and if you don't talk about it and just pray about it I think that it works. I just believe that that tongue--we have to be so careful with it (Adam).

Religiosity was important to many of the cultural group and there seemed to be a common belief that complaining was just not something that Christians of faith should be doing (field notes). Zora even referenced the scripture found in Philippians 2:14-15 of the bible that speaks about murmuring and complaining (field notes):

> Do everything without grumbling or arguing, so that you may become blameless and pure, “children of God without fault in a warped and crooked generation.” Then you will shine among them like stars in the sky (NIV).

Zora went on to speak about people who always seemed to complain about aches, pains and other maladies. It bothered her in that their negativity could deleteriously impact others. It was the same negativity Jane, mentioned earlier, spoke about having to combat negative comments or questioning of her actions in order to maintain her positive mind frame. Zora even stated:

Zora: You know, some people are complainers. Some people … you know—and, they're young. You probably got some young friends that whine out there.

Sheria: Um-hmm (affirmative).

Zora: You know, hey, say, "Do you ever have a good day?" (Laugh). You know, don't you have a friend that every time-you talk to her, there's always something wrong?

Sheria: Um-hmm (affirmative).

Zora: You know what I mean. And you probably want to say, "Do you ever have a good day?"

Sheria: Um-hmm (affirmative).

Zora: You know, we’re just … Okay, just pretend sometime.

Sheria: Fake it.

Zora: You know what I mean, fake it (laugh). You're damn right, fake it (laugh). Shoot, you ain't going to break or something. That affects people around you. (Zora)

It was Zora's preference for individuals to keep negative comments about how poorly they were doing to themselves. It was better to pretend that all was alright and perhaps positively influence someone with their positive demeanor rather than their negative spirit (Zora, field notes).

While some participants seemed to carry the idea that you could speak pain into existence, others simply did not find talking about pain to be helpful—even to providers (field notes). As it were, most elders were not interested in receiving additional medications for pain, but more often than not the solution to increased pain was more medication. It was better to just be quiet (field notes). Additionally, elders did not want to consume their family members with their problems. As Paul mentioned, "They [my family] don't need me yeah their on their mind. You know. And they know what I've been through and it ain't solved—so they know I just rough it out….I mean what can they do" (Paul). It was better to keep complaints about pain to oneself. However, there was some value recognized in talking about pain to help others that were struggling with pain management (field notes).

As Adam stated: "A person that can really relate to one that's walked that walk. And so there are different levels of ministry. And with this pain, I can tell people about that. I can tell em you know how to deal with this pain--when you have pain in the body" (Adam.) And this statement seemed to be true for others as well. Though most other participants did not view talking about pain as part of their religious ministry, any pain talk that did occur, with friend and neighbors in particular, was usually within the context of discussing medications and treatments one or the other had found to be successful in the past (field notes). However, faith remained very important to many.

### Give God some praise.

Faith played a major role in the lived experience of the Black American older adults participating in this study. On any given weekday when visiting the facility in the afternoon one would find themselves swaying to the familiar rhythm of gospel melodies belted out by a make-shift choir (field notes). Many of the participants of the study began their day with prayer and quiet meditation that often included the reading of religious texts, such as the bible and Our Daily Bread, a book that provided a daily meaningful scriptural text that allowed for reflection (field notes). Though about half of the participants were Baptist (51%), the religious faiths of the group were diverse (see Table 4).

Faith allowed participants to express gratitude and empowered them to deal with stressors such as pain. They felt blessed to be alive and understood that life would not be easy (field notes). As James said,

> “You know grace of God ...here I am today. My faith played an important part in the healing I believe. Not that I believe, I KNOW my faith carried me through. Because if I had resigned myself...okay here it is--I'm going out this way--I probably would be [dead]. So I know that there is strength in faith.”

Black elders have a common saying that derives from the church. The minster would tell the congregation, “God is good.” And the congregation responds, “All the time.” He would then say, “And all the time…” “God is good” was the final response. This call and response was used to reinforce to membership that no matter what was happening in life, whether there were good times or bad times, joys or sorrows, God was ever present and bestowing blessings upon his followers. So when the elders at the facility would talk about difficulties they were experiencing, they would often end by saying, “But God is good” (field notes). For example, when Jane confided that she lost her husband two-years ago, she followed that by saying, “But God is good” (Jane) When Laura spoke about the difficulties she faced in recovering from a stroke she noted that her mindset allowed her to deal with the tough things that came her way—that and Gods help (Laura). Lois believed that God had spared her life and that of her son, so she was therefore dedicated to live a life that gave testimony to God’s grace. “I'm going to live life gratefully, you know, because I do serve God,” she said. She went on to say, “To have a relationship with God is the most important thing in the world today” (Lois).

Faith seemed to be an imbedded part of the culture for many of the participants of this group. In fact, when asked what health care providers could do to improve care for patients, Adam responded “to pray with them”. He went on to say, “Pray with them and let them know that when they are in that pain to never be forgetful that Jesus promised us healing. And by his stripes we are the healed[2]. And I just believe that that's part of my ministry and that's exactly what I would do. Always direct them to the ministry of Christ and it is a healing ministry” (Adam). Deep faith helped to mediate stress and motivate elders to keep going. Continuing forward often meant learning to live with pain.

**Accepting pain.**

It seemed to be readily accepted by the participants of the study that life would be difficult. In fact, during one interview a resident (Paul) began to quote the opening lines from the book *The Road Less Traveled* by M. Scott Peck (1978):

> Life is difficult. This is a great truth, one of the greatest truths. It is a great truth because once we truly see this truth, we transcend it. Once we truly know that life is difficult-once

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[2] References the bible 2 Peter 2:24 Who his own self bare our sins in his own body on the tree, that we, being dead to sins, should live unto righteousness: by whose stripes ye were healed. King James Version (KJV)

> we truly understand and accept it-then life is no longer difficult. Because once it is accepted, the fact that life is difficult no longer matters (p.15).

The participants of the study were older adults. There was a view amongst them that as they got older they would have increased difficulties with various sicknesses and ailments (field notes). Pain was an anticipated ailment. As Peter noted, “When you get seventy four years old somethins gon' grab you” (Peter). Elders simply made adjustments as they had to in order to maintain as much mobility and functional status as they could. As Daphene stated, “It's just everything ages with time, and sooner or later, something's going get bad on you.… Like my grandmother said, "You ain't old until you're cold." You keep on living, to the best of your ability” (Daphene). Other elders reiterated similar sentiments in both formal and informal interviews (field notes). They recognized the fact that eventually it was highly likely that they would become dependent upon others to have their basic needs met but, they were not going to go down that road willingly. They were not willing to submit to taking medications that they did not fully understand the benefits for, or those that caused bothersome side effects. They were not willing to use assistive devices unless it was the only way that they could remain active, and they remained active, even if that meant activities took them longer to complete.

### Keep moving.

Despite the changes to mobility and functional status caused by pain, participants were determined not to allow pain to stop them—it only slowed them down. Keep moving was the phrase stated by almost every elder that was able to still walk on their own (13 sources). Diet and exercise were seen as the primary gateways to good health (field notes). Surprisingly, very few residents could speak to specific dietary changes to improve health other than limiting portion sizes, however they were all clear that moving was important—even limited movement (field notes). There was a 91 year old woman named Emily who walked around the building daily--inside and outside weather permitting. Nearly every person the researcher spoke with that had some difficulty with walking spoke about Emily and how seeing her provided some motivation to be active (field notes). As one participant Zena stated, “by all outward appearances [Emily’s] healthier than many” (Zena).

Emily was a sight to see indeed. She was a thin woman with long wavy gray and black hair that she wore in two braided pony tails—one to the side and one to the back. She often wore a studded blue jean jacket, with matching pants and sneakers. She walked with the assistance of wheeled walker that had a decorated basket attached to the front. Though she didn’t want to do a recorded interview with the researcher or complete the questionnaire, she regularly engaged in informal conversation (field notes). She was from the South and cooked good homemade southern meals like beans and rice, with ham hocks and corn bread regularly. She was highly independent and radiated joy. Her cackle of a laugh always made the other residents smile. Emily was what many of the resident aspired to be (field notes). Several elders were not able to maintain desired activity levels due to pain. Though they remained relatively actively, some stated that their activity level was significantly lower as compared how they moved around in younger years (5 sources field notes). But again they did not allow pain to stop them. As Peter stated, “pain don't stop ... the pain come, I just keep going on” (Peter) Yvette added, “I keep right on going. And one time I had gout ... worst than I had now, where I limped, I limped it by. And I limped right on, and kept right on going… As long as I can move, I'm gonna keep right on moving” (Yvette). Resident were determined to remain active and thereby remain independent. The most common accommodation made to allow for continued movement was pacing of time.

### *I just take my time.*

"I just take my time" was a common saying amongst the elders when asked about how they completed daily activities (field notes). They refused to give up and give in to pain. When the researcher asked Naomi why she gets up out of the bed though she has pain that makes it difficult for her to move at all in the morning she responded, "Now you ask me why I get up. Now you tell me why I should lay there?... It's not gonna change anything if I lay down in bed and look up at the ceiling and sing the organ song…And [if I get up] maybe I see something that makes me happy." Naomi knew that she was going to be in pain when she woke up in the morning. She was in pain every morning when she woke up. She anticipated this and planned for it. Because she knew that the researcher was coming for her interview, a time was planned that was not very early--10am. She told the researcher that she got up to take her pain medication so that it would be working by the time that she arrived (Naomi). After she mentioned this, the researcher realized that other residents that had met with the researcher had also done the same thing (field notes). Visits were almost always around 10am, though most indicated that they were early risers. They got up early and generally planned ahead for the additional time required to complete activities. Resting and learning to wait were a normal part of daily life (field notes). Esther captured the essence of what these elder do when she stated, "I just take my time, and think and be creative about what kind of moves I make" (Esther).

The elders that resided within this study site were incredibly creative. The building was filled with artists of all types, from those who were dancers and actresses to singers, painters, sculptures, and writers (field notes). They were observed turning dollars into floral bouquets and developing full choreography for Black History Month programming. Perhaps the most creative thing the elders were observed doing was effectively managing being poor (field notes).

### Managing Poverty.

Though not initially evident, poverty was a way life for these individuals. Being poor created a variety of stressors, including worry about having enough money to cover expenses, dealing with pests such as roaches and bed bugs, concerns about personal property crimes such as theft, and worry about safety (field notes). Interestingly, despite the many concerns with being poor, the residents had creatively developed their own cash based microeconomy within the facility (field notes).

When the researcher first arrived at the facility, she observed elders being very helpful in a variety of settings. It later learned that much of the helpfulness was rewarded by cash payments for service. During lunch for example, there was a person, assumed was a volunteer, that plated the food that was donated and assisted with clean up (field notes). In fact, the researcher was initially informed by a participant that this person was a volunteer. However, after some informal interviews with additional residents, it was discovered that this person was a volunteer, but everyone consuming the meal was asked to provide a $2 donation to eat and the money collected was then used to give the volunteer a “donation” for her time (field notes). Also, in the mornings in the Community Room, while residents chatted and played Bid Wiz there was usually a woman serving coffee. Though the woman might vary, the set-up remained the same. She had a tray with a pot of coffee, paper cups, cream, sugar, and stirs. The researcher thought these women were just being hospitable, it was soon learned that people were purchasing coffee from them for 50 cents per cup or so (field notes).

Others were able to make money by serving as drivers and taking residents to go and run their errands, while still others assisted with tasks such as meal preparation, mending clothes, “makin plates,” carrying groceries, doing taxes and a variety of other positions (field notes).

Several residents even kept regular part-time employment as ushers, teacher's aides and other paraprofessionals and similar service work. Unfortunately, this need for money at times resulted in the sale of prescription pain relievers. Though the researcher of course, never observed or spoke with a resident that was selling their medications, many residents reported concern that this was taking place. James noted:

> I think that it's just the underground economy. There's a lot of people uh...in particular seniors who are out there and just lost but they are dependent on the pain medication to supplement their monthly incomes. And the doctors prescribe, prescribe, prescribe. And it's a whole new industry.

Daphene reiterated this,

> Now, these people complain all the time if they're not getting the right type of medication, and the people who really don't need it is getting it, and they're not taking it, and they're using it to benefit them financially. You know they're going to downsize it, the government is, eventually. (Daphene)

Being able to generate some income was important to the residents. A lack of access to financial resources was distressing for individual's accustomed to working sometimes multiple jobs. Having an understanding of the day-to-day stressors of poverty and pain made it that much more remarkable that elders only found themselves only "a bit stressed" according to the PSM-9 (see Table 11). Being concerned about safety was an additional stressor that these low income elders had to worry about.

### Managing safety.

The concern about safety was prominent in the daily life activities of the elders--though it was not as apparent initially to the researcher. The residents would remind the researcher regularly to be safe and to be careful. They would ask her to pay attention to who she was getting onto the elevator with, to be mindful of the amount of cash she kept on her person and to think about whose apartments she would go into (field notes). However, the researcher was an urban research nurse accustomed to the provision of both home care and data collection within low income, high crime areas. Additionally, there was a shared sense of community with the elders.

Being Black was found to be advantageous. There was a shared knowing between the researcher and the participants of the intrinsic challenges that come with living in dark skin. There was also a comfortable familiarity and understanding by the researcher of what it is like to be poor. It was therefore quite surprising when an incident occurred in which the researcher had to face safety concerns head on (field notes).

#### ***Meeting with Mason.***

A new gentleman to the facility was waiting on a cable installation appointment (field notes). He was interested in the completing the research questionnaire but did not want to miss his appointment. The researcher offered to accompany him back to his apartment to complete it as she had been doing with other residents for the past several months. As the researcher walked back to the gentleman's apartment she made eye contact with a maintenance man and smiled, briefly wondering if this was a bad idea (field notes). The gentleman opened the door and allowed the researcher to enter first. She entered and then turned around to get direction on where to sit and set-up her materials. He closed the door, licked his lips and said, "You're the first piece of wind I've had in here" (field notes).

Now, that probably should have been the researcher's cue to leave, however as a nurse, and particularly a geriatric nurse, she had grown accustomed to older men flirting and at times even being inappropriate with sexually suggestive comments. Her usually effective tactic is to ignore them and continue professionally, which is what she did. Ultimately, the participant was able to pass the cognitive screening exam and completed the questionnaire making the occasional lewd comments throughout. For example, one of the questions on questionnaire asks if the participant feels calm. He responded, “I haven’t cum in anybody in a while” again smiling while licking his lips and narrowing his eyes (field notes). He was corrected in a, matter-of-factly and unemotionally way stating, “I said calm” (field notes).

The conversation continued in this manner moving from lewd to random and possibly delusional. He spoke about stressors from his childhood including having created the names of every popular car on the market as a child and having his grade school teacher steal his list of names and sell them (field notes). The researcher continued to redirect him and keep him on task. After he was paid his $10 incentive for participating, he asked the researcher if she kept lot of cash on her. She promptly responded that she did not, thanked him for his time and left. That was the last time the researcher entered a home.

This particular event gave the researcher an acute understanding of the fear that caused many residents to be wary of who they allowed into their home and the time of day that they ventured outside of the home (field notes). John specifically spoke about this fear of crime and concern about his girlfriend enjoying going out to social events after dark. He said, “I ain't got to be around all them kids no more. They don't know how to act or no consideration for you. Damn a grown-up. Jump on us. Beat us up. I can't afford for them to beat me up or jump on me. I got a pace maker” (John). After the incident with Mason, the researcher had a much clearer understanding as to why the elders at the facility tended to answer the phone initially in a deep and abrupt vocal tone (field notes). They made the conversation uncomfortable so that the unrecognized caller was forced to get to the point and state their business (field notes). However, the tone generally softened almost immediately when they recognized the researcher's voice—it was a safety mechanism that few even recognized (field notes). Many safety mechanisms were built into the usual activities of daily living to maintain safety (field notes). One of these safety mechanisms was not complaining about concerning happenings, such as loud music and drug use around the building (field notes).

***Complaints.***

It was interesting how frequently the issue of complaints came up (field notes). Though residents would often talk to the researcher about concerns that they had regarding building maintenance, safety and bad neighbors, they tended to be keep this information to themselves (field notes). According to the building manager, it was not common for the elders to file formal complaints (field notes). The manager noted that on the few occasions that residents mentioned a concern to a member of the management team, they were never really interested in relaying details regarding the individual involved in the complaint process (field notes). This of course greatly affected the complaint process at the facility. There seemed to be a fear of retaliation. As one resident stated during an informal conversation, "I don't want no problems" (field notes).

Within low income neighborhoods where crime rates are high, there is a common saying—"snitches get stitches." It is understood that unless a crime has affected you directly, you look the other way or risk harm to yourself or your family from retaliation of those committing the crime. Management at the facility could not understand why residents would make informal complaints but were not comfortable making formal complaints or disclosing the names of individuals involved (field notes). Unfortunately, living in a senior housing complex with secured gated-entry did not make these residents feel any safer (field notes). When the researcher initially began visiting the facility she naively thought that it did.

### *Security.*

The community is supposed be gated with electronic controlled access. More often than not, the gate was malfunctioning and open (field notes). After reaching the primary entry way, visitors had to be buzzed in by residents and then signed in at the front desk that was manned by what appeared to be a security guard (field notes). However, one resident rolled her eyes and informed the researcher that the personnel at the desk were not were not security at all, but rather “courtesy personnel” (field notes). If anything were to occur, the only thing that they would do is call the police. This was confirmed by other residents (field notes). Various members of the administrative staff would take turns sitting at the front desk acting as courtesy personnel. At times, personnel from an actual security company, as evidenced by their uniforms, would fill in (field notes). Despite this supposed controlled access, there were still instances of homeless persons sleeping in stairwells and other non-invited persons walking around the building.

In considering the wide range of stressors that these participants were exposed to, it was quite amazing that they were able to adapt to poor physical health and moderate to severe pain while maintaining good mental health and a low stress levels. Religion, positive support systems, and not focusing attention on pain or disability seemed to play an important role in how these elders coped. Effective coping often meant that the elders could remain active longer. However, good medical management of pain could further increase positive health outcomes for this community.

## Managing Pain

The final research question of this study was, given their experiences with pain, pain management, and coping strategies, what advice might older Black American adults give to improve pain management in nursing practice. Interestingly, nursing care was only mentioned once in regards to pain management practice (Adam, field notes). Generally, when participants spoke about medical treatment, they only referenced concerns, likes, and dislikes as it related to the physician providing care (field notes). However, the most common pieces of advice given, were to listen (10 sources) and not be so quick to prescribe medications (5 sources).

**Being listened to.**

When residents spoke about their satisfaction with providers, they mentioned feeling cared for when they were listened to and providers had a good understanding of their concerns (10 sources, field notes). Being listened to, meant being heard in a way that resulted in appropriate follow-up that either clarified or cured problems (field notes). When physicians completed diagnostics and reviewed the medications patients were taking—eliminating medications as they were able—they were viewed favorably as doctors who were both skilled and listened well (field notes). Although diagnostic exams like laboratory work, scans of various types, and general assessment were overall viewed highly and seemed to legitimize providers in the eyes of residents, listening seemed to be viewed as the most important skill-set (field notes). However, what participants did not want was to be pacified. As Ms. Naomi stated:

> I'm tired of y'all saying, 'Hello, Ms. Naomi. How are you today?' and pattin' my hand, and saying ‘Take her blood and uh okay, I'll see you next time.’ I said, ‘I want you to listen to me and hear what I've got, 'cause I've got problems just like Mary Sue and she's 35.

For Naomi, being truly heard was not just a friendly request, but rather an expectation. Jane said that if she could give any advice to providers she would tell them to “Be patient. And listen. And try to encourage [people with pain]….You know, that attention mean more than medication sometime to me” (Jane). Listening seemed to fulfill both an emotional and social need of residents seeking care for physical ailments. When residents spoke about being listened to, many smiled in reflection, and highly praised their doctors (5 sources, field notes). Although it seemed to be the norm to be listened to by a nurse, it was unusual and desired to be listened to by the physician. Adam for example, who was very happy with his doctor, described how good it felt to have the doctor sit down and talk with him and then follow up directly later. He said:

> And that's unusual. Not a doctor calling! Maybe the nurse or someone may call. But it was the doctor that called me. And I told her she really blessed me--cause this is a new doctor. My old doctor just moved out of town to a new practice and she recommended her to me and I'm so glad. And I was very pleased. We sit in the office. We always sit in the office and we go over everything and we talk about everything.

Paul also reiterated the importance of being heard by the physician. When he was asked by the researcher what he would tell health care providers to do to improve care, and he stated, “Listen to them, and by your um experience, you know, suggest to them some things that you might know to help em. It’s all you can do” (Paul).

When Esther was asked what information she would like pass on doctors or nurses managing pain for people that hurt, she responded:

> They need to understand, and stop assuming. A lot of times, they assume …Sometimes people be in pain, sometimes pain can put you in a mental state, and it can wind up being a mental … a phantom pain. Phantom pain is just as bad as a regular pain (Esther).

She went on describe an incident of particular medical professionals not listening to her needs during therapy—they just stuck to the protocol—so she was forced to take matters into her own hands and stop the exercise she was working on in order not to cause harm to herself (Esther). Esther recognized that pain was not something that was visible, and therefore perhaps not as easy to treat, perhaps even impossible to treat, but if providers accepted the patient's report of pain as being true, pain could be more effectively managed for some (Esther, field notes).

This idea that listening to patients specific pain needs might allow providers to more readily understand that pain comes in various forms was reiterated by James. He spoke about pain sometimes being "psychosomatic" in addition to physical and that this crossover between having physical aches and pains and mental anguish is what he believed lead to addiction—which is why he chose to forego most pharmacological treatments for his moderate to severe pain (James). He noted that life in general could be painful:

> But there is also real pain too you know. I'm not talking about something imagined. There are some people who actually it's a chore to get up out the bed. Thank God I'm not there you know. A lot of times I think that psychologically we get so engrossed in...uh...false pain I should say (chuckles) that you know "I need a pill….I have a sniffle--I have a little pain in my toe--okay Doc I need some pain medicine." I just deal with it the best I can (James).

James was concerned that reliance on medications to solve all pain types is what lead to addiction. For him it was important to just deal with the pain as best as he could, without reliance on medication—this prevented what he called falling into the trap of addiction. What he and other participants felt contributed to others having difficulty with addiction was the perceived eagerness of physicians to prescribe opioid analgesics (James, field notes).

#### Over prescribing of medications.

The participants of this study did not like taking medications (12 sources, field notes). While most recognized the value of prescribed medications (field notes), some were concerned that medication usage was in overabundance (5 sources). James, mentioned earlier, spoke about using tai-chi and yoga to manage his pain because “A lot of times the pain management people over prescribe” (James). Macy spoke about only taking the tramadol that she was prescribed rather than the “Tylenol #3® and some other crazy stuff” the doctor gave her. Like James, she was concerned about over prescribing, particularly of opioid analgesics which she also felt lead to addiction. She said, “I know people that buy those. I don't want to be dependent on that” (Macy). Monica noted, “All that medicine stresses me out, and going to these doctors stresses me out” (Monica). Over prescribing was not just limited to analgesics in her opinion. Furthermore, the prescribing was a part of much larger problem. She went on to say:

> If they had results, then they lose money, because they won't be making no money if they heal-- if everybody feel good, they wouldn't have no reason to go back to the doctor. So I think the doctor just pacifies you with their medicines. And they do all right, but there's nothing really working for the important part. If I can’t get that sugar, and the blood pressure, and the itching under control—I’m going to have to go to the doctor.

This idea, that there was a larger clandestine purpose of healthcare, mostly as the result of financial incentives given to providers for prescribing and general experimentation, was frequently referred to as “the game” (9 sources).

#### ***The game.***

“The game” was essentially mistrust of health care providers. Unfortunately, it seemed to be understood by many participants that most doctors simply completed the tasks of their work and did not truly care for the people they treated. Rather, they were more interested in making money or experimenting on patients (9 sources, field notes). One resident, Daphene, spoke to me about the game in a conversation about medication usage and addiction. She believed that nearly everything, including Coca Cola® could cause addiction (Daphene) and that doctors contributed to addiction by forcing patients to take medication, whether they had pain or not, with the threat of taking away all pain relief. She stated:

Daphene: For my back medicine, I was on them pills and everything. I didn't take them like I was supposed to, because I wasn't hurting all the time. Then when I go to see them, they say, "Oh, it's not in your system." Well, I don't need it like that. So, they cut me off--

Sheria: Completely?

Daphene: Completely.

Sheria: For not taking it every single day.

Daphene: For not taking it.

Sheria: So, you didn't have it when you needed it?

Daphene: Right.

Sheria: Do you think that happens to other people as to why they wouldn’t say--

Daphene: Yeah, it happens.

Sheria: because then, why wouldn't you say you have it all the time if they're going to be--

Daphene: Right. So, why should I take it every day just because you give it to me and it says take daily?

Sheria: So, you think they're trying-- they want people to be addicted to it?

Daphene: Yeah, so you can have a sleepy mind, baby. That's all in the game.

Sheria: So then they could do whatever?

Daphene: They want to. "Oh, you need to be cut here. You need this. You need that. You need this." When I told them I didn't-- when they cut me off from the medication and I was still having pain, they gave me this thing you can plug into the wall and stick little things on you for you, like a little shock wave.

Sheria: Oh a TENS unit?

Daphene: That works. Girl, that works good too.

Sheria: So, when you say you didn't want it, they suddenly came up with some other way to manage your pain?

Daphene: Yeah. Right. And then my insurance company wouldn't pay for it--

92 year old Naomi, mentioned earlier, expanded on this idea that the "the game" was set up in a way that only patients who were willing to be tested upon received good treatment. She said, "…the young doctors are learning and teaching and if they can't find anything to experiment with or to increase their knowledge of about you, they don't wanna be bothered with it" (Naomi). Other residents echoed similar thoughts that medications—particularly pain medications--were a means of psychological control and a way to minimize work involved in providing care (9 sources).

This mistrust made participants feel as though they had to verify the validity of treatments and medications that they received (field notes). Although this verification took place by conferring with others, it most often took place through written materials. It was found that several members of the surveyed group were avid readers (13 sources, field notes).

### Reading health information

The participants of this study really seemed to enjoy reading and often relied upon written material for information regarding health practices (13 sources, field notes). Written materials were found at a variety of sources such as physician offices, pharmacies, books, and of course the internet (field notes). Theresa for example, was very knowledgeable about herbs, supplements, and various medications. She indicated that she had been reading up on things for years. She would access information most often though books recommended from various sources including health food store associates (Theresa, field notes). Naomi was also clear about how important it was to read things for yourself. As she said, “If you can read you can do anything” (Naomi). Like Theresa, she knew quite a bit about medications and their side effects. When she was asked how she came to know so much about medication side effects, she responded, “When they give me my medication, they give me a print-out. Sometimes it's so much, it takes me three weeks to read it all. But they do have on it side effects (Naomi).” If she wanted additional information on something, she would have her grandson look it up for her online (Naomi). Zora too was comfortable finding written materials she needed about important health information online. While Zora had a variety of interesting health beliefs, when she was asked if she would find it helpful to receive more information from providers about natural remedies and treatments she said no. “No I can look up anything I want to do on my computer. That computer right there. No it's computer now a days so I don't need no help. I can look up anything wrong with whatever everyday” (Zora). Reading seemed to increase self-reliance and autonomy for the participants and perhaps allowed for the additional time sometimes necessary to process important health information.

### Pain in Black elders

As evidenced by the preceding chapter, pain is a multifaceted problem that effects nearly every domain of self: physical, social, and emotional. The Black elders who participated in this study had moderate to severe pain daily. This pain decreased their quality of life—particularly their physical health. However, through a variety of effective coping mechanisms they were able to minimize their stress and moderate the negative effects to their mental health. These coping mechanisms included maintaining a positive mind frame, utilizing good social supports, and relying on faith to help persevere through stressors caused by physical disability, pain, and poverty.

Mistrust of medical providers, fears about dependence, hesitancy to talk about pain needs, and a dislike of oral medications—particularly opioids—can make pain very difficult manage for Black elders. However, despite these barriers the elder participating in this study have found ways of living with pain and maintaining their independence. In thinking about how pain management overall could be improved, elders wanted to heard more and prescribed to less. Pain management was primarily seen as a job for the physician. Nurses were generally not who participants identified as who they spoke with about their pain needs. In considering how the Roy Adaptation Model resonated with the lives of the participants, it provided an appropriate framework, for understanding the relationships between pain, coping, and quality of life outcomes. The following chapter will provide further discussion on the findings of this study and their relationship to the Roy Adaptation Model.

# CHAPTER 5

## Discussion

Pain is a costly problem that effects millions of Americans. For 91 Black American older adults residing in a senior housing complex, having pain meant having to deal with daily discomfort that caused diminished functional status, decreased quality of life and increased stress. Multiple comorbidities, such as osteoarthritis, diabetes, cardiovascular disease, anxiety, depression and chronic obstructive pulmonary disease (COPD), along with the added stressor of poverty, contributed to the overall stress and quality of life concerns of these elders. Like other Black American older adults, the elders participating in this study had unmet pain needs. While treatment preferences for non-opioid analgesics and a hesitancy to discuss pain needs may present a challenge in providing adequate pain management for these elders, effective adaptive coping responses still allowed for positive health outcomes. These findings are consistent with the literature and may provide useful clinical implications that may improve pain management nursing practice. Furthermore, the Roy Adaptation Model (Roy, 2009) provides a means of identifying and relating important care concepts identified in the study to nursing practice.

### Findings in the Literature

Findings from this study will add to the current body of knowledge regarding the experience of managing chronic pain. The chronic pain experiences of these elders were described by participants and identified by the researcher through questionnaire responses, participant observations and interviews. Study results mirror similar studies found in the literature.

Davis, Hiemenz, and White (2002) explored the barriers to pain management experienced by older adults. Using eight focus groups and a total sample size of 57, older adults aged 65 and older, including 7 Black Americans, were found to have a variety of barriers to pain management.

In particular, participants' personal decision making in how they chose to manage pain, along with the relationships with providers, negatively affected pain management. Similar to the current study, the Davis study identified multiple comorbidities and a hesitancy on the part of the participants to take medications due to concerns about side effects, fears about addictions, and only taking medications when pain was at its worse as factors negatively influencing their pain management choices. Additionally, participants described decreased social interactions and difficulty in maintaining hobbies due to pain. Like the current study, participants also accepted pain as a normal part of the aging process. Finally, participants of the Davis study similarly described concerns with poor communication, unmet care expectations, and general mistrust of providers as additional barriers to pain management. The major difference between the Davis study and the current study was the reluctance of the participants of the Davis study to use nonpharmacological treatments for pain management. This difference may be accounted for by race. While 7 participants of the Davis study were Black, and 9 were Latinos, the majority of the participants (72%) were White. Black older adults may have a preference for home remedies and nonpharmacological management of pain due to concerns about side effects (Figaro, Russo, & Allegrante, 2004; Loeb, 2006; Martin et al., 2010; Meghani, Chittams, Hanlon, & Curry, 2013).

Park, Lavin, and Couturier (2014) also had similar findings. The authors used a cross sectional descriptive design to evaluate 281 adults, aged 60 and older, with moderate to severe persistent pain, to evaluate factors associated with nonpharmacological pain management choices. Participants completed a demographic questionnaire, the Brief Pain Inventory, and they were asked about the different types of nonpharmacological pain therapies they used. Similar to the current study, the majority of the participants in the Park study were women (77%) and 49% of the population were Black (Afro-Caribbean or African-American). Additionally, participants were religiously diverse with about 20 percent of the population considering themselves to be protestant, while 31 percent noted “other” religious affiliations. Only about 30 percent of the participants were married. Also similar to the current study, sixty-five percent of the surveyed group rated their pain at a 7 or higher on a 0 to 10 scale and pain interference was noted in the areas of general activity, mobility and sleep. Additionally, the majority of the population (82%) were found to be using nonpharmacological pain therapies—particularly nonaquatic exercise (83%) and prayer (51%). The greatest reason given for using nonpharmacological therapies was a dislike of pain medications (46%). Also, like to the current study, the authors found participants frequently used exercise as a means of managing pain. Finally, ethnicity was found to be a predictor for the use of prayer as a pain intervention. The findings by Park, Lavin, and Couturier (2014), support the current study results.

Eggermont et al. (2014) completed a longitudinal study of 634 older adults with an average age of 78 to determine the effects of chronic pain in developing disability. Pain assessments were completed by means of the Brief Pain Inventory (BPI) and disability was measured using various domains of self-reported activities of daily living (ADLs), instrumental activities of daily living (IADLs), and the Short Physical Performance Battery (SPPB). Like the current study, the majority of the population (65%) in the Eggermont study reported multi-site pain at baseline assessment. Additionally, multiple pain sites decreased self-reported functional mobility in elders with chronic pain three-fold. Multi-site pain was associated with decreases in activities of daily living. Furthermore, being female, obese, and having comorbidities such as rheumatoid or osteoarthritis, lung disease, and depression were associated with having multiple pain sites. At 18 month follow-up, multi-site pain predicted about half of all of the new reports of difficulty with mobility and activities of daily living. Single site pain was found to be rare amongst the group. These finding also support the current study that found multiple pain sites to be the norm within the group along with decreases in functional status that effected mobility and ability to carry out several usual activities of daily living.

Loeb (2006) completed a qualitative study of 28 Black adults aged 55 and older to identify strategies used to manage chronic health conditions. Data collection by means of focus groups identified 9 major health strategies used by the Black elders of the study to manage pain: 1) dealing with it, 2) engaging in life, 3) exercising, 4) seeking information, 5) relying on God, 6) changing dietary patterns, 7) medication, 8) self-monitoring, and 9) self-advocacy. Like the current study, participants of the Loeb study were able to use effective adaptive coping strategies to mediate the effects chronic disease. Common health conditions effecting participants included hypertension (48%), diabetes (21%), and cardiovascular/ circulatory concerns (17%).

Similar to the previous studies, most of the participants were female (69%) and either widowed or divorced (69%). “Dealing with it” meant maintaining a positive attitude and not focusing on disability, but rather, using laughter and reframing to manage changes in health. Engaging in life was similar to the theme of community engagement in the present study. Participants of the Loeb study also used volunteerism and religious service to provide distraction and opportunities for social engagement. Interestingly, the author included creative pursuits such as quilting, flower arranging, and sewing within this theme—which were also noted as forms of distraction used by participants within the current study. Walking was the most common form of exercise used by the participants and reading materials obtained from the internet, pharmacists, doctor offices, and books were used to obtain health information. Dietary modifications were associated with positive health, but participants were challenged to implement dietary changes that allowed for the usual foods of the culture. Finally, though the participants took medications for the management of their health conditions, they were concerned about side-effects and utilized self-monitoring to pace activities and remain active.

While almost all of the results of the Loeb study reflected the results of the current study, the one major difference was self-advocacy. While in Loeb study participants spoke about the need to openly talk with providers to understand treatments, procedures and their outcomes, the participants in the present study did not discuss this type of self-advocacy. Rather, participants within the current study spoke about matter-of-factly telling providers what medications and treatments they were not going to partake in (8 sources).

Similar findings were also noted by Martin et al. (2010). Martin and colleagues completed a phenomenological study of 15 Black elders aged 60 and older to understand the role of culture and discrimination on care seeking behaviors. 10 of the 15 participants were women, 8 of whom identified themselves as marred. Additionally, 8 of the 15 participants noted using nonpharmacological treatments for health concerns. The seven major themes identified in the study included: 1) the perception of health as being active, 2) reluctance towards prescription medication use, 3) lack of trust in doctors, 4) avoidance of bad news, 5) preference for race of doctor effecting care choices, 6) use of home remedies, and 7) the importance of God and spirituality in health, illness, and healing.

Like the current study, being active in the Martin study did not just mean increased mobility, but rather having the ability to both work and assist others. Also similar to the current study, reluctance to use prescription medication was associated with both mistrust of providers and concerns about side effects. Interestingly, though reading was not identified as a theme within the Martin study, participant responses indicate that health information was obtained by reading books. A unique finding in the Martin study was an association between use of nonpharmacological treatments and spirituality. The current study made no such connection. Additionally, the Martin study found that participants believed others within the cultural group avoided going to the doctor in order to avoid bad news which was not evaluated within the present study. Furthermore, Martin asked participants about preferences regarding care providers. The participants in the Martin study were apparently split in whether or not the race of the provider made a difference in care choices. Similar findings were also noted in the current study though not reported due to no clear themes being present in the responses. However, during informal interviews of participants of the present study, participants were asked if provider race made a difference care choices and similar to the Marin study responses were split with no clear preference either way. Finally, similar to the other study finding, religiosity was an important aspect of health, however the idea that spirituality was tied to health was not a clear theme in the present study.

The final study noted with similar findings to the current study was that completed Przekop (2015). Przekop evaluated pain interference by reviewing 9,506 responses of community dwelling adults, aged 40 and older who participated in the Biopsychosocial Religion and Health Study, a study of cancer, diet and lifestyle amongst Seventh-Day Adventist living in the US and Canada. The average age of participants was 62, and similar to the other studies nearly 69 percent of participants were women. About 33 percent of the sample were Black. For this study, pain interference was calculated by evaluating responses to a single item on the SF-12v2 which asked participants if pain had interfered with normal work in the past 4 weeks on a 1 (not at all) to 5 (extremely) scale. General health was evaluated by responses to a questionnaire item that asked how health was rated on a 5-point scale ranging from 1 (fair) to 5 (excellent). BMI was calculated by self-reported height and weight measures and sleep quality and depression were evaluated based on responses to 4-point and 3-point scales respectively. Prezekop found that being female, being overweight, having poor health, and financial strain were correlated with higher pain interference ratings. Moderate to severe pain interference effecting normal work was noted in slightly more than half of respondents (51.8%). The younger age of participants within this large sample may have skewed the results somewhat in comparison to the other studies and the present one, however the results still reflect similarities to the current research findings.

As evidenced by the noted studies, the results of the current research findings are similar to those found in large population samples as well as those found in small qualitative studies. Though the small sample size of the this study, n=106 limits generalization of findings to the wider population, the findings are still helpful in understanding the adaptive coping strategies that are likely to be used by Black elders and how nursing practice might be adjusted to assist these elders within the adaptive process. The Roy Adaptation Model, provides an appropriate frame work for relating the themes and concepts discovered in this work to nursing practice.

## Theoretical Implications

The primary role of nursing actions is to facilitate improved health of humans relative to both context and culture (Robinson, 2013b). Health is determined by adaptive coping to stress and is both a state of being as well as a process of becoming integrated and whole (Roy, 2009). Humans learn to use adaptive coping strategies, or cognitive and behavioral efforts, to manage or reduce negative health outcomes which can diminish quality of life (Dunn, 2004). Both the professional nurse and the nurse scientist seek to understand and improve the adaptive processes that impact the well-being of the person, family, and community. These actions are in alignment with the core value of nursing—providing caring relationships that facilitate adaptation and promote the well-being of humans across the life span within a variety of environments (American Nurses Association, 2010). The internal and external environment play a key role in how individuals adapt to changes in health, as the environment influences a person's perception and therefore effects their expectations of health. Understanding the laws that govern life processes, identifying patterns of interaction between human behavior and the environment, and then relating how this understanding can improve health is how nursing knowledge is generated (Donaldson & Crowley, 1978). The advancement of knowledge within the discipline of nursing takes place through theory construction and development.

Theory provides a means of expressing the relationships between primary nursing actions and anticipated outcomes. Middle range theories, specifically, allow for the description of concepts within limited parts of reality that the nurse is likely to encounter in practice (Roy, 2014). This limitation in scope, allows concepts within the theoretical framework to be more easily defined operationally, which more readily allows for testing in research. Additionally, the simplicity of the middle range theoretical model allows for the knowledge generated from the theory to be more easily adopted into nursing practice.

The Roy Adaptation Model (Roy, 2009), described in Chapter 2, provides a strong model for practice based research and theory development. As previously noted, the model is grounded in the idea that humans are holistic adaptive systems that continuously respond to changes in both the internal and external environment. Stimuli from these environments, such as pain, will illicit responses that the system must respond and adapt to in order for the individual to maintain or achieve a measure of self-determined health. The main philosophical assumptions of the model focus on humanism and veritivity. Roy describes humanism as the recognition of the "individual and subjective dimensions of human experience" that are central to knowing and valuing (Roy, 2009, p. 28). In other words, human understanding and values are based on individualized experiences and determine behavior. The concept of veritivity, which was later expanded to *knowledge as a universal cosmic imperative,* is a created term derived from the Latin word *veritas* meaning truth, and refers to “the common purposefulness of human existence” (Roy, 2009, p. 28). Spirituality is also a clear component of the philosophical assumptions of the model. So the model is therefore appropriate for the development of middle range theories of coping relevant to the Black American older adult population. The Roy Adaptation Model was used as the basis for informing a middle range theory of coping.

### A Middle Range Theory of Coping.

Roy presented a middle range theory of coping, within her 2014 book, *Generating Middle Range Theory: From Evidence to Practice*. Here Roy describes the process of developing a middle range theory and provides an example of a middle range theory of coping she developed using five research reports that covered 13 studies focused on coping. Particular propositions of the theory linked to the current research included: 1) adaptive coping strategies caused decreased perceived stress and less psychological distress, 2) active coping strategies lead to adaptation, 3) religious coping increases self-concept and diminishes depression and psychological distress, 4) religious and nonreligious coping strategies are used by elders to manage increased pain intensity, 5) gender and race effect religious coping strategies which were more likely to be used by women and non-White participants, and 6) race has some effect on creativity—particularly amongst Black participants. All of these propositions were noted to some extent within the current study.

Though PROMIS global physical health scores were diminished significantly for participants with pain and decreased functional status, global mental health scores were not as low indicating some adaptive coping taking place. Participants in general also did not report high levels of stress according to the Psychological Stress Measure. Active coping strategies, such as exercise allowed participants to have decreased pain and maintain some mobility. Participants with increased pain used combinations of prayer, medications and non-pharmacological treatments to manage pain. Roy noted a higher incidence of the use of religious coping amongst women and non-Whites. The present study, which was a completely Black population, the majority of whom were women, also found religious coping to be actively used. Finally, creative pursuits were used frequently by participants to allow for distraction from pain and social engagement. Each of these propositions are linked back to concepts outlined within the Roy Adaption Model.

The Roy Adaptation Model, Roy (2009) identifies a stimulus as something that evokes an internal or external response. A Stimulus may be focal, contextual, or residual depending upon how it effects the body system and how it is identified by either the nurse or the patient. As the main goal of the system is to maintain homeostasis, or achieve full integration where all body systems are operating at optimum levels, when stressors present that diminish the functionality of the system, adaptive coping processes are employed to again achieve optimal levels of health. Focal, contextual, and residual stimuli were identified in the current study.

### ***Focal stimuli***

The primary, or focal stimulus of the present study was persistent pain. The intensity of pain experienced by the participants often required immediate interventions such as medication, or other treatments, and modification of activities to prevent exasperation of the pain. Pain also limited social interaction and the ability to work. Though pain is a symptom caused by disease, pain in itself can become so life limiting that it remains a sole focal stimulus. The other stimuli that effect the total pain experience, or contextual stimuli, included disease, changes in functional status, and poverty.

### *Contextual stimuli.*

Participants had multiple comorbidities. Diseases such as diabetes, cardiovascular and lung disease caused bothersome symptoms such as changes in cognition, difficulty with breathing, difficulty with ambulation, dizziness, anxiety, and increased risk of infection. Diseases such as diabetes and cardiovascular disease also generally require dietary changes. Additionally, disease management frequently requires medications and physician office visits. As a result of disease, participants had to adjust behaviors to manage bothersome symptoms, new dietary requirements, and their time.

Changes in functional status are the result of diseases or health conditions such as obesity, cardiovascular disease and other organ failure, arthritis, osteoporosis, frailty, and of course pain. However, like pain, changes to mobility alone can cause illicit behavioral responses such as decreased social interaction, inability to work, use of assistive devices, and changes to usual daily routine.

Finally, poverty was noted as an additional stimulus that likely caused behavioral responses from participants. Poverty in itself was a source of worry and stress for participants. Concerns about safety and pests within the income-based housing complex effected how elders interacted with others, when they chose to leave their apartments, and the types of assistance they sought out from others. Poverty also effected health choices including access to care and medical devices.

The stress of being poor, having changes in functional status, and dealing with multiple comorbidities is what the made these pain experiences unique and meaningful to these participants. It was these extra stressors that, at times, could make dealing with pain seem almost unbearable and what likely had the greatest negative impacts to quality of life. Underlying these stimuli, was a fear of dependence.

***Residual stimuli.***

The fear of dependence was not recognized by participants, or the researcher initially, as an additional stimuli effecting care choices and decisions. Recall that residual stimuli tend to have effects that are unclear in the current situation. The fear of dependence seemed to be the motivational factor that encouraged participants to remain active and engaged despite pain. This fear of dependence also seemed to influence care choices such as medication usage. Despite the various stimuli attempting to cause interference to the functionality of the participants' body systems, they were able to employ a variety of appropriate adaptive coping responses to reduce the negative impacts of stress.

***Positive coping.***

Roy (2009) identified four adaptive modes, or levels of coping, used by humans to manage stress. Recall, these modes are simply a means of grouping behaviors into four categories that describe how individuals handle stimuli from the environment and areas where further assistance is needed to achieve adaptation. The major adaptive modes are physiologic, self-concept, role function, and interdependence.

Participants employed coping strategies within each of the four modes. Within the physiological mode, which is inclusive of the physical and chemical processes required to maintain normal body functioning, participants used assistive devices, exercise, analgesics and non-pharmacological treatments to manage the physical effects of pain, disease, and changes to mobility. Within the self-concept mode, participants engaged in prayer, meditation, and had a general sense of stick-to-itiveness, or constancy. These adaptive coping responses integrated faith, beliefs, and views of one-self to allow for spiritual integrity and the positive reframing of health conditions.

The participants continued to find ways to be engaged in the community and developed creative means of earning income which supported their role function. Enduring societal roles, despite pain, provided participants with additional opportunities to continue to experience worth and meaning in life. Finally, support systems provided participants with the personal connections they needed to remain encouraged and connected to others. As a result of employing the noted adaptive coping strategies, participants were able to experience a variety of positive health outcomes including adaptive self-concept responses, decreased psychological distress, spiritual well-being, adaptive role responses and ability, and satisfaction in caring for each other. Figure 3 provides a visual schema of the relationships between the noted stimuli, adaptive coping responses, and outcomes. The observed outcomes were the same as those noted in the Middle Range Theory of Coping presented by Roy (2014).

## Implications for Clinical Practice

The primary objective of this work was to understand the experiences of managing pain amongst Black American older adults. It was expected that the findings from the study would provide important clues on how to improve the strategies used by nurses to assist Black elders in effectively managing their persistent pain. The following clinical implications were garnered from this work and should be considered within pain management nursing practice.

One of the most surprising findings of the study was that a nurse was not mentioned by any of the participants as a primary interventionist or person they sought assistance from directly in pain management. During discussions about pain management, or even health care in general, participants almost always referenced the physician. This points to the need for nurses to be visible in care and more vocal regarding their role in care. For example, if the nurse meets with the patient prior to meeting with the physician with the intention of discussing care concerns, unmet needs, or uncovering opportunities for teaching, the nurse should clearly introduce themselves as the nurse caring for, or working with the patient, describe how they are going to provide care, and what the patient can expect from them. Additionally, as participants tended to have a mistrust of physicians, low compliance with taking prescription medications as ordered, and a desire to be heard, nurses should consider the development of telemedicine or phone-follow up programs within pain management practice settings that would allow nurses and patients to communicate more readily about medication usage and concerns, recommendations for effective non-pharmacological treatments that might be used, and other relevant health concerns that might affect the pain experience. These phone calls may reduce the need for in-office follow-up visits which some older adults found to be costly and unnecessary. This lack of acknowledgement, or perhaps recognition, of the role of nurses in pain management also illuminates a practice gap that may be addressed by community/public health nursing practice.

Community health nurses oftentimes have increased access to the home environment of patients, which allow for more realistic conversations regarding pain needs and current self-care practices. As unmet pain needs may ultimately result in disability for the older adult, these field nurses are primely positioned to provide the most thorough assessments and culturally appropriate interventional strategies for community dwelling elders with pain. It is also likely that increased follow-up nursing visits would result in decreased pain, improved medication use, decreased overall disability, a reduction in related health care costs, and perhaps even a diminished use of illicit drugs secondary to poor symptom management amongst disparate populations.

In addition to engaging the practice area of community/ public health nursing, work should be done to facilitate meetings with the nurse, physician, patient, and other care team members for the specific purpose of collaborative care planning. In having care team meetings for pain management, patients would have opportunities to discuss their pain needs and treatment plans within the structured setting of a care team meeting. One of the interesting findings of the study that was noted upon reflection, was that rather than being passive recipients of care, Black elders were actually very thoughtful about their pain management practices and took active control of how they chose to manage, or not manage, their pain. When it came to pain management, physicians seemed to be viewed more as consultants, or advisors, rather than directors of care. Therefore, engaging patients in collaborative care planning that includes all members of the care team reinforces the autonomy and self-care practices these elders value. Additionally, meetings could also provide platforms for providers to discuss diagnostics and other rationales for care. As Black American older adults continue to have some mistrust of healthcare providers, it would be important to facilitate trusting relationships during these meetings by presenting balanced information on all interventions chosen. So for example, if a medication is chosen as the primary treatment intervention, team members should review the benefits of the medication along with the rationales for the times it should specifically be taken, and any troublesome side effects to monitor.

As noted in Chapter 4, Black American older adults, like other older adults, do not like taking medications. Many have a preference for natural remedies and herbal preparations. Pain management nurses should therefore be knowledgeable about the common herbal preparations and home remedies used to self-manage pain. They should be prepared to share accurate information, including references and applicable resources as appropriate. In the least, nurses should have ready access to reference materials specific to herbal remedies so that they can evaluate the safety of treatments patients may be taking, or making, on their own.

The participants of this study, and some of the other studies referenced, had a preference for reviewing written material to understand prescribed medications and treatments. Besides referencing books and reviewing literature at doctors' offices and pharmacies, participants often chose to look up health related information online. With this in mind, nurses should be prepared to support the educational preferences of patients by providing a variety of educational mediums, specifically supplementing oral education with written material and handouts. Additionally, patients should be directed to appropriate health information websites that have been evaluated for accuracy, bias, and of course patient utility.

Spirituality was another clear component of care for many of the elders who chose to participate in the present study as well those noted within other studies discussed. Some participants may be appreciative of a deeper integration of spiritual aspects of care into practice. Booker (2015) provides a few spiritual care interventions that patients might find helpful and should be considered for integration into practice. For example, as many older Black adults frequently use prayer and believe fervently in its healing power, prayers (silent or audible) could be used by health providers before, during, or after office visits to reinforce faith and the congruency between faith and healthcare practice. Bible readings, said aloud, recorded, or even providing printed versus of selected scriptures, may provide needed encouragement and improve mood. Similarly, integration of gospel or serene meditative type music can assist patients in achieving a more relaxed and reflective state which may improve the effectiveness of other therapies and interventions. Understandably, faith is deeply personal and culturally linked to behavior. As Black older adults represent a diverse group of religious affiliations, or have no affiliation at all, it would be important to ask patients about preferences, and consider the demographics of the geographic area so that care may be culturally appropriate.

Finally, there should be some consideration of pain management programs that include exercise and dietary interventions. The participants recognized the value of continued mobility despite pain. Black elders could benefit from a structured strength training program specifically aimed at reducing pain and increasing mobility. Maintenance of strength and mobility could limit the need for assistive devices and provide additional opportunities for social interaction and support. There may even be opportunities for program development that provide financial incentives for participation, which may particularly appeal to low-income patients dealing with the added stressor of poverty.

Cardiovascular disease and diabetes were common comorbidities of the participants. Although obesity was not measured within the present study, several participants were observed to be overweight and obesity has been noted as a comorbidity in itself that can cause joint pain and reduce mobility. Though many participants spoke about "watching what they ate" as a means to improving health, the most common dietary intervention was changes in portion sizes—essentially eating less. Unfortunately, there was little knowledge about appropriate food choices and portion sizes based on illness or health concern. Elders in similar residential facilities would likely benefit from structured nutrition classes that included culturally appropriate cooking demonstrations and menu selections.

There are many opportunities for improvements in the clinical management of pain. Nurses are in a prime position to facilitate the practice changes and education that could reduce pain severity, improve mobility and increase trust between patients and providers. Additionally, the holistic nature of nursing care adequately prepares nurses to serve as case managers that can facilitate healing across all domains of care—making appropriate disciplinary referrals as necessary.

## Strengths and Limitations

This study is the first study of its kind to capture PROMIS Global Health scores in a geriatric population. As other researchers begin to evaluate populations of elders, Black Americans, and those managing multiple comorbidities, data from this study may be used as a means of comparison. An additional strength of the study is its use of observational and interview data to support and explain quantitative research findings in a minority older adult population. This additional data helped to more fully illuminate the experience of managing pain amongst Black American older adults. The findings from this study will advance understanding of opportunities and barriers to effective pain management. Findings from this study also support the Roy Adaptation Model as framework for understating and managing chronic pain.

The small sample size was a limitation of this study. While generally, qualitative studies range in numbers of participants from 9-20, depending on the type of study, larger samples are helpful in generalizing data to the wider population. After removing participants who did not meet eligibility criteria due to age, as well as the removal of participants who completed more than one questionnaire during the year spent at the facility, there was a total of 106 participants in this qualitative study. Data from one participant in the study had to be excluded after it was discovered that she was not truthful regarding her age—she was under the age of 55. This omission was discovered by the researcher during a formal interview. Though the anticipated number of participants was 120, it was found that recruitment had been maxed using the available methods of recruitment for the site—presence and participant referral. Formal recorded interviews were completed with 20 participants along with multiple informal interviews and follow-up interviews to confirm data findings. It should be noted, that as an exploratory study only a sample size of 104 was necessary to achieve an average standard deviation of 13 with a confidence interval of 5 and a confidence level of 95% ($N = 4Z\alpha2S2/W2$). Though the sample size is small, findings from the study are still useful in understanding the experience of Black American older adults managing pain.

An interesting limitation of the use of the Brief Pain Inventory within this study was its inability to capture neuropathic type pain. As the researcher was assisting the participants in completing the Brief Pain Inventory, it was often noted that participants would circle the initial response indicating that they had no pain. Upon further questioning of individuals with self-identified diagnoses often associated with neuropathic type pain, such as diabetes and peripheral vascular disease, most participants who initially indicated that they had no pain later revealed that they did in fact have neuropathic type pain that caused discomfort. An additional relevant clinical implication based upon this information would be for nurses and providers to consider the language used to describe pain. As neuropathic pain feels different from the usual musculoskeletal pain elders frequently experience secondary to various forms of arthritis and injuries, they are not likely to associate neuropathic type pain as pain, but rather a discomfort or soreness. Standard pain scale may continue to be used by simply replacing the word pain with the word or phrase the patient most readily identifies with for their pain type. In this study, data was not collected on the number of patients whose primary pain type was neuropathic rather than nociceptive.

A final limitation of the study was that almost all of the participants had enough mobility to be recruited within a common area of the facility. Potential participants experiencing the most severe pain may not have been accessed. While IRB approved flyers were distributed and placed on community bulletin boards, their time on display was limited and the anticipated mailbox, or door distribution, was not permitted as originally planned. After spending such a significant amount of time at the facility, on retrospect it is recognized that a better means of recruitment may have been to distribute flyers directly to floor captains to obtain participant referrals and attempt to get on the agenda of the monthly meeting, or distribute flyers directly afterwards. Nevertheless, useful information was obtained regarding elders whom nurses are likely to encounter in urban settings and this data will direct future research.

## Future Research Directions

Pain management is a broad topic area with multiple opportunities for future research using older adult and/ or Black American populations. In the immediate future there will be further analysis of the relationships between pain severity, pain interference, stress, and the Global Health measures of mental and physical health. As this is the first study of its kind to evaluate Global Health within a Black older adult population, consideration should also be given to repeating the measures within a larger sample size and developing comparison studies to review findings with other persistent pain older adult populations.

Addiction was a topic that came up frequently with participants and presented as a barrier to opioid analgesic use. Future research to understand the co-occurrence and management of addition and pain would be particularly helpful to providers. Additionally, as emotional pain, which some participants also spoke of, is often linked to histories of personal trauma, it might be helpful to explore the relationships between personal trauma, pain, quality of life, coping, and addiction.

Interventional studies may focus on exercise and dietary management programs as a means of reducing pain and improving mobility for community dwelling elders. Studies may be implemented at or in collaboration with current sites that offer elder fitness and strength training programs such as community centers and the YMCA (Sliver Sneakers Program). Additionally, as insurers have a financial incentive to improve mobility and decrease pain amongst their insured, these companies may provide another source of programming that may be implemented and tested.

In addition to furthering participant research, there is also opportunity to continue to expand the middle range theory of coping presented here as well as the use of the Roy Adaptation Model as framework for understanding adaptive coping to pain. The middle range theory may be further developed by evaluating additional studies of persistent pain in Black older adults and identifying related concepts and linkages to the model.

After nearly a year of observing, interviewing, and interacting with residents of a community based elder housing establishment, the researcher has an acute understanding of the defining attributes of how Black American older adults experience pain and pain management operationally, emotionally, and qualitatively. One hundred six of these elders completed questionnaires and twenty allowed the researcher into their homes and spaces for interviews. They spoke with the researcher about day-to-day happenings, joys and sorrows. Most importantly, they spoke to her about their pain.

For these elders, pain secondary to both injuries and disease progression, caused limitations in their ability to move and function optimally. In turn, these functional deficits limited, changed, or in some instances completely eliminated their ability to complete day-to-day activities, exercise, work, and pursue creative interests. These changes also negatively affected their relations with others and ability to earn an income. Elders found coping with pain to be a necessary prerequisite for living. They keenly managed their pain by continuing to engage in various activities despite discomfort. Prayer, meditation and reliance on social supports, helped to get them through difficult days. While medications were often used to assist in the management of pain, provider mistrust, the preference for topical preparations and natural remedies along with concerns about addiction and dependence to opioids, limited optimal pharmacological treatment. However, provided written educational materials were used and found to be helpful. Interestingly, dietary changes, were viewed as an important means of maintaining overall health and functional status despite the limited knowledge of many participants on the specific dietary changes necessary for improved health.

Persistent pain is certainly a complicated problem to manage. However, the experiences of managing pain that were shared by the participants of this study will positively change pain management nursing practice and perhaps eventually change how pain is managed for these elders in the future.

## Tables

### Table 1 Data Collection Matrix

Data Collection Matrix

| Research Questions | Participant Observation | Interview 1 | Interview 2 | BPI | PROMIS | PSM-9 |
|---|---|---|---|---|---|---|
| 1. How do Black American older adults experience pain and pain management operationally, emotionally, and qualitatively (the defining attributes). | √ | √ | √ | √ |  |  |
| 2. How do Black American older adults cope with pain, particularly, what are the relationships between pain management and health related quality of life (HRQOL) and what does this tell us about the extent to which the Roy Adaptation Model resonates with these participants' lives? | √ | √ | √ | √ | √ | √ |
| 3. Given their experiences with pain, pain management, and coping strategies, what advice might older Black American adults give to improve pain management in nursing practice? |  | √ | √ |  |  |  |

**Table 2 Participant Age Ranges**

| Age | Frequency | Percent |
|---|---|---|
| 55-59 | 15 | 14.2 |
| 60-64 | 35 | 33.0 |
| 65-69 | 28 | 26.4 |
| 70-74 | 14 | 13.2 |
| 75-79 | 7 | .07 |
| 80+ | 7 | .07 |
| **Total** | **106** | **100.0** |

**Table 3 Participant Marital Status**

| Status | Frequency | Percent |
|---|---:|---:|
| Single | 41 | 38.7 |
| Married | 9 | 8.5 |
| Divorced | 25 | 23.6 |
| Separated | 10 | 9.4 |
| Widowed | 21 | 19.8 |
| **Total** | **106** | **100.0** |

**Table 4 Participant Religious Affiliations**

| Religion | Frequency | Percent |
|---|---|---|
| Baptist | 54 | 50.9 |
| Catholic | 4 | 3.8 |
| Jehovah's Witness | 6 | 5.7 |
| Mormon | 3 | 2.8 |
| Pentecostal | 3 | 2.8 |
| Presbyterian | 8 | 7.5 |
| None | 15 | 14.2 |
| Other | 10 | 9.4 |
| **Total** | **106** | **100.0** |

**Table 5 Participant Medical Conditions**

| Diagnosis | Frequency | Percent |
|---|---|---|
| Anxiety | 23 | 21.7 |
| Coronary Artery Disease | 14 | 13.2 |
| COPD | 22 | 20.8 |
| Hepatitis | 7 | 6.6 |
| Diabetes | 39 | 36.8 |
| Neuropathy | 19 | 17.9 |
| Renal Failure | 6 | 5.7 |
| Osteoarthritis | 62 | 58.5 |
| Rheumatoid Arthritis | 7 | 6.6 |
| Cancer | 10 | 9.4 |
| Stroke | 7 | 6.6 |
| Depression | 27 | 25.5 |
| Emphysema | 3 | 2.8 |
| Acid Reflux | 7 | 6.6 |
| Congestive Heart Failure | 10 | 9.4 |
| Hypertension | 73 | 68.9 |

**Table 6 Brief Pain Inventory Average Scores**

Brief Pain Inventory Average Scores

| | | Pain Severity | | | | | Pain Interference | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | Pain Sites | Worst Pain | Least Pain | Avg Pain | Current Pain | General Activity | Mood | Walking Ability | Normal Work | Relations w/others | Sleep | Life Enjoyment |
| N | Valid | 91 | 91 | 91 | 91 | 91 | 91 | 90 | 91 | 90 | 90 | 91 | 91 |
| | Missing | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 0 | 1 | 1 | 0 | 0 |
| Mean | | 4.93 | 7.04 | 3.85 | 6.68 | 4.37 | 5.59 | 4.58 | 5.73 | 5.70 | 3.38 | 4.80 | 4.09 |
| Mode | | 2 | 10 | 0 | 5[a] | 0 | 0 | 0 | 10 | 10 | 0 | 0 | 0 |
| Std. Deviation | | 3.221 | 2.569 | 3.296 | 2.304 | 3.220 | 4.300 | 3.626 | 3.340 | 3.797 | 3.590 | 3.953 | 3.726 |
| Variance | | 10.373 | 6.598 | 10.865 | 5.308 | 10.370 | 18.488 | 13.146 | 11.157 | 14.415 | 12.889 | 15.627 | 13.881 |
| Std. Error of Skewness | | .253 | .253 | .253 | .253 | .253 | .253 | .254 | .253 | .254 | .254 | .253 | .253 |
| Minimum | | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Maximum | | 12 | 10 | 10 | 10 | 10 | 30 | 10 | 10 | 10 | 10 | 10 | 10 |
| Skewness | | .520 | -.923 | .356 | -.430 | .115 | 1.844 | .016 | -.435 | -.312 | .590 | .008 | .222 |

a. Multiple modes exist. The smallest value is shown

### Table 7 Participant Pain Medication Usage

| **Medication** | **Frequency** | **Percent** |
|---|---|---|
| Hydrocodone with Acetaminophen | 26 | 28.6 |
| Nothing | 15 | 16.5 |
| Acetaminophen with Codeine | 11 | 12.0 |
| Tramadol | 9 | 9.9 |
| Ibuprofen | 5 | 5.5 |
| Naproxen | 4 | 4.4 |
| Other | 4 | 4.4 |
| Acetaminophen | 3 | 3.3 |
| Aspirin | 3 | 3.3 |
| Cyclobenzaprine | 2 | 2.2 |
| Morphine | 2 | 2.2 |
| Oxycodone | 2 | 2.2 |
| Capsaicin | 1 | 1.1 |
| Gabapentin | 1 | 1.1 |
| Meloxicam | 1 | 1.1 |
| Methadone | 1 | 1.1 |
| Oxycodone with Acetaminophen | 1 | 1.1 |
| **Total** | **91** | **100.0** |

**Table 8 Global Physical Health and Mental Health for Participants Experiencing Pain**

| | | GPH | GMH |
|---|---|---|---|
| N | Valid | 91 | 91 |
| | Missing | 0 | 0 |
| Mean | | 35.9407 | 43.7000 |
| Std. Error of Mean | | .83618 | .87735 |
| Mode | | 39.80 | 43.50 |
| Std. Deviation | | 7.97665 | 8.36938 |
| Variance | | 63.627 | 70.046 |
| Skewness | | -.393 | .174 |
| Std. Error of Skewness | | .253 | .253 |
| Minimum | | 16.20 | 25.10 |
| Maximum | | 54.10 | 67.60 |

**Table 9 Global Health Scores for Participants with Pain**

Global Health Scores for Participants with Pain

| | | General Health | QOL | Physical Health | Mental Health | Social Satisfaction | Carry out Roles | Carry out Activities | Emotional Problems | Fatigue | Pain |
|---|---|---|---|---|---|---|---|---|---|---|---|
| N | Valid | 91 | 91 | 91 | 91 | 91 | 91 | 91 | 91 | 90 | 91 |
| | Missing | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 0 |
| Mean | | 2.34 | 2.81 | 2.26 | 3.05 | 3.11 | 3.09 | 2.66 | 2.93 | 2.78 | 6.76 |
| Std. Error of Mean | | .086 | .102 | .088 | .111 | .127 | .127 | .119 | .123 | .119 | .261 |
| Mode | | 2 | 3 | 2 | 3 | 3 | 3 | 3 | 3 | 3 | 7 |
| Std. Deviation | | .819 | .977 | .841 | 1.058 | 1.215 | 1.208 | 1.137 | 1.172 | 1.130 | 2.491 |
| Variance | | .672 | .954 | .707 | 1.119 | 1.477 | 1.459 | 1.294 | 1.373 | 1.276 | 6.208 |
| Skewness | | .281 | .094 | .152 | .464 | .013 | -.017 | .476 | -.039 | .356 | -.674 |
| Std. Error of Skewness | | .253 | .253 | .253 | .253 | .253 | .253 | .253 | .253 | .254 | .253 |
| Minimum | | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 0 |
| Maximum | | 5 | 5 | 4 | 5 | 5 | 5 | 5 | 5 | 5 | 10 |

* Quality of life

**Table 10 Global Physical Health and Mental Health Scores for Participants without Pain**

| | | GPH | GMH |
|---|---|---|---|
| N | Valid | 15 | 15 |
| | Missing | 0 | 0 |
| Mean | | 52.1400 | 50.8600 |
| Std. Error of Mean | | 1.90155 | 2.17260 |
| Mode | | 50.80 | 38.80[a] |
| Std. Deviation | | 7.36466 | 8.41443 |
| Variance | | 54.238 | 70.803 |
| Skewness | | .507 | .327 |
| Std. Error of Skewness | | .580 | .580 |
| Minimum | | 42.30 | 38.80 |
| Maximum | | 67.70 | 67.60 |

a. Multiple modes exist. The smallest value is shown

**Table 11 Average Psychological Stress Measure Scores (PSM-9) for Patients without Pain**

| | | |
|---|---|---|
| N | Valid | 15 |
| | Missing | 0 |
| Mean PSM-9 | | 19.5333 |
| Std. Error of Mean | | 1.51459 |
| Mode | | 20.00 |
| Std. Deviation | | 5.86596 |
| Variance | | 34.410 |
| Skewness | | 1.003 |
| Std. Error of Skewness | | .580 |
| Minimum | | 11.00 |
| Maximum | | 34.00 |

**Table 12 Average Psychological Stress Measure Scores (PSM-9) for Participants with Pain**

| | | |
|---|---|---:|
| N | Valid | 86 |
| | Missing | 5 |
| Mean PSM | | 36.4302 |
| Std. Error of Mean | | 1.46799 |
| Mode | | 48.00 |
| Std. Deviation | | 13.61361 |
| Variance | | 185.330 |
| Skewness | | .131 |
| Std. Error of Skewness | | .260 |
| Minimum | | 13.00 |
| Maximum | | 70.00 |

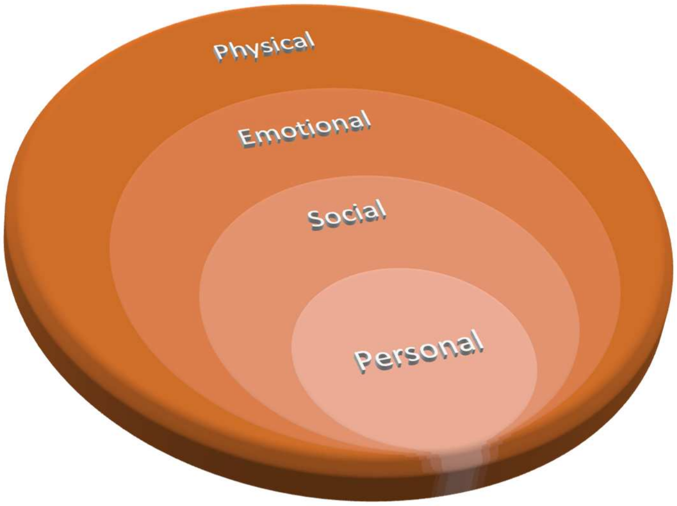
**Table13 Psychological Stress Measures for Participants with Pain**

Psychological Stress Measures for Participants with Pain

| | | Calm | Rushed | Physical Aches | Worry | Confusion | Energetic | Weight on Shoulders | Emotional Control | Stress |
|---|---|---|---|---|---|---|---|---|---|---|
| N | Valid | 90 | 91 | 91 | 91 | 89 | 90 | 89 | 91 | 91 |
| | Missing | 1 | 0 | 0 | 0 | 2 | 1 | 2 | 0 | 0 |
| Mean | | 3.51 | 3.85 | 6.42 | 4.04 | 3.01 | 4.29 | 3.94 | 3.42 | 4.19 |
| Std. Error of Mean | | .221 | .263 | .215 | .255 | .255 | .211 | .273 | .261 | .269 |
| Mode | | 1 | 1 | 8 | 1 | 1 | 4 | 1 | 1 | 1 |
| Std. Deviation | | 2.100 | 2.512 | 2.050 | 2.435 | 2.410 | 2.001 | 2.578 | 2.486 | 2.569 |
| Variance | | 4.410 | 6.309 | 4.201 | 5.931 | 5.807 | 4.005 | 6.645 | 6.179 | 6.598 |
| Skewness | | .554 | .324 | -1.233 | .207 | .904 | .503 | .239 | .560 | .090 |
| Std. Error of Skewness | | .254 | .253 | .253 | .253 | .255 | .254 | .255 | .253 | .253 |
| Minimum | | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 | 1 |
| Maximum | | 8 | 8 | 8 | 8 | 8 | 9 | 8 | 9 | 8 |

# Figures

## Figure 1 Biopsychosocial Model of Pain



The pain experience is comprised of physical, emotional, social, and personal components. Pain is personal in that it is influenced by personal history, values, expectations, motivations, and manner of coping. Spirituality is not included in the model as it is not a constant across cognitive domains and may be grouped into the category of personal.

**Figure 2 Conceptual Framework**

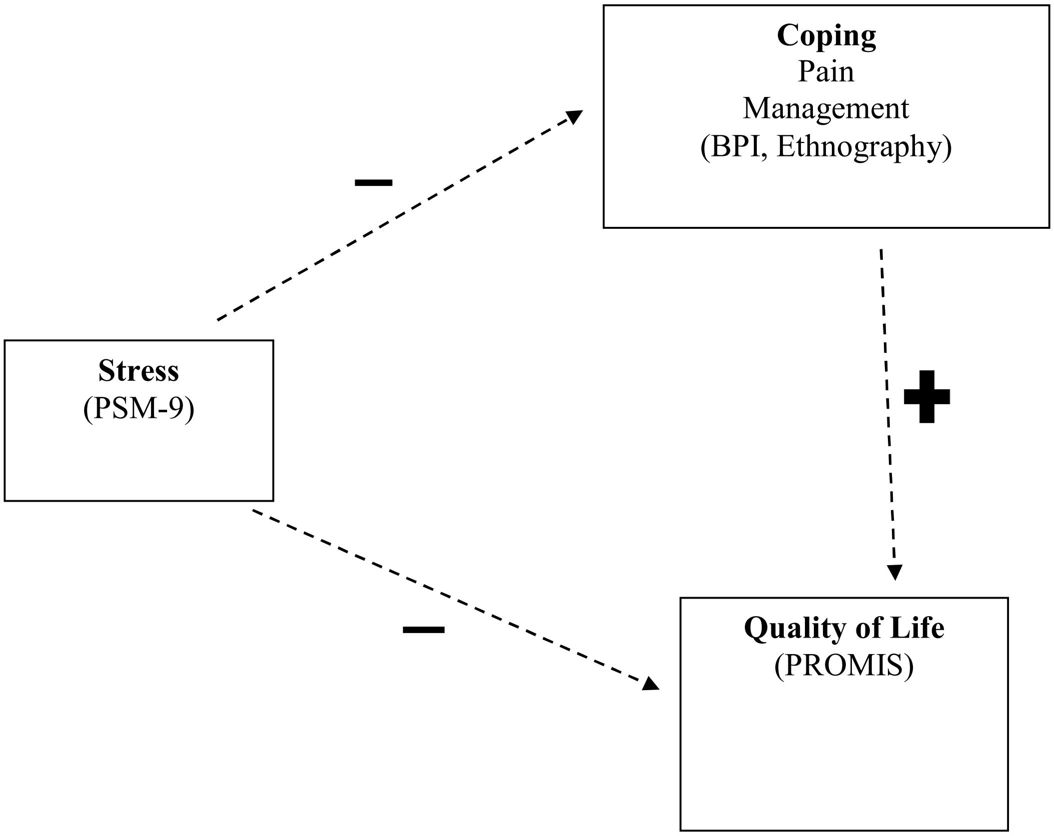
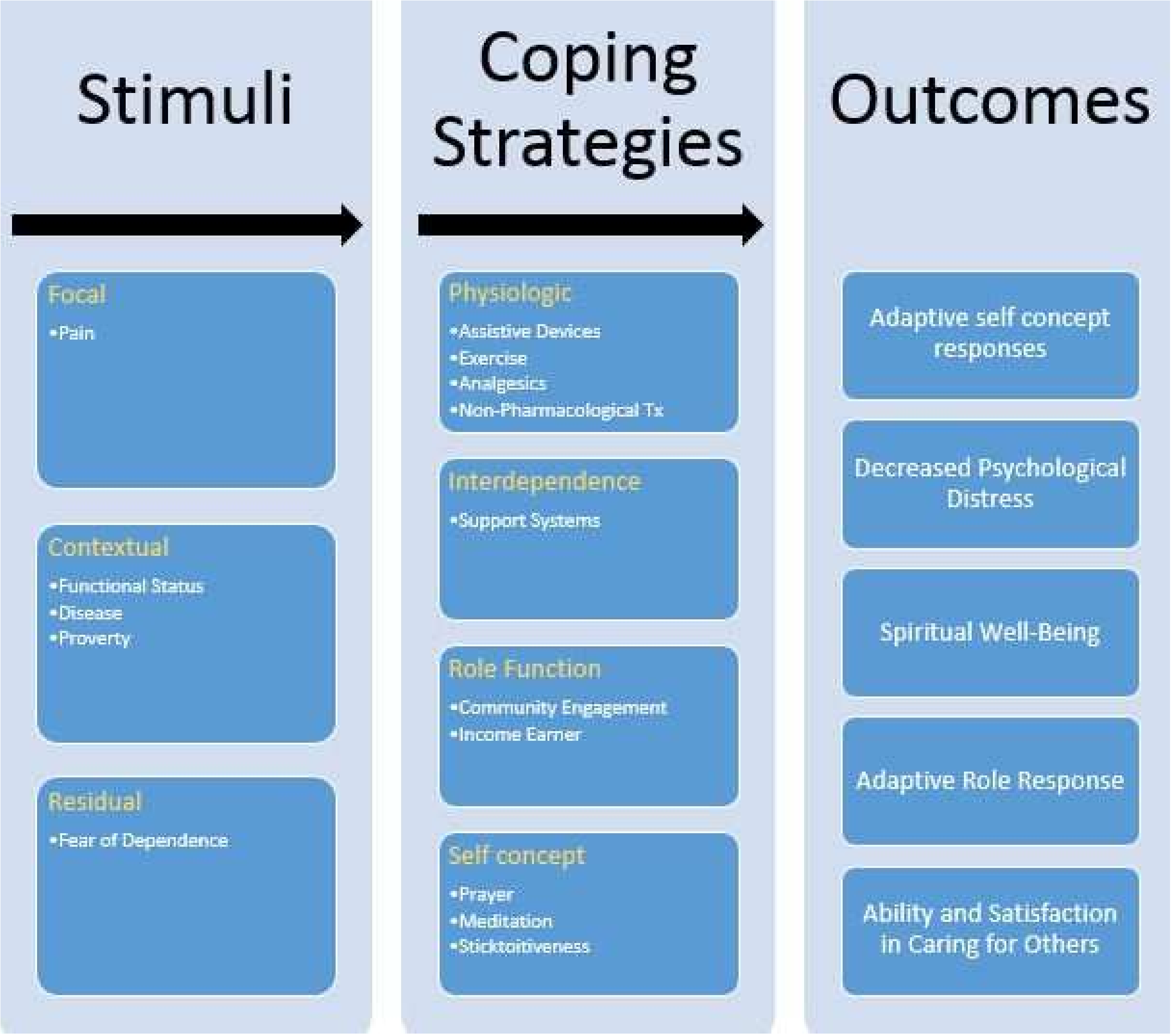
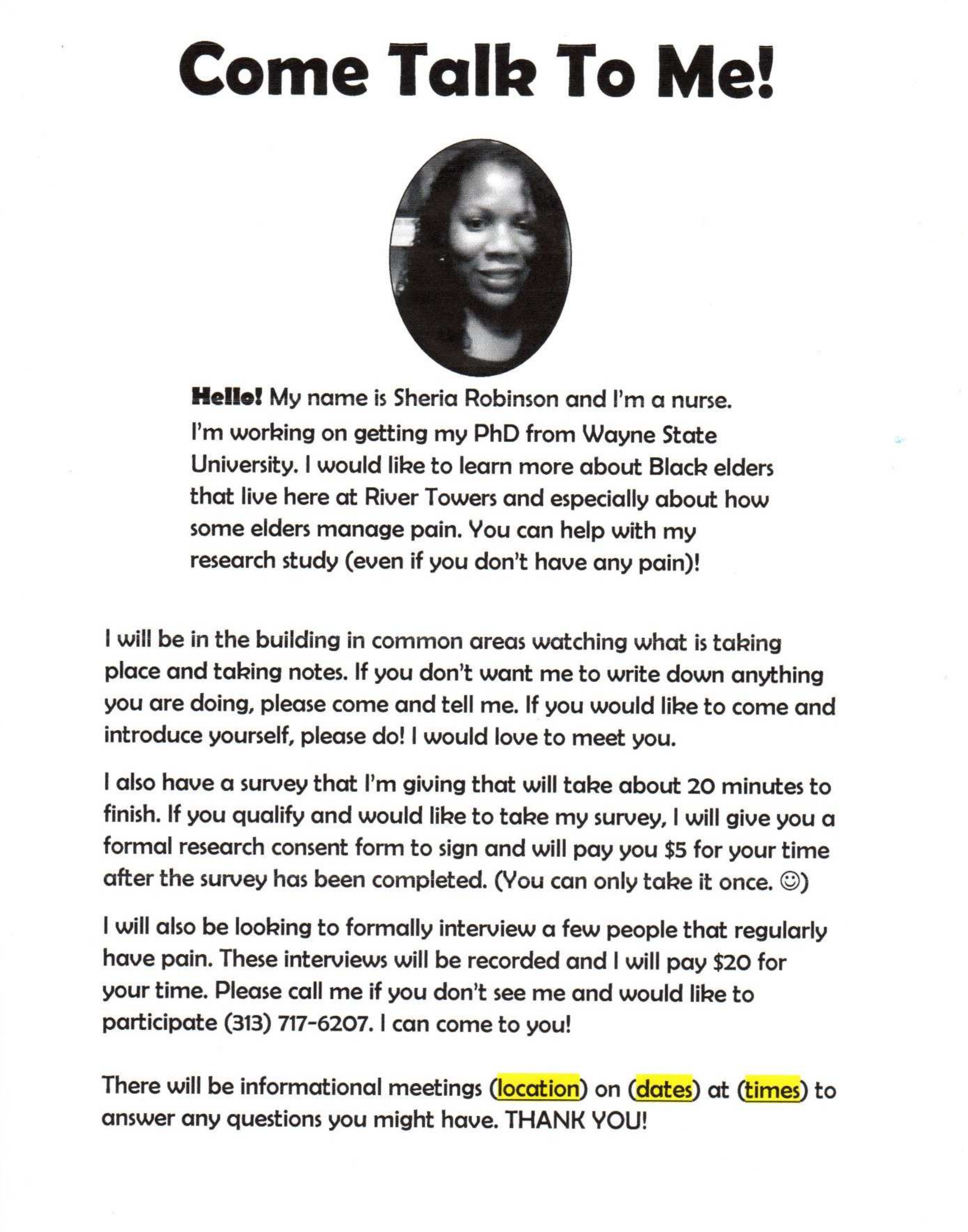


**Figure 3 Schema of Middle Range Theory of Coping with Pain**



# Appendices

## Appendix A Informational Flyer



# Come Talk To Me!

**Hello!** My name is Sheria Robinson and I'm a nurse. I'm working on getting my PhD from Wayne State University. I would like to learn more about Black elders that live here at River Towers and especially about how some elders manage pain. You can help with my research study (even if you don't have any pain)!

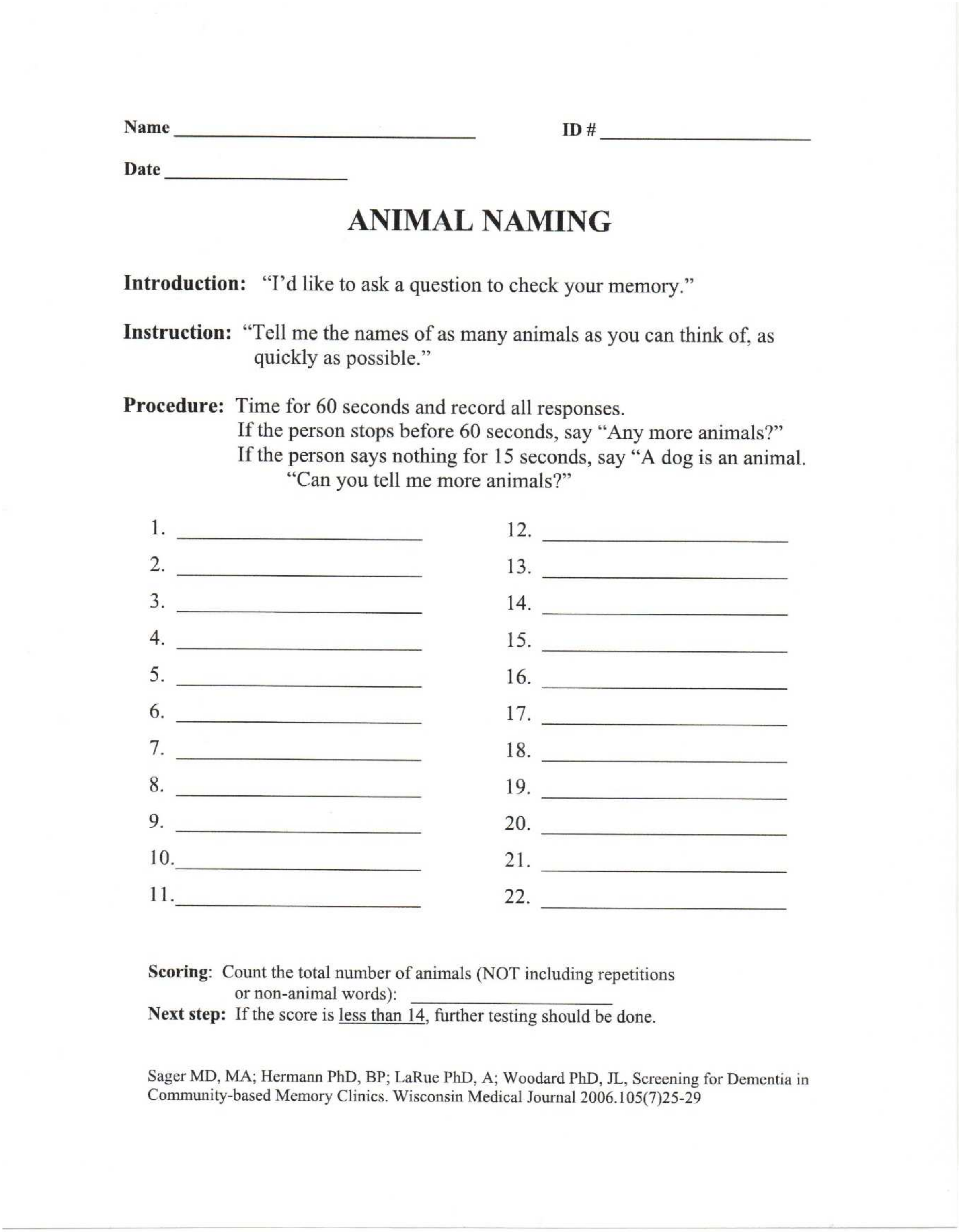
I will be in the building in common areas watching what is taking place and taking notes. If you don't want me to write down anything you are doing, please come and tell me. If you would like to come and introduce yourself, please do! I would love to meet you.

I also have a survey that I'm giving that will take about 20 minutes to finish. If you qualify and would like to take my survey, I will give you a formal research consent form to sign and will pay you $5 for your time after the survey has been completed. (You can only take it once. ☺)

I will also be looking to formally interview a few people that regularly have pain. These interviews will be recorded and I will pay $20 for your time. Please call me if you don't see me and would like to participate (313) 717-6207. I can come to you!

There will be informational meetings (location) on (dates) at (times) to answer any questions you might have. THANK YOU!

## Appendix B Animal Naming Test



**Name** ______________________________ **ID #** ____________________

**Date** __________________

### ANIMAL NAMING

**Introduction:** "I'd like to ask a question to check your memory."

**Instruction:** "Tell me the names of as many animals as you can think of, as quickly as possible."

**Procedure:** Time for 60 seconds and record all responses.
If the person stops before 60 seconds, say "Any more animals?"
If the person says nothing for 15 seconds, say "A dog is an animal.
"Can you tell me more animals?"

1. ________________________
2. ________________________
3. ________________________
4. ________________________
5. ________________________
6. ________________________
7. ________________________
8. ________________________
9. ________________________
10. ________________________
11. ________________________
12. ________________________
13. ________________________
14. ________________________
15. ________________________
16. ________________________
17. ________________________
18. ________________________
19. ________________________
20. ________________________
21. ________________________
22. ________________________

**Scoring**: Count the total number of animals (NOT including repetitions or non-animal words): ____________________

**Next step:** If the score is <u>less than 14</u>, further testing should be done.

Sager MD, MA; Hermann PhD, BP; LaRue PhD, A; Woodard PhD, JL, Screening for Dementia in Community-based Memory Clinics. Wisconsin Medical Journal 2006.105(7)25-29

## Directions for Scoring Animal Naming Screen

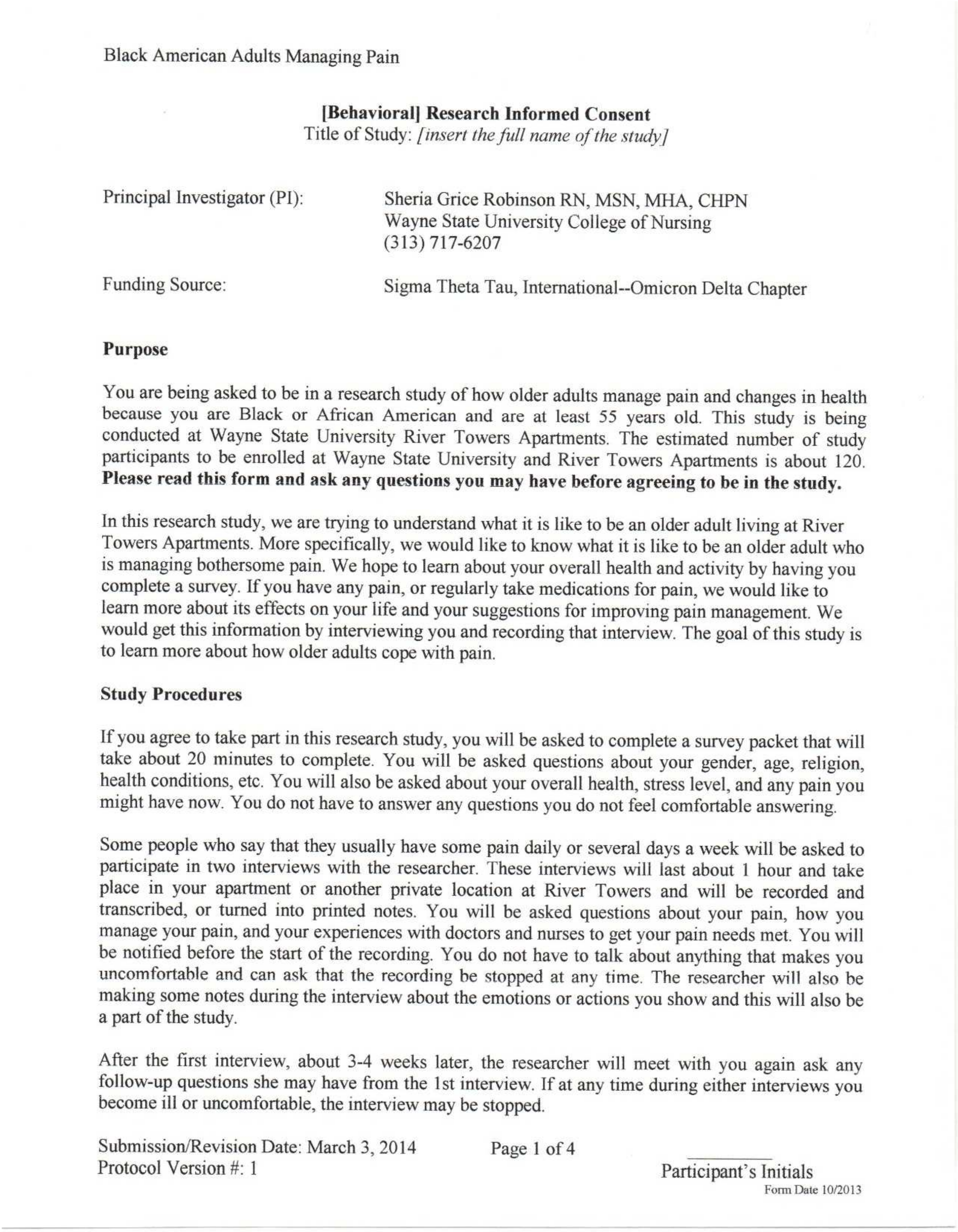
Instructions: "Tell me the names of as many animals as you can think of, as quickly as possible."

If the person says nothing for 15 seconds, say "A dog is an animal. Can you tell me more animals?" If the person stops before 60 seconds, say "Any more animals?"

Scoring: Count all animals, including birds, fish, reptiles, insects, humans, extinct animals, etc. Credit can be given for general category terms (e.g., dog) and for specific instances (e.g., terriers) when both are given. Credit only one item when people name the same animal at different developmental stages (e.g., sheep, lamb).

Note: These minimalist initial instructions date back to an early research study on verbal fluency in aging and dementia by Wilma Rosen (1980) in which subjects were instructed to "give the names of as many animals as you can think of" for 60 seconds. These very brief instructions have been subsequently used in several normative studies (e.g., Tombaugh et al., 1999 and Mayo's MOANS studies such as Lucas et al., 1998) and in some other recent studies of the efficacy of verbal fluency as a diagnostic tool for dementia (e.g., Canning et al., 2004).

## Appendix C Informed Consent Form



Black American Adults Managing Pain

**[Behavioral] Research Informed Consent**
Title of Study: *[insert the full name of the study]*

| | |
|---|---|
| Principal Investigator (PI): | Sheria Grice Robinson RN, MSN, MHA, CHPN<br>Wayne State University College of Nursing<br>(313) 717-6207 |
| Funding Source: | Sigma Theta Tau, International--Omicron Delta Chapter |

**Purpose**

You are being asked to be in a research study of how older adults manage pain and changes in health because you are Black or African American and are at least 55 years old. This study is being conducted at Wayne State University River Towers Apartments. The estimated number of study participants to be enrolled at Wayne State University and River Towers Apartments is about 120. **Please read this form and ask any questions you may have before agreeing to be in the study.**

In this research study, we are trying to understand what it is like to be an older adult living at River Towers Apartments. More specifically, we would like to know what it is like to be an older adult who is managing bothersome pain. We hope to learn about your overall health and activity by having you complete a survey. If you have any pain, or regularly take medications for pain, we would like to learn more about its effects on your life and your suggestions for improving pain management. We would get this information by interviewing you and recording that interview. The goal of this study is to learn more about how older adults cope with pain.

**Study Procedures**

If you agree to take part in this research study, you will be asked to complete a survey packet that will take about 20 minutes to complete. You will be asked questions about your gender, age, religion, health conditions, etc. You will also be asked about your overall health, stress level, and any pain you might have now. You do not have to answer any questions you do not feel comfortable answering.

Some people who say that they usually have some pain daily or several days a week will be asked to participate in two interviews with the researcher. These interviews will last about 1 hour and take place in your apartment or another private location at River Towers and will be recorded and transcribed, or turned into printed notes. You will be asked questions about your pain, how you manage your pain, and your experiences with doctors and nurses to get your pain needs met. You will be notified before the start of the recording. You do not have to talk about anything that makes you uncomfortable and can ask that the recording be stopped at any time. The researcher will also be making some notes during the interview about the emotions or actions you show and this will also be a part of the study.

After the first interview, about 3-4 weeks later, the researcher will meet with you again ask any follow-up questions she may have from the 1st interview. If at any time during either interviews you become ill or uncomfortable, the interview may be stopped.

Submission/Revision Date: March 3, 2014
Protocol Version #: 1

Page 1 of 4

__________
Participant's Initials

Form Date 10/2013

Everyone participating in this study has the choice to stop at any time. Your personal information including your place in the study, your name, contact information, and the answers you give will be held securely to protect your privacy and identity. Your participation in this survey does not affect any of the services you receive at River Towers Apartments.

**Benefits**

As a participant in this research study, there will be no direct benefit for you; however, information from this study may benefit other people now or in the future.

**Risks**

By taking part in this study, you may experience the following risks: you may feel sad or nervous about talking about your pain or health. In the proposed research, the risk to participants is minimal and unlikely. If distress occurs, the researcher is a registered nurse and will be able to provide assistance.

The following information must be released/reported to the appropriate authorities if at any time during the study there is concern that:

- child abuse or elder abuse has possibly occurred,
- you have a reportable communicable disease (i.e., certain sexually transmitted diseases or HIV)
- you disclose illegal criminal activities, illegal substance abuse or violence

There may also be risks involved from taking part in this study that are not known to researchers at this time.

**Study Costs**

- Participation in this study will be of no cost to you.

**Compensation**

For taking part in this research study, you will be paid for your time and inconvenience. You will receive $5 for completing the survey packet and $20 at the end of each recorded interview.

**Confidentiality**

All information collected about you during the course of this study will be kept confidential to the extent permitted by law. You will be identified in the research records by a code name or number. Information that identifies you personally will not be released without your written permission. However, the study sponsor, the Institutional Review Board (IRB) at Wayne State University, or federal agencies with appropriate regulatory oversight [e.g., Food and Drug Administration (FDA), Office for Human Research Protections (OHRP), Office of Civil Rights (OCR), etc.) may review your records.

When the results of this research are published or discussed in conferences, no information will be included that would reveal your identity.

If photographs, videos, or audiotape recordings of you will be used for research or educational purposes, your identity will be protected or disguised. All digital recordings will be uploaded electronically, transcribed, and stored on a password-protected computer. Following upload, the recordings from the device will be deleted. The researcher will have access to the recordings and transcripts along with members of the dissertation committee at Wayne State University. All recordings and transcripts of recordings will be kept electronically for 3 years and then deleted. After the recordings have been analyzed, participants will have the opportunity to meet with the researcher during a 2nd interview to clarify any information provided and discuss findings.

## Voluntary Participation/Withdrawal

Taking part in this study is voluntary. You have the right to choose not to take part in this study. If you decide to take part in the study you can later change your mind and withdraw from the study. You are free to only answer questions that you want to answer. You are free to withdraw from participation in this study at any time. Your decisions will not change any present or future relationship with Wayne State University or its affiliates, or other services you are entitled to receive.

The PI may stop your participation in this study without your consent. The PI will make the decision and let you know if it is not possible for you to continue. The decision that is made is to protect your health and safety, or because you did not follow the instructions to take part in the study

Additionally, participation in this research is for residents of the United States over the age of 18; if you are not a resident of the United States <u>and/or</u> under the age of 18, please do not complete this survey.

## Questions

If you have any questions about this study now or in the future, you may contact Sheria Grice Robinson at the following phone number (313) 717-6207. If you have questions or concerns about your rights as a research participant, the Chair of the Institutional Review Board can be contacted at (313) 577-1628. If you are unable to contact the research staff, or if you want to talk to someone other than the research staff, you may also call (313) 577-1628 to ask questions or voice concerns or complaints.

Black American Adults Managing Pain

**Consent to Participate in a Research Study**

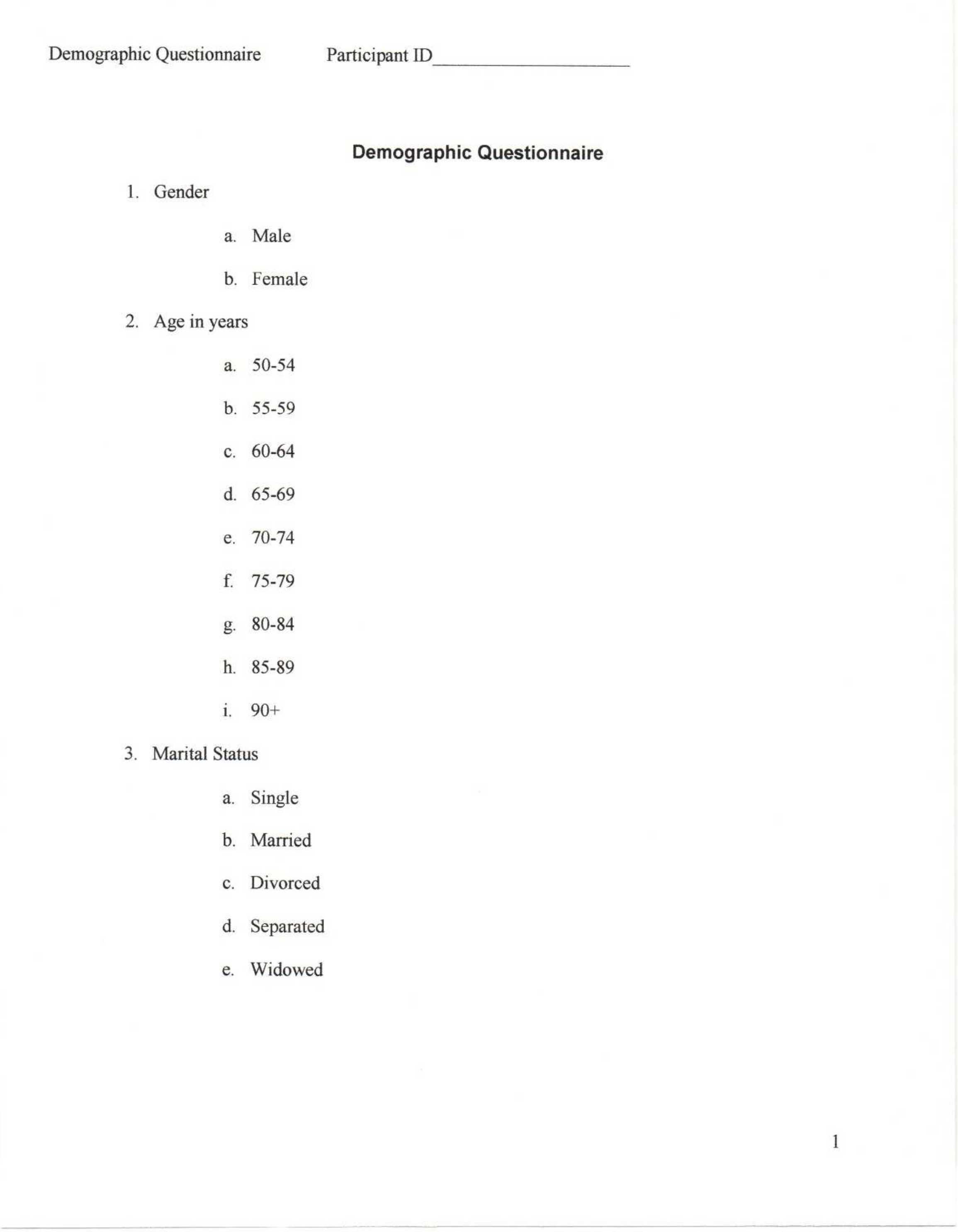
To voluntarily agree to take part in this study, you must sign on the line below. If you choose to take part in this study you may withdraw at any time. You are not giving up any of your legal rights by signing this form. Your signature below indicates that you have read, or had read to you, this entire consent form, including the risks and benefits, and have had all of your questions answered. You will be given a copy of this consent form.

| | |
|---|---|
| Signature of participant | Date |
| Printed name of participant | Time |
| Signature of witness* | Date |
| Printed of witness* | Time |
| Signature of person obtaining consent | Date |
| Printed name of person obtaining consent | Time |

*Use when participant has had this consent form read to them (i.e., illiterate, legally blind, translated into foreign language).

| | |
|---|---|
| Signature of translator | Date |
| Printed name of translator | Time |

## Appendix D Demographic Questionnaire



Demographic Questionnaire Participant ID____________________

### Demographic Questionnaire

1. Gender
    a. Male
    b. Female
2. Age in years
    a. 50-54
    b. 55-59
    c. 60-64
    d. 65-69
    e. 70-74
    f. 75-79
    g. 80-84
    h. 85-89
    i. 90+
3. Marital Status
    a. Single
    b. Married
    c. Divorced
    d. Separated
    e. Widowed

Demographic Questionnaire Participant ID____________________

4. Religion
    - A. Agnostic
    - B. Atheist
    - C. Baptist
    - D. Catholic
    - E. Church Of God In Christ
    - F. Holiness
    - G. Jehovah's Witness
    - H. Jewish
    - I. Lutheran
    - J. Methodist
    - K. Morman
    - L. Muslim
    - M. Pentecostal
    - N. Presbyterian
    - O. Other______________________________
    - P. None
5. Do you have any of the following diagnoses?

Anxiety
CAD
COPD
DJD
Fractures
Hepatitis
Compression Fractures

Diabetes
Peripheral Neuropathy
Renal Failure
Sickle Cell
Arthritis - Osteo
Arthritis - Rheumatoid
Cancer

CVA
Depression
Emphysema
GERD
Ulcers
CHF
Hypertension

6. Do you have any other painful conditions not listed above? If so please describe.

______________________________________________________________________
______________________________________________________________________
______________________________________________________________________

Demographic Questionnaire Participant ID____________________

7. Do you have insurance that covers your prescriptions?

YES NO

8. If you have insurance that covers your prescriptions, is the co-pay affordable for you?

YES NO

9. What is your annual income?

A. Less than $5,000

B. $5,000 – 10,000

C. $10,000 – 20,000

D. $20,000 – 30,000

E. $30,000 – 40,000

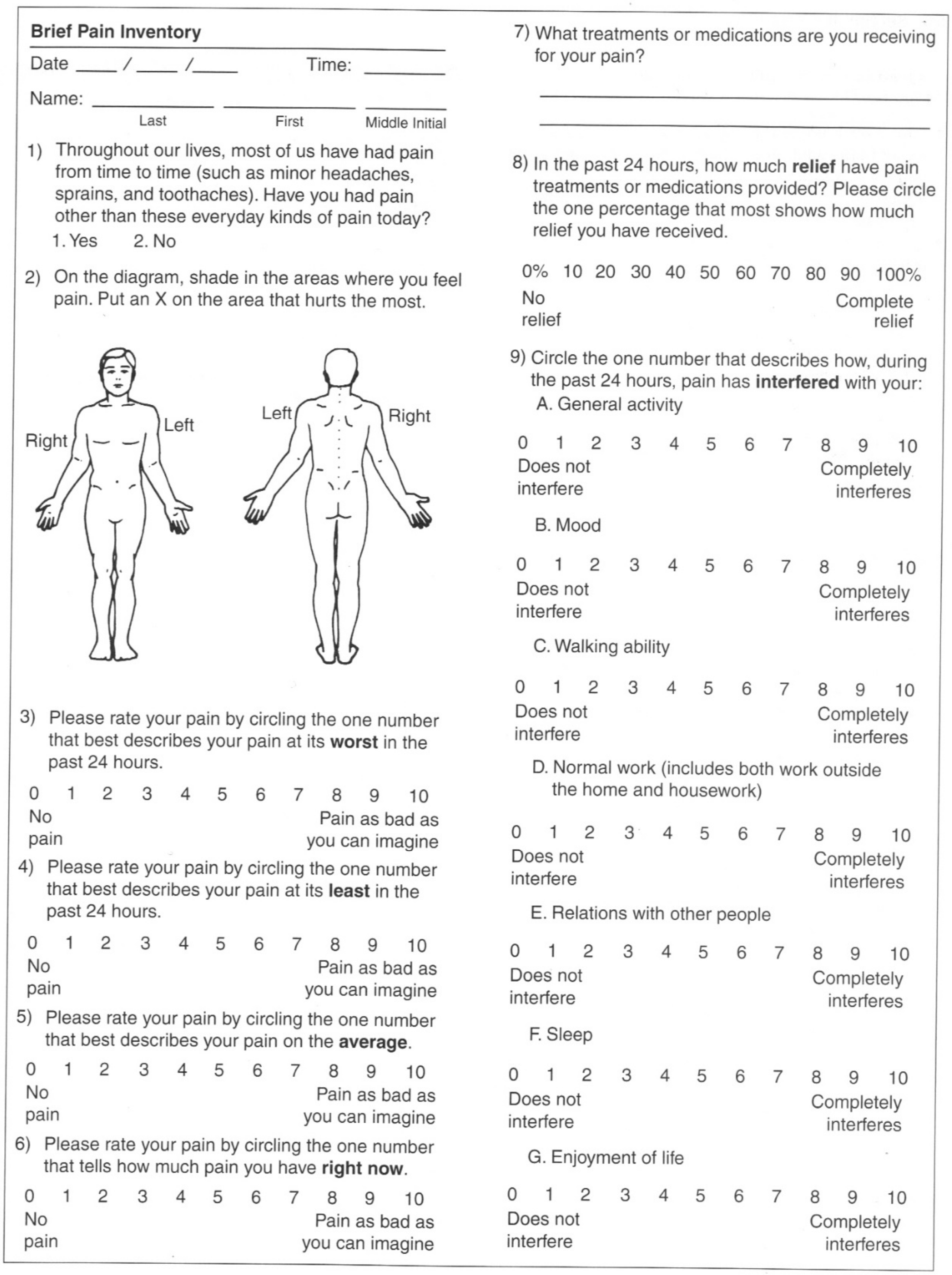
F. $40,000 – 50,000

G. $50,000 – 60,000

H. Greater than $60,000

10. Who do you currently live with?

# Appendix E Brief Pain Inventory (BPI)



**Brief Pain Inventory**

Date ____ / ____ /____ Time: ________

Name: ____________ ____________ ________
Last First Middle Initial

1) Throughout our lives, most of us have had pain from time to time (such as minor headaches, sprains, and toothaches). Have you had pain other than these everyday kinds of pain today?
1. Yes 2. No

2) On the diagram, shade in the areas where you feel pain. Put an X on the area that hurts the most.

3) Please rate your pain by circling the one number that best describes your pain at its **worst** in the past 24 hours.

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 circling the one number that best describes your pain at its **least** in the past 24 hours.

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

5) Please rate your pain by circling the one 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

6) Please rate your pain by circling the one 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

7) What treatments or medications are you receiving for your pain?

________________________________________

________________________________________

8) In the past 24 hours, how much **relief** have pain treatments or medications provided? Please circle the one percentage that most shows how much relief you have received.

0% 10 20 30 40 50 60 70 80 90 100%
No relief — Complete relief

9) Circle the one 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 interfere — Completely interferes

B. Mood

0 1 2 3 4 5 6 7 8 9 10
Does not interfere — Completely 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

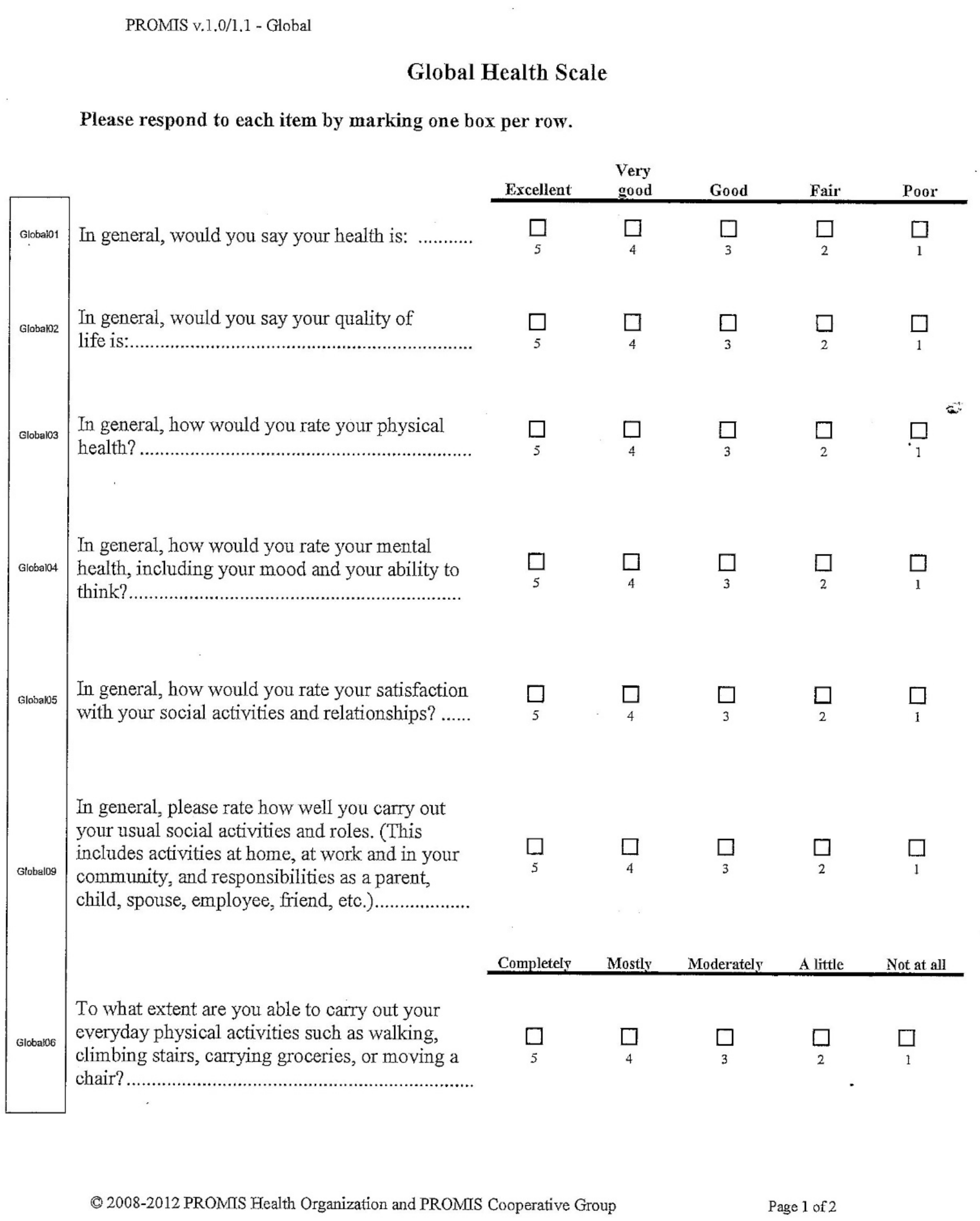
F. Sleep

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 F PROMIS Global Health Scale



PROMIS v.1.0/1.1 - Global

## Global Health Scale

**Please respond to each item by marking one box per row.**

| | | Excellent | Very good | Good | Fair | Poor |
|---|---|---|---|---|---|---|
| Global01 | In general, would you say your health is: .......... | ☐ 5 | ☐ 4 | ☐ 3 | ☐ 2 | ☐ 1 |
| Global02 | In general, would you say your quality of life is:................................................................ | ☐ 5 | ☐ 4 | ☐ 3 | ☐ 2 | ☐ 1 |
| Global03 | In general, how would you rate your physical health? ............................................................... | ☐ 5 | ☐ 4 | ☐ 3 | ☐ 2 | ☐ 1 |
| Global04 | In general, how would you rate your mental health, including your mood and your ability to think?................................................................ | ☐ 5 | ☐ 4 | ☐ 3 | ☐ 2 | ☐ 1 |
| Global05 | In general, how would you rate your satisfaction with your social activities and relationships? ...... | ☐ 5 | ☐ 4 | ☐ 3 | ☐ 2 | ☐ 1 |
| Global09 | In general, please rate how well you carry out your usual social activities and roles. (This includes activities at home, at work and in your community, and responsibilities as a parent, child, spouse, employee, friend, etc.).................. | ☐ 5 | ☐ 4 | ☐ 3 | ☐ 2 | ☐ 1 |
| | | Completely | Mostly | Moderately | A little | Not at all |
| Global06 | To what extent are you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair?................................................................. | ☐ 5 | ☐ 4 | ☐ 3 | ☐ 2 | ☐ 1 |

Page 1 of 2

**In the past 7 days...**

| | | Never | Rarely | Sometimes | Often | Always |
|---|---|---|---|---|---|---|
| Global10 | How often have you been bothered by emotional problems such as feeling anxious, depressed or irritable? ............................................................ | ☐ 1 | ☐ 2 | ☐ 3 | ☐ 4 | ☐ 5 |

| | | None | Mild | Moderate | Severe | Very severe |
|---|---|---|---|---|---|---|
| Global08 | How would you rate your fatigue on average? .... | ☐ 1 | ☐ 2 | ☐ 3 | ☐ 4 | ☐ 5 |

| | | | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| Global07 | How would you rate your pain on average?.................. | ☐ 0 No pain | ☐ 1 | ☐ 2 | ☐ 3 | ☐ 4 | ☐ 5 | ☐ 6 | ☐ 7 | ☐ 8 | ☐ 9 | ☐ 10 Worst imaginable pain |

## Appendix G Psychological Stress Measure (PSM-9)

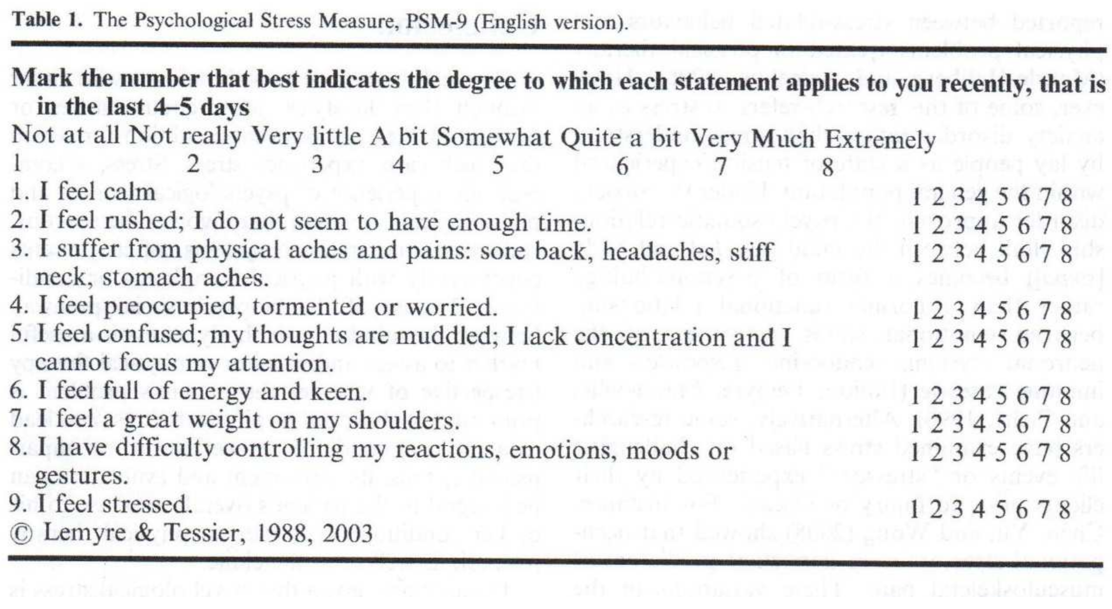


**Table 1.** The Psychological Stress Measure, PSM-9 (English version).

**Mark the number that best indicates the degree to which each statement applies to you recently, that is in the last 4–5 days**

| Not at all | Not really | Very little | A bit | Somewhat | Quite a bit | Very Much | Extremely |
|---|---|---|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 |

| | |
|---|---|
| 1. I feel calm | 1 2 3 4 5 6 7 8 |
| 2. I feel rushed; I do not seem to have enough time. | 1 2 3 4 5 6 7 8 |
| 3. I suffer from physical aches and pains: sore back, headaches, stiff neck, stomach aches. | 1 2 3 4 5 6 7 8 |
| 4. I feel preoccupied, tormented or worried. | 1 2 3 4 5 6 7 8 |
| 5. I feel confused; my thoughts are muddled; I lack concentration and I cannot focus my attention. | 1 2 3 4 5 6 7 8 |
| 6. I feel full of energy and keen. | 1 2 3 4 5 6 7 8 |
| 7. I feel a great weight on my shoulders. | 1 2 3 4 5 6 7 8 |
| 8. I have difficulty controlling my reactions, emotions, moods or gestures. | 1 2 3 4 5 6 7 8 |
| 9. I feel stressed. | 1 2 3 4 5 6 7 8 |

## Appendix H Interview Guide

Thank you for agreeing to participate in this interview with me. As you are aware, this conversation is being recorded. If at any point you would like me to stop the recording, please let me know and I will do so. Once you are ready to begin again I will restart the recording. We can also take a break anytime you feel that you need one. Following the interview you will be compensated $20 for your time. As we chat I will also be taking a few notes.

**Key Event:**

Do you find that you are able to get out much?

Prompts:

- Can you tell me about all of the places that you are able to get out to?
- Are there any others?
- What activities do you usually participate in?
- Are there any others?

**Segue 1:**

So, when I was observing residents, and I noticed that many folks tended not to move so fast or really not at all in some instances, can you tell me why you think that might be?

**Segue 2:**

Can you tell me about your pain?

Interviewer Directives: For each of the types of pain ask “How do you manage that?” Keep note cards available if respondent has several types of pain.

Prompts:

- Does anything anything else hurt?
- Of the types of pain you have described, which ones would you say bothers you the most.

**Segue 3:**

I'm curious about all of the ways that you feel like pain effects your health. Can you tell me about that?

Prompts:

- Are there other ways you think it effects your health?
- What are the most bothersome ways that pain effects your health?
- How do you manage each of those ways?

Interview Directives: For each type of health effect ask "How do manage that?"

**Segue 4**

I'm wondering who you talk to about your pain?

Prompts:

- Are there others you talk with?
- What is something you might say when you are talking about your pain?

Interview Directive: If a doctor or nurse is mentioned as a person that is spoken to regarding pain, ask “What do you tell your doctor or nurse about your pain.”

If a health provider is not mentioned say: “You didn’t mention talking with your doctor or nurse is that right?”

## Appendix I Letter of Support

River Towers

Wayne State University
IRB Administration Office
87 E Canfield, $2^{nd}$ Floor
Detroit, MI 48201

To whom it may concern:

Sheria Grice Robinson is a doctoral student with the College of Nursing at Wayne State University. Ms. Robinson would like to complete data collection on her dissertative study titled, “The Experiences of Black American Older Adults Managing Pain: A Nursing Ethnography” here at River Towers. As the manager of this senior housing complex I am happy to support this student’s work and grant permission for data collection on these premises.

Ms. Robinson has explained that residents will be notified of the study through flyer distribution as well as an informational meeting. She has also noted that she will be at the facility regularly to observe residents in common areas and have the interested residents complete questionnaires and recorded interviews.

Ms. Robinson is familiar with our facility and has presented health information to our seniors in the past. I do not foresee any conflict of interest that may arise from her dissertative work with this population. Pain is certainly a common concern effecting our elders and this work will likely provide further information on how manage pain more successfully.

If you have any questions, please do not hesitate to contact me using the information noted below.

Sincerely,

Almira Mathis

Almira Mathis
Senior Services Coordinator
almiram2@myway.com
(313) 824-2244

7800 E. Jefferson • Detroit, MI 48214 • (313) 824-2244 • Fax: (313) 824-5875

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# ABSTRACT

# THE EXPERIENCES OF BLACK AMERICAN OLDER ADULTS MANAGING PAIN: A NURSING ETHNOGRAPHY

by

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**Introduction**: Pain can negatively affect quality of life for Black elders. They are less likely to report pain concerns and have voiced pain needs adequately met. To better understand the pain management experiences and concerns of Black elders, an ethnographic study was completed within an urban, low-income, elder housing facility. **Methods:** 106 participants completed a questionnaire comprised of a demographic tool, the PROMIS Global Health Scale (PROMIS), the Brief Pain Inventory (BPI), and the Psychological Stress Measure (PSM-9). Additionally, participant observation, informal interviews, and 20 formal recorded interviews with individuals identified as having pain were completed. Qualitative and frequency analysis and were finished using NVIVO 10 qualitative data analysis software, and IBM SPSS Statistics 22. **Results** indicate that 86 percent of the sample had an average pain rating of 7 on a 0 to 10 scale with 5 pain sites. Pain interference, was about 4, on a 0 to 10 scale. Specific areas of interference included general activity (5.59), walking (5.73) and normal work (5.7). Participants preferred nonpharmacological treatments for pain such as exercise and Epsom salt soaks along with non-opioid analgesics that came in cream/liquid form. Preferences were related to concerns with side effects, fears of addiction, and provider mistrust. Prescription medications most commonly used

for pain included hydrocodone with acetaminophen, acetaminophen with codeine, tramadol, and ibuprofen. Seventeen percent of the population took no pain medications. Global physical health scores for patients with pain were 36, while Global mental health scores were about 44--respectively 2 and 0.5 standard deviations lower than US norms. Mild to moderate stress was reported by the PSM-9. Adaptive coping strategies used by participants to manage pain included: remaining positive, exercise/ remaining active, being engaged in the community, prayer/meditation, and maintaining positive support systems. Poverty was an additional stressor to managing pain. **Discussion**: Pain management may be improved in Black elders by proving balanced health information—in written form—with both benefits and burdens of treatments, questioning and discussing medication concerns in-office, increasing patient follow-up post-office visit for pain related visits, and increasing provider familiarity with commonly used home remedies and treatments.

# AUTOBIOGRAPHICAL STATEMENT

Sheria Grice Robinson is a certified hospice and palliative care nurse practicing in long term care and hospice. Her experiences in long term care have ranged from nursing assistant to director of nursing with particular skill in improving quality and culturally congruent care for organizations. She currently works as an education specialist for the Hospice of Michigan Institute and a national lecturer for PESI Healthcare. Ms. Robinson also serves as a legal nurse consultant for matters related to elder care in nursing homes. She has published 5 articles and 1 book chapter on matters relating to aging, nursing, and pain. Ms. Robinson plans to continue in the study of pain in diverse populations and the positive adaptive coping measures used by older adults to manage changes in health.