

**HELP FOR OSTEOARTHRITIS PAIN IN AFRICAN AMERICAN ELDERS (HOPE):
PATTERNS, PREDICTORS, AND PREFERENCES OF OSTEOARTHRITIS AND
CHRONIC JOINT PAIN SELF-MANAGEMENT**

by

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CERTIFICATE OF APPROVAL

PH.D. THESIS

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Dedicated to the memory of my beloved granny, Clara Henderson; supportive parents, Donald and Clara Booker; wonderful brother and dedicated activist, Minister Devin Flowers; and sister and best Occupational Therapist, Rashida Booker; and HOPE participants.

For I know the plans I have for you, declares the LORD, plans to prosper you and not to harm you, plans to give you hope and a future.

Jeremiah 29:11 NIV

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ABSTRACT

Introduction: Chronic joint (CJ) pain is the foremost osteoarthritis (OA) symptom that affects older African Americans' (AAs) functional ability. Every effort should be made to reduce the development of high-impact chronic pain. One way to effectively do this is for older AAs to consistently engage in self-management utilizing the recommended OA treatments. Recommended behaviors include land-based exercise, water-based exercise, strength (muscle and endurance) training and stretching, self-management education, analgesic medications, thermal (warm/cool) modalities, and use of assistive and/or orthotic devices. However, evidence suggests these core behaviors of chronic pain self-management are not optimally utilized in older AAs.

Methods: A convergent, parallel mixed-methods study explored patterns, preferences, and predictors of stage of engagement (pre-contemplation, preparation, or action) in recommended OA and CJ self-management behaviors. One hundred ten AAs aged 50 and older from communities in north Louisiana completed quantitative surveys, and a subset of 18 participated in audio-recorded qualitative interviews. Using SPSS, multinomial and binomial regression were used to build predictive models to determine which contextual and cognitive factors predict stage of engagement in each recommended and complementary OA self-management behaviors. A qualitative descriptive approach underscored a conventional content analysis of qualitative data.

Results: Older AAs were “dealin’ with it [pain]” in a variety of ways, and their experience of having OA and CJ pain was based on their ability and willingness to bear the pain, understand the nature of OA pain, and experience life with daily pain. These dimensions of dealin’ with pain acted as a catalyst for engagement in complementary and

recommended behaviors. In addition, participants' and providers' cultural receptivity may limit or enable engagement in certain recommended evidence-based OA behaviors. Specifically, each recommended OA self-management behavior was associated with different predictors of engagement. Confidence to manage pain was a predictor for land-based exercise, while there were no factors associated with water-based exercise. The most reasonable explanation for this finding of lack of participation in water-based exercise is likely due to inability to swim and lack of access to a personal or community pool. Engagement in strength training was significantly associated with confidence, knowledge of strength training recommendation, motivation, pain interference, and spirituality. For self-management education, only knowledge of self-management education recommendation was a predictor. Most AA older adults were unaware that this was recommended or didn't have access to a self-management program; subsequently the majority had never participated in such but were in the preparation stage. Predictors for medication use included confidence, knowledge, and pain interference. Almost all AAs were using either over-the-counter or prescribed medications. Use of thermal modalities was predicted by pain interference. Lastly, using assistive and/or orthotic devices was significantly associated with employment status, OA pain severity, pain interference, and perceived social support. Assistive and/or orthotic device use was evenly split between users and non-users. Pain interference emerged as the most salient factor predicting stage of engagement in any of the recommended behaviors. Depending on the specific behaviors, pain interference prevented or motivated engagement.

Conclusion: OA and CJ pain is a significant symptom in older AAs. This study's mixed method approach uncovered what older AAs do to manage pain. More specifically,

these results illuminate the daily patterns and preferences for self-management. We identified specific barriers and motivators that influence engagement in OA self-management behaviors, and determined the most relevant predictors for each stage of engagement. In addition, we were able to develop a model of OA and CJ pain self-management based on the predictors.

PUBLIC ABSTRACT

Many older African Americans have chronic joint (CJ) pain due to osteoarthritis (OA). To control pain, individuals typically engage in certain pain-relieving behaviors. It is recommended that people with OA participate in land-based exercise; water-based exercise; strength training; self-management education, and use analgesic medications; thermal (warm/cool) modalities; assistive and/or orthotic devices. However, multiple contextual and process factors, barriers and facilitators, and cultural preferences impact older AAs ability to engage in recommended behaviors. Thus, the major purpose of this study was to understand how AA older adults manage pain by examining patterns of use of recommended behaviors.

We found that each recommended behavior was associated with a unique set of barriers, facilitators, and predictors. Some common barriers included the pain itself, fear of water, lack of motivation, mobility difficulty, and lack of access to resources, time, and Similarly, many of the barriers were opposite facilitators to engage in certain recommended behaviors: pain (and seeking pain relief), being motivated, mobility maintenance, and perceived helpfulness. Common predictors of engagement in recommended behaviors were pain interference, motivation, confidence, number of chronic conditions, social support, employment status, and OA pain severity. The most consistent predictor was pain interference- how pain impacts various aspects of their physical and mental activities. If barriers are reduced and motivators enhanced, we can increase older AAs' engagement in OA behaviors that are known to reduce pain.

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CHAPTER 1: INTRODUCTION

Overview

Few studies have investigated the pain self-management behaviors of older African Americans (AAs) living in the community. Therefore, the goals of this dissertation are to describe patterns of and preferences for osteoarthritis (OA) and chronic joint (CJ) pain self-management and determine predictors of engagement in self-management behaviors in older AAs. This topic is timely because OA and CJ pain are the leading causes of chronic pain in older adults across ethnicities (Parker et al., 2011). More pertinent was the designation of 2016 as the Global Year Against Pain in the Joints (International Association for the Study of Pain, 2015). Chapter one presents an overview of the problem, specific aims, and study significance; chapter two consists of an integrated literature review for OA and CJ pain and self-management; chapter three discusses research methodology while chapter four presents the findings; and chapter five concludes with a comprehensive discussion and implications for community-based practice, education, research, and policy.

Problem Statement

The Institute of Medicine (IOM, 2011) report, *Relieving pain in America: A blueprint for transforming prevention, care, education, and research*, identified older adults and racial minorities as two populations experiencing or at risk for disparities in chronic pain management. Consequently, AA older adults are at greater risk for chronic pain. Older AAs (i.e., 65 and older) comprise less than 9% of the U.S. population (United States Department of Commerce, 2010), but within this small proportion, a larger

proportion of AAs 45 and older experience severe, persistent chronic pain in contrast to Caucasian, Hispanic, and Asian Americans (Nahin, 2015). Up to 78% of community-dwelling AA older adults experience chronic pain (Bazargan, Yazdanshenas, Gordon, & Orum, 2016a; Karter et al., 2015), and of these, 67% report arthritis as the major source of chronic pain (Bazargan et al., 2016a). This is not surprising given their higher lifetime risk of developing OA as compared to CAs, 50% and 43% respectively (Murphy et al., 2008).

While joint pain is the most bothersome and frequently reported arthritis symptom by older AAs (Baker, 2003), a slightly higher proportion of AA women experience CJ pain even in the absence of OA (Lachance et al., 2001). Despite this, AAs are less likely to have seen a physician about OA or CJ pain, undergo radiographic imaging to confirm OA, or receive an official physician diagnosis of OA (Centers for Disease Control and Prevention [CDC], 1996; Mikuls, Mudano, Pulley, & Saag, 2003; Mingo, McIlvane, Jefferson, Edwards, & Haley, 2013; Yang, Jawahar, McAlindon, Eaton, & Lapane, 2012). As a result, “the major burden of care falls on the individual, who tailors his or her own personal systems of care to alleviate troublesome symptoms and promote independent functioning” (Silverman, Nutini, Musa, King, & Albert, 2008, p. 320); this is referred to as self-management.

Individuals engage in self-management in the context of and conjunction with their environment, families, and communities (Grey, Schulman-Green, Knafl, & Reynolds, 2015), and various contextual factors impact cognitive and behavioral process factors which subsequently moderate their level of engagement. These contextual and process factors also serve as risk and protective factors (i.e., barriers and facilitators)

(Ryan & Sawin, 2009). Multiple contextual and process factors contribute to older AAs' inadequate self-management with major barriers identified in the literature including:

1. Contextual factors:

- a. Limited opportunities to participate in chronic pain (Group, Haas, Fairweather, Ganger, & Atwood, 2005; Townley et al., 2010), arthritis (McIlvane, Baker, Mingo, & Haley, 2008), and chronic disease (Korda et al., 2013) self-management programs or OA intervention studies (McIlvane et al., 2008b; Shengelia, Parker, Ballin, George, & Reid, 2013; Sperber et al., 2013). Many AAs reported cost and safety of their neighborhood as barriers to participation in community- and home-based self-management programs (Mingo et al., 2013). Costs and financial difficulty are major sources of stress for AAs with arthritis (McIlvane, 2007).
- b. Absence of cultural tailoring of standardized arthritis, chronic pain, and chronic disease self-management programs (Chen, Reid, Parker & Pillemer, 2013; Goeppinger et al., 2007; Mingo et al., 2013; Parker et al., 2012; Reid, Chen, Parker, Henderson, & Pillemer, 2014), a stronger preference for someone of their race to facilitate an OA self-management program (Mingo et al., 2013), and lack of evidence-based, culturally-congruent OA self-management behaviors (Shengelia et al., 2013; Sperber et al., 2013).

2. Process Factors:

- c. A lack of OA pain management education and skills (Parker et al., 2012; Mingo et al., 2013) and low expectations for OA pain improvement and treatment effectiveness (Goodwin, Black, & Satish, 1999) has resulted in low

self-efficacy (i.e., skills, knowledge, confidence) for OA and CJ pain self-management (Goeppinger et al., 2007; Mingo et al., 2013; Parker et al., 2011).

- d. Difficulty finding motivation is a barrier to participation in a self-management program. AAs were significantly less likely than CAs to believe that a self-management program will be helpful (Mingo et al., 2013), and when combined with contextual barriers may help explain a lower determination to participate in a self-management program. Allen et al. (2010b) reported that more non-white (26% versus 12%), eligible veteran affairs' patients declined to participate in a telephone-based OA self-management program. Park and collaborators (2013a) conclude that more empirical studies are needed to understand and address older adults' inadequate motivation to engage in pain management.

The Osteoarthritis Research Society International (OARSI) (McAlindon et al., 2014) recommends five core behaviors: land-based exercise, water-based exercise, strength training, weight management, and self-management education. Additional behaviors recommended by American College of Rheumatology (ACR) (Hochberg et al., 2012) for symptomatic OA across joint locations include analgesic medications, thermal (warm/cool) modalities, and use of assistive and/or orthotic devices. However, the cited contextual and process factors limit older AAs' engagement in self-management and triggers greater reliance on passive self-management behaviors, such as prayer/hoping (Jones et al., 2008), rest, and attention diversion (Jordan, Lumley, & Liesen, 1998; Jones et al., 2008; Booker, 2016), and less likely on recommended active behaviors. It is not surprising then that only 22% of older AAs practice optimal OA self-management

(Albert, Musa, Kwoh, & Silverman, 2008b), leaving many older AAs to experience greater severity of OA and CJ pain and have less control over pain and health (Baker, Buchanan, & Corson, 2008; Bolen et al., 2010; Green, Baker, Smith, & Sato, 2003; Parmelee et al., 2012; Tan, Jensen, Thornby, & Anderson, 2005; Vallerand, Hasenau, Templin, & Collins-Bohler, 2005). In contrast, one study found that while older AAs with OA reported greater perceived control over health than did CAs, this was not significantly associated with their practice of optimal self-management (Albert et al., 2008b). Optimal self-management included engagement in behaviors such as exercise and use of warm compresses, both of which are recommended behaviors.

Gaps in the Literature

Existing research on OA and chronic pain self-management in older AAs has generally focused on describing the types of practices used (e.g., Sperber et al., 2013; Silverman et al., 2008) or evaluating change in outcomes (e.g., pain, function, and self-efficacy) after participation in a self-management program. These studies identify the characteristics of older AAs, but rarely explore which factors predict engagement in self-management behaviors or participation in a self-management program nor describe older AAs' unique needs and preferences necessary to engage in self-management. Nour and colleagues (2005) suggest that "...pain self-management programs should be constructed considering the unique profiles and needs of this population [older adults with arthritis]" (p. 57). In order to do this, we need to reach community-dwelling older AAs and determine (1) which contextual and process factors actually predict stage of engagement in self-management behaviors, (2) barriers and facilitators, and (3) specific cultural preferences for individual self-management. Then we can move toward individualized,

culturally-congruent, and cost-effective behaviors to support engagement pain self-management for vulnerable populations. This includes minimizing barriers and enhancing facilitators to help older AAs optimally engage in recommended self-management behaviors.

Other issues with existing studies include adjusting for demographic factors rather than understanding how these personal characteristics impact engagement in self-management. Another common practice among current studies is to examine inter-race differences between CAs and AAs, which deduces the opportunity to fully understand the degree to which intra-race differences mediate divergent patterns of engagement in OA and CJ pain self-management. This study fills that gap by examining multiple demographic, behavioral, and cognitive predictors from a quantitative and qualitative standpoint, and provided novel insight into intra-ethnic similarities and differences in older AAs' capacity to engage in chronic pain self-management. It is hoped this study similarly “demonstrates the value of research focusing on within-group factors impacting a single population, thereby understanding the myriad of factors that may explain the unique pain experience of older black [adults]” (Baker et al., 2008, p. 869).

Significance of Study

Chronic pain in particular affects functional health and quality of life of older adults (Gignac et al., 2006; Nicholas et al., 2013). One study with AAs and CAs found 76% of the total variance in function (as measured by the Western Ontario and McMaster Universities Arthritis Index) was explained by pain (with select demographics, body mass index, and depression), compared to 26% without pain (Allen et al., 2009). Studies comparing the severity of OA pain and functional disability of AAs to CAs show

inconsistent findings: *equal pain and disability* (including pain interference) (Burns, Graney, Lummus, Nichols, & Martindale-Adams, 2007; Onubogu, 2014), *equal disability but greater pain* (Bruce et al., 2007), and *greater pain and disability* (Allen et al., 2009; Parmelee et al., 2012), but no studies show *less pain and less disability*. Divergent findings lend themselves to heterogeneous subjective and objective pain and functional measurement instruments, varied sample sizes (and effect size), and racial disproportion in severity of clinical and radiographic OA. The unexplained variance in pain outcomes for racial minorities showcases the complexity of pain management disparities, and highlights the incomplete understanding of pain management in this ethnic group.

Quite despairing are the outcomes reported in the literature: AAs have higher pain intensities (Allen, 2010; Allen et al., 2012; Golightly, Allen, Stechuchak, Coffman, & Keefe, 2015; Parmelee et al., 2012; Park, Engstrom, Tappen, & Ouslander, 2015b), severe and disabling OA pain (Albert et al., 2008b; Bolen et al., 2010; Golightly et al., 2015; Parmelee et al., 2012), and worse pain rehabilitation outcomes (Hooten Knight-Brown, Townsend, & Laures, 2012). A larger proportion of older AAs (64.3%) reported moderate-severe chronic pain intensities (7-10/10) compared to CAs, Hispanics, and Afro-Caribbeans (35.6, 54.5, & 59.7%, respectively) (Park, Lavin, & Couturier, 2014). Bazargan and colleagues (2016a) found similar results when they revealed over two-thirds ($\approx 67\%$) of older AAs with chronic pain reported a pain intensity of 5 or higher for at least 1 pain item while nearly 50% reported a pain intensity of 7 or higher. Experimental research confirms higher pain intensity in older AAs (Cruz-Almeida et al., 2014; Green & Prabhu, 2013), wherein advancing age may increase pain sensitivity and temporal summation (defined as the summation of sensations from repeated stimuli over

a period of time) and reduce pain inhibition AAs with OA (Lachance et al., 2001; Cruz-Almeida et al., 2014; Riley et al., 2014). Older AAs also experience greater anxiety and depression (Horgas, Yoon, Nichols, & Marsiske, 2008; Ndao-Brumblay & Green, 2005; Phillips, 2000; Portenoy, Ugarte, Fuller, & Haas, 2004), activity limitations (Allen et al., 2010a; Horgas et al., 2008; Parmelee et al., 2012), and lower quality of life (Ibrahim, Burant, Siminoff, Stoller, & Kwoh, 2002a) and life satisfaction (Baker, Buchanan, Small, Hines, & Whitfield, 2011) as a result of OA.

Jordan and colleagues (1998) observantly asked, “are ethnic or cultural differences in the psychosocial determinants of... arthritis pain...worthy of study?” (p. 81). The evidence of disparities clearly suggests that understanding ethnic differences is worthy and greatly needed; however, only a small amount of pain disparities research in ethnic minority populations has focused on multiple determinants due to various problems such as ethnic under-representation in research and low funding (Campbell et al., 2012). Achieving quality and equity in OA care, access to evidence-based arthritis interventions, and promotion of self-management in older AAs requires transforming the culture of pain care by impacting patients’ approach to pain management (i.e., self-management of chronic pain) (IOM, 2011; Lubar et al., 2010). The paucity of research regarding factors (e.g., contextual, process, and cultural) that facilitate and limit engagement in pain self-management behaviors in older AAs provide an inadequate basis to “refine recommended intervention behaviors...and examine emerging evidence on additional promising interventions” (Lubar et al., 2010, p.325). Hence, this study serves as a first step in refining recommended intervention behaviors, determining culturally-congruent behaviors for chronic OA and CJ pain self-management behaviors, and

identifying important factors necessary to support older AAs engagement in self-management.

Theoretical Framework

The major theory guiding this dissertation is the Individual and Family Self-Management Theory (Ryan & Sawin, 2009), while the Social Cognitive Theory (Bandura, 1977; 2001), Self-Regulation and Expectancy Theory of Motivation (Baumeister & Vohs, 2007; Vroom, 1964), and Transtheoretical Model (Prochaska & DiClemente, 1984) provide additional theoretical support. Following is a discussion of these theories and introduction of the theoretical model developed for this dissertation.

Individual and Family Self-Management (IFSM) Theory

Major theories of chronic disease (or conditions) self-management include Self and Family Self-Management (SFSM) (Grey, Knafl, & McCorkle, 2006; Grey et al., 2015) and Individual and Family Self-Management (IFSM) (Ryan & Sawin, 2009). The goal of each theory is to understand the complex process, dynamic relationship, and human response that individuals and their families use to manage chronic disease and life. There has been some contention between each theory although there are clear similarities and differences (Grey, Knafl, Ryan, & Sawin, 2010). Both frameworks identify risk and protective factors and outcomes germane to self-management, but Ryan and Sawin delineate proximal and distal outcomes. In particular, Ryan and Sawin (2009) articulated engagement in self-management behaviors as proximal outcomes rather than as a mediator of outcomes (Grey et al., 2006). Each framework addresses self- (or individual) management, and differ on the conceptualization of family self-management.

This dissertation is not concerned with the family management aspect, except in the context that it impacts an individual's engagement and performance of self-management. Self-management has been defined and described in various ways, but it essentially is the daily process and tasks that an individual takes to manage their chronic illness (Grey et al., 2015). The IFSM provides the theoretical basis for the model to be tested in this dissertation.

IFSM is a mid-range, situation-specific theory describing self-management as a dynamic phenomenon consisting of three dimensions: context, process, and outcomes. The IFSM expands upon Grey and colleagues' work (2006) by defining context and process factors. According to Ryan and Sawin, contextual (risk and protective) factors directly impact self-management processes. They also argue that contextual factors directly influence outcomes, but as currently modeled in their figure, contextual factors feed into process factors, which mediate and/or moderate outcomes. Contextual factors are further delineated into categories of condition-specific, physical and social environment, and individual and family. Condition-specific factors may be physiological, structural, or functional characteristics the condition, including treatment, that impact the type and intensity of self-management behaviors. Environmental factors are those relating to physical or social elements such as, but not limited to, access to care, social capital, transportation, and culture. The individual and family factors describe personal characteristics of the individual and family directly.

A gap in Grey and colleagues' (2006) initial SFSM was the absence of process factors, that is, those factors that individuals need and use to engage in self-management. These factors include health knowledge and beliefs, self-regulation abilities, and positive

social facilitation (Ryan & Sawin, 2009). Schulman-Green and partners (2012) advanced this work with a meta-synthesis and identified self-management processes as focusing on illness needs, activating resources, and living with a chronic illness. However, Schofield and partners (2014) reported that online resources for pain self-management for older adults are scarce to non-existent. Each process has general tasks and specific examples of skills for each task. According to Ryan & Sawin (2009), knowledge and beliefs affect behavior-specific self-efficacy, expectations for outcomes, and goal congruence.

According to the theory, enhancement of knowledge and alignment of personal beliefs influence engagement in self-regulation activities. Self-regulation as conceptualized by Ryan and Sawin (2009) is reflective of psychology's standpoint as a process used to change health behavior through goal setting, self-monitoring, decision-making, self-evaluation and management of physical, and emotional and cognitive responses. Ryan's self-regulation tasks are similar to Grey et al.'s (2015) process factors. These self-regulation tasks are necessary for engagement in self-management behaviors specific to the chronic disease, which serves as one proximal outcome. Distal outcomes include healthcare cost, quality of life, and perceived well-being. It is theorized that proximal outcomes partially affect distal outcomes, but there are no directional indications to show which or how other factors relate to the distal outcomes.

According to the IFSM, self-efficacy and motivation are pre-requisites to engagement in self-management behaviors and health behavior change, while Grey and colleagues' (2015) framework suggest that self-efficacy and motivation are proximal outcomes of self-management. Shively and others (2013) suggest that motivation, information, and skills are necessary to engage in self-management of chronic illness.

These cognitive mechanisms (i.e., self-efficacy and self-regulation) are linked with efficacy and outcome expectancies for behavioral change. Self-efficacy expectations are concerned with the conviction that an individual can successfully execute a behavior, whereas outcome expectations are an individual's personal appraisal that a particular behavior will lead to a certain or desired outcome (Bandura, 1977). Both self-efficacy and self-regulation are needed because an individual may believe that a pathway of action will result in a desired outcomes, but if they do not have the confidence, knowledge, and motivation to perform necessary behaviors, they are less likely to engage.

Social Cognitive Theory (SCT)

A scoping review found that Social Cognitive Theory, Transtheoretical Model of Change, Theory of Planned Behavior, and The Information-Motivation-Behavior theory accounted for 63% of all behavior theories used in arthritis and chronic low back pain self-management programs (Keogh, Tully, Matthews, & Hurley, 2015). Du and colleagues (2011) similarly found that 11 of 19 musculoskeletal pain self-management studies reviewed used Social Cognitive Theory, also referred to Self-Efficacy Theory. According to Bandura (1977), self-efficacy is the extent and belief to which individuals feel capable to perform intentional management tasks and/or accomplish pre-determined goals. Capacity involves having the confidence, knowledge, and skills to perform a specific behavior.

Social cognitive theory also posits that individuals acquire knowledge and skills and use cues to action to implement new behaviors/behavioral change in the context of their internal and external environment, social interactions, and personal experiences. In simpler terms, individuals reformulate their “cognitions to control behavior-event

contingencies” (Gitlin et al., 2008, p. 699). According to SCT, outcome expectations along with self-efficacy and health goals are determinants of health behavior. Self-efficacy exerts its influence through four major processes: motivational, cognitive, affective, and selection processes. Specifically, motivation is primarily concerned with activation and persistence of behaviors which is partially rooted in cognitive and affective processes (Bandura, 1977).

Self-regulation Theory and Expectancy Theory of Motivation

Self-regulation is one’s ability to alter behaviors, and is purported to encompass and enhance self-efficacy which subsequently plays a strong role in motivation, action, and willpower to engage in self-management behaviors (Bandura, 1991; Baumeister & Vohs, 2007; Ryan & Sawin, 2009). According to SCT, intentional control of behavior works through two cognitive sources of motivation (Bandura & Simon, 1977).

Motivation is one of four components of self-regulation; however, the role of motivation is often underappreciated in self-regulation theories (Baumeister et al., 2007). In one expectancy-value model of motivation for pain self-management, self-efficacy was an important component (Jensen, Nielson, & Kerns, 2003a), given that individuals have different capacities that affect motivation. “The capacity to represent future consequences in thought provides one cognitively based source of motivation” (Bandura, 1977, p. 178).

Motivation and expectancy theories serve to examine the human subjective experience and characterize the process by which individuals use information, skills, and intentions to engage in behaviors. They attempt to bridge the process between knowledge and action. Thus, Expectancy Theory of Motivation proposes that an individual voluntarily chooses to enact a specific behavior because they are motivated by the

expected result, typically a desirable outcome (Vroom, 1964). In the IFSM this is referred to as outcome expectancy, “the belief that engagement in a particular behavior will result in desired outcomes” (Ryan & Sawin, 2009, p. 225.e5; Bandura, 1977). Formulating self-reward to be conditional upon attaining a specified level of behavior, individuals persist in their attempts until personal standards are met (Bandura, 1977). In a sample of individuals with multiple sclerosis, task persistence was theorized to be a critical factor in an individual’s ability to be actively involved in specific pain self-management behaviors (Kratz, Molton, Jensen, Ehde, & Nielson, 2011). This further supports Bandura’s idea that “Those who persist in subjectively threatening activities that are in fact relatively safe will gain corrective experiences that reinforce their sense of efficacy...” (Bandura, 1977, p. 194). An individual’s motivation is grounded in their own values, beliefs, and interests. These beliefs may be cognitive representations of their illness, health, and/or ability to change or engage in behaviors, also known as illness perceptions (Leventhal et al., 1997). In the IFSM, this concept is labeled knowledge and beliefs: “Factual information and perceptions about a health condition or health behavior (Ryan & Sawin, 2009, p. 255e5). Illness perception is another key component of self-regulation theory proposed by Leventhal, who suggests that patients construct their own health representations as a means to make sense of their experience and influences their preferences for coping and health behaviors (Leventhal et al., 1997).

Autonomous motivation refers to doing things for oneself, and this type of motivation is predictive of self-care. In fact, motivation is one facilitator of using non-pharmacological pain self-management (Park et al., 2013a), but “self-care motivation may be limited by physical capacity to follow-through with intended behaviors” in older

adults (Dattalo et al., 2012, p. 1074). Individuals have different cognitive (e.g., self-efficacy) and physical capacities as well as various restrictions on their capacities that affect motivation (Mittler, Martsof, Telenko, & Scanlon, 2013). At the crux of self-management is an empowered and motivated individual with adequate self-efficacy. Self-management intervention studies shown to be effective included patient education sessions (e.g., self-management programs) to increase self-efficacy and motivational counselling (Boren, Gunlock, Schaefer, & Albright, 2007).

Transtheoretical Model (TTM)

“Given the importance of patient engagement in behavioral change and self-management in chronic pain treatment, it seems natural that researchers would begin to study the applicability of the readiness to change construct in chronic pain” (Jensen, Nielson, Turner, Romano, & Hill, 2003b, p. 529). Some postulate “that patients will engage in specific pain self-management behaviors as a function of their readiness to use these behaviors” (Jensen et al., 2003a, p. 484). Pain readiness to engage or maintain arose from Prochaska and DiClemente’s TTM (Prochaska & DiClemente, 1984; Prochaska, DiClemente, & Norcross, 1992). The TTM is a comprehensive, biopsychosocial model that conceptualizes the process of intentional behavior change using five stages of change: pre-contemplation, contemplation, preparation, action, and maintenance. Because OA is not a stable condition, individuals’ confidence, motivation, and ability to engage in self-management may fluctuate and individuals may move back and forth between stages and progress through the stages at varying rates. The current version of the TTM even suggests that self-efficacy increases in the preparation, action, and maintenance stages.

Although there are several conceptual frameworks and models for pain self-management (Matthias et al., 2012; Carnes et al., 2013; Kerns & Habib, 2004; Jensen et al., 2003a), there is no one definition for chronic (or persistent) pain self-management as this could describe a range of interventions and processes across diverse populations (Blyth, 2014). In a concept analysis, Stewart and colleagues (2014) define pain self-management as:

A multidimensional process occurring when an older adult perceives the need to self-manage pain and is willing and able to do so with support from others. It involves an older adult with persistent pain being an active individual in their treatment, engaged in the personal development of skills and being aware of their own responses to symptoms. The older adult initiates, participates, and develops their own methods of symptom control by using pain management techniques that lead to improvements in the physical, psychological, and social health domains (p. 220).

A key attribute to point out in this definition is the “active individuals.” To be active, older adults must be aware of motivations and beliefs, empowered, responsible, and be willing to take an active role in pain management (Stewart et al., 2014). These same descriptors or antecedents are the basis for other chronic pain self-management models (Jensen et al., 2003a; Matthias et al., 2012), chronic conditions self-management (Lawn, McMillan, & Pulvirenti, 2011), and patient activation (Hibbard & Cunningham, 2008; Hibbard & Greene, 2013). Ersek and colleagues (2004) determines the goal of pain self-management is “to enhance function, improve mood, and decrease pain intensity by changing the emotional, cognitive, and behavioral responses to pain” (p. 2 of 11). These

goals center on creating meaningful life roles, coping with the emotional consequences of pain, and improved treatment management (Hadjistavropoulos, 2012).

In order for pain self-management to be effective, individuals must find behaviors that work for them and be motivated to engage in these behaviors. The caveat, however, is that little is known about pain self-management in older adult populations (Blyth, 2014; Ersek, Turner, Cain, & Kemp, 2004; Hadjistavropoulos, 2012), much less in older ethnic minority populations. Thus, we have limited evidence on how to help older adults find effective behaviors, motivate them to engage in self-management, or best deliver chronic pain self-management education. This may be one reason for Ersek and colleagues' findings (2008) of no significant effects for pain reduction or functional improvement in older adults after a chronic pain self-management program. Repeatedly, meta-analyses and systematic reviews suggest that participation in self-management programs for chronic musculoskeletal conditions, including OA, results in small-moderate effects in improving pain (Carnes et al., 2012; Du et al., 2011; Nolte & Osborne, 2013; Nunez et al., 2009). Nevertheless, the chronicity of OA necessitates pain self-management in older adults, and given issues with pain under-treatment and advocacy, engagement in pain self-management is becoming increasingly more important (Hadjistavropoulos, 2012).

Individual self-management model in older AAs. Based on the IFSM theory and the evidence, or lack thereof, on OA and CJ pain self-management, the Individual Self-Management Model in Older African Americans (Figure 1) was developed to guide this dissertation. This model, like the IFSM, indicates that contextual and process factors directly impact process factors which directly affects proximal outcomes (i.e., stage of

engagement in recommended self-management behaviors) and proximal outcomes influence distal outcomes. Distal outcomes include pain control, quality of life, and functional ability. This dissertation does not investigate distal outcomes as these refer to long-term program of research outcomes.

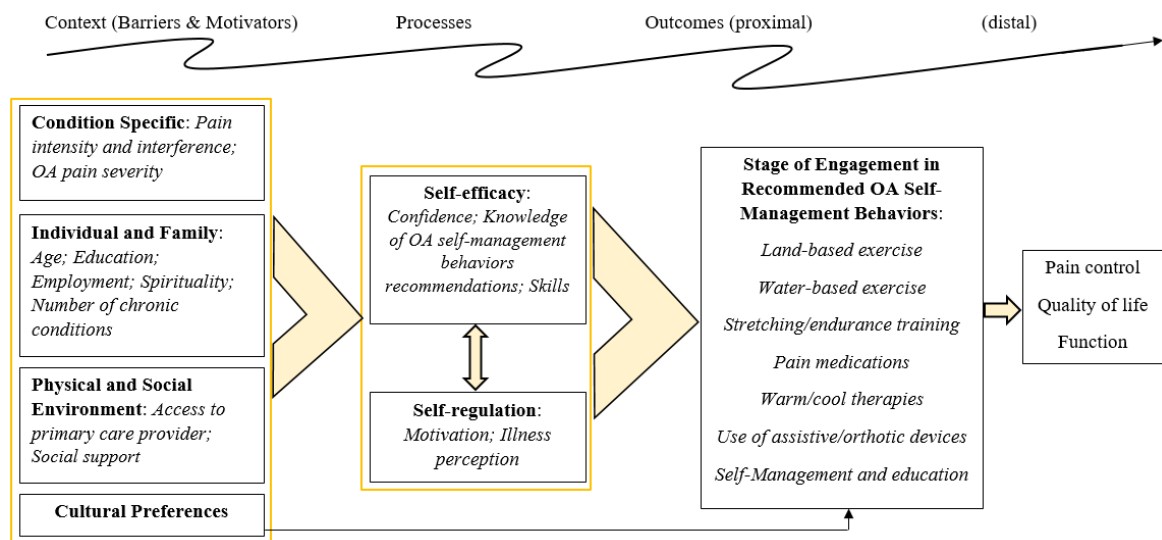


Figure 1- *Individual Self-Management Model in Older African Americans.*

Adaptation to the IFSM. The literature was clear in showing pain intensity, spirituality, the number of chronic conditions, social support, and self-efficacy as major predictors of self-management. However, there is less research to show that pain interference, demographic factors, illness perception, access to a provider, and motivation predict engagement in self-management behaviors; these were theoretically chosen as they were identified as barriers and facilitators to chronic pain self-management. Demographic factors were often ‘controlled’ in analyses of self-management in older AAs and Caucasian Americans (CAs), thus limiting understanding on how these impact self-management. Ryan and Sawin (2009) state culture as an example of an environmental factor. However, they were not explicit as to the connotation of culture.

For the purposes of this dissertation, cultural preferences comprises its own category within the contextual factors, and is directly associated with process factors and proximal outcomes.

Ryan (2009) acknowledges that motivation and desire are necessary for change, and Eccles et al. (2012) acknowledge a need to understand how motivation translates into action. Given that (1) self-efficacy (confidence and knowledge) is a major predictor of chronic disease and arthritis self-management and (2) self-regulation (motivation and illness perception) is necessary for chronic pain self-management, the IFSM process factors were modified to focus on these two concepts. This model purports that self-efficacy and self-regulation, in their reciprocal relationship, interact with each other and when one changes, so does the other. The exact direction of the relationship is unknown, but a linear relationship is suspected. For example, when self-efficacy is low, so is motivation. The model further assumes that individual, environmental, and condition-specific contextual factors affect motivation and self-efficacy, either increasing or decreasing these. Both are proposed to be necessary to engage in pain self-management behaviors, and analysis determined that these assumptions are not major driving forces for pain self-management in this population. One hope is that statistical analyses help to distinguish older AAs' who are unmotivated from incapable.

The proximal outcome of interest for this study is stage of engagement in recommended OA and CJ pain behaviors. This is measured along a continuum of engagement, from readiness to engage to maintenance. The staging and time frame represent a temporal dimension that can change over time. A time frame for each stage is provided "Because an individual can exhibit a preference for a future outcome (time

preference) only to the degree that they can resist the desire for immediate gratification (self-regulate), the concepts of time preference and SR [or motivation] are closely aligned” (Saffer, 2014, p. 1). For example, one possible answer on the PSMEQ is “No, but I intend to within the next 6 months.”

The arrows from context and processes signify directionality and inter-relatedness: contextual factors affect processes and processes in return influence outcomes. The meandering line just above the list of factors is indicative of a dynamic and fluid process toward self-management. There will be times when contextual and process factors change which may result in changing levels of self-management engagement.

Purpose and Specific Aims

The literature suggests that AAs may need more assistance with self-management, but factors which limit or facilitate self-management are not clearly known. Without this knowledge, we cannot support best practices for engagement in chronic pain self-management; therefore, establishing a research priority to understand areas within self-management where older AAs may need critical assistance is essential. Thus, the broad purpose of Help for Osteoarthritis Pain in African American Elders (HOPE), a convergent parallel mixed-methods study, was to understand engagement in OA and CJ pain self-management behaviors. Guided by the IFSM Theory (Ryan & Sawin, 2009), the specific aims were to:

1. Describe current patterns of OA and CJ pain self-management in a sample of older AAs.

2. Determine which model variables (contextual and process) predict stage of engagement in (1) seven recommended self-management behaviors that provide immediate and long-term relief for OA and CJ pain and (2) two most commonly-used complementary self-management behaviors for OA and CJ pain.
3. Describe barriers and facilitators to engagement in the recommended behaviors for OA.
4. Discover older AAs' preferences for culturally tailoring interventions to promote engagement in OA and CJ pain behaviors.

Assumptions

While there are no formative hypotheses for this study, it is valuable to acknowledge any assumptions that may bias or impact the design or application of the study. Reflexivity or the awareness of researcher-participant relationship and researcher position (including social location and educational status, biases, and power/privilege) is important in rigorous qualitative research and reduces what Hartrick-Doane (2014) terms “relational oblivion.” Key assumptions are as follows:

1. Spirituality in most AAs greatly influences all dimensions of life, including managing chronic diseases (Newlin, Knafl, & Melkus, 2002; Spruill, Magwood, Nemeth, & Williams, 2015).
2. Many AAs have low research literacy and likely have never participated in a health research study. Thus, my approach and language was tailored to relieve any apprehension related to participation. A recent editorial illustrates the influence of culturally-appropriate communication when nurse researchers discovered the

word “study” rather than “research” reduced negative perceptions among older AAs (Jones & Jablonski, 2014). Similarly, when speaking with participants I referred to this research either as a “study” or “project” in which I am the “project lead” rather than the “primary investigator (PI).”

Key Terminology

Table 1 presents conceptual and operational definitions for major concepts and variables.

Table 1- Definition of Major Concepts and Variables

Concept	Conceptual Definition	Operational Definition
Older Adult	An older adult can be defined by chronological age, a change in social role, or transition in health or capabilities; generally, an older adult is a person in the final stage of life.	Traditionally, an individual with a chronological age of 65 years or older is considered an older adult, but for this study, it is any AA who self-reports as 50 years of age or older during the eligibility screening.
Osteoarthritis	A degenerative and inflammatory joint disease causing pain, stiffness, limited range of motion, and degradation of cartilaginous tissues.	(A) Answer “yes” to “Have you been told by a healthcare provider that you have OA?”, or (B) self-report of persistent pain, stiffness, swelling, and/or crepitus occurring in any major joint site, including shoulder, elbow, hand, spine, hip, knee, and ankle on the Eligibility Screening Questionnaire, or (C) documentation from the participant of an OA diagnosis.

Table 1- continued

Concept	Conceptual Definition	Operational Definition
Chronic Joint Pain	Persistent pain in any joint caused by pathological (i.e., OA), but not due to other major chronic conditions or medications.	Self-report of pain three months or longer in any major joint, either occurring constantly or intermittently. Eligibility screening assessed for the presence of joint pain for at least three months, and the Participant Characteristics Questionnaire (PCQ) evaluates frequency and severity.
Pain Self-Management	The daily tasks an individual uses to manage symptoms and the impact of disease.	“It involves an older adult with persistent pain being an active individual in their treatment, engaged in the personal development of skills and being aware of their own responses to symptoms. The older adult initiates, participates, and develops their own methods of symptom control by using pain management techniques that lead to improvements in the physical, psychological, and social health domains” (Stewart et al., 2014, p. 220). The investigator-developed Pain Self-Management Engagement Questionnaire (PSMEQ) asked about engagement in pain behaviors and interviews will elicit additional information on daily pain self-management.
Recommended OA Self-Management Behaviors	A set of evidence-based physical, pharmacological, and psychosocial behaviors, with demonstrated effectiveness in decreasing pain and improving function, recommended for all persons with OA.	Behaviors include land-based exercise, water-based exercise, strength training, self-management education, analgesic medications, thermal modalities, and use of assistive and/or orthotic devices; evaluated on the PSMEQ.

Table 1- continued

Concept	Conceptual Definition	Operational Definition
Complementary OA Self-Management Behaviors	A set of various physical, pharmacological, and psychosocial behaviors used by persons with OA to manage pain and other symptoms of OA. These behaviors range from folk remedies with anecdotal effectiveness to behaviors with demonstrated effectiveness in decreasing pain and improving function.	Example behaviors include pain medications, topical rubs and creams, transcutaneous electrical nerve stimulation, massage, rest, and spiritual practices. The Arthritis Pain Self-Management Inventory (APSI) captured the types, frequency, helpfulness, and reason for use of both complementary and recommended behaviors.
Barriers	Condition-specific, individual and family-related, and physical and environmental obstacles that prevent or limit engagement in OA and CJ pain self-management.	Physical, social, spiritual, financial, and mental reasons that prevent older AAs from engaging in recommended OA self-management behaviors. Open-ended questions on the PSMEQ elicited these data.
Facilitators	Condition-specific, individual and family-related, and physical and environmental factors that support engagement in OA and CJ pain self-management.	Physical, social, spiritual, financial, and mental reasons that motivate older AAs to engage in recommended OA self-management behaviors; open-ended questions on the PSMEQ elicited these data.
Contextual Factors	Condition-specific, individual and family-related, and physical and environmental factors that prevent or facilitate an individuals' engagement in self-management (Ryan & Sawin, 2009). These may serve as barriers and facilitators.	Example condition-specific factors include pain intensity, frequency, and interference, and perceived control over pain. Individual and family-related factors include age, education, employment, illness perception, spirituality, and # of chronic conditions; physical and environmental factors encompass income, access to a provider, and social support.

Table 1- continued

Concept	Conceptual Definition	Operational Definition
<i>Pain intensity</i>	Sensorial perception of the severity of pain.	The Brief Pain Inventory-Short Form (BPI-SF) assessed pain intensity using a 0-10 Likert scale.
<i>Pain interference</i>	The intrusion of pain on daily affective, cognitive, and physical ability.	The BPI-SF assessed pain interference on physical and affective function using a 0-10 Likert scale.
<i>OA pain severity</i>	The perceived degree of seriousness based on radiographic findings and subjective representations of pain intensity and activity limitations.	Perception that OA is mild, moderate, or severe as reported on the PCQ.
<i>Age</i>	The number of years lived since a person's date of birth.	A person's reported age in years at eligibility screening.
<i>Education</i>	Process of receiving formal, systematic instruction to acquire basic knowledge, skills, and values.	Level of academic training completed: < High school, high school only/trade, high school and some college, college degree, and graduate degree reported on PSMEQ.
<i>Employment</i>	Act of working for someone or self; occupation.	Current employment status, working or unemployed, is assessed on the PCQ.
<i>Spirituality</i>	"African-American spirituality is faith in an omnipotent, transcendent force; experienced internally and/or externally as caring interconnectedness with others, God, or a higher power; manifested as empowering transformation of and liberating consolation for life's adversities; and thereby inspiring fortified belief in and reliance on the benevolent source of unlimited potential" (Newlin et al., 2002, p. 65).	Active use of at least one of the following: prayer, music, faith healing (e.g., laying of hands), Biblical reading, church attendance, and religious television, as reported on the APSI.

Table 1- continued

Concept	Conceptual Definition	Operational Definition
<i>Number of chronic conditions</i>	The quantity of long-term health conditions.	A numerical count of the major chronic health conditions as reported on the PCQ.
<i>Access to a provider</i>	Ability (cognitive, physical, and financial) to have access to a healthcare provider.	Report of having a regular doctor; assessed on the PCQ.
<i>Social support</i>	“Emotional, instrumental, or informational support provided to a person or family with the explicit goal of assisting or facilitating their engagement in health behaviors” (Ryan & Sawin, 2009, p. 255e5).	Having help from family, friends, or other caregivers in performing daily duties; yes/no as measured on the PSMEQ.
Cultural Preferences	Specific choices and needs for OA and CJ pain self-management preferred and used by older AAs.	Preferences on methods to acquire self-management education, need for a brochure tailored to AAs, use of spirituality, and types of self-management behaviors were elicited through qualitative interviews.
Process Factors	Interacting cognitive and behavioral factors that impact engagement in self-management (adapted from Ryan & Sawin, 2009).	Self-efficacy and self-regulation level to engage in OA self-management behaviors.
Self-efficacy: 1. <i>Confidence</i> 2. <i>Knowledge</i>	The extent and belief to which individuals feel capable to perform intentional management tasks and/or accomplish pre-determined goals; confidence, knowledge, and skills.	1. Report of confidence level in being able to complete specific self-management tasks, as scored on a 0-10 Likert scale on the Chronic Disease Self-Efficacy Scale. 2. Knowledge that each particular OA self-management behavior was recommended for pain as measured on the PSMEQ.

Table 1- continued

Concept	Conceptual Definition	Operational Definition
Self-regulation: 1. <i>Motivation</i> 2. <i>Illness perception</i>	1. "...An iterative process people engage in to achieve a change in health behaviors" (Ryan & Sawin, 2009, p. 255e5); One's capacity to moderate thoughts and emotions in order to alter or change health behaviors; 2. Cognitive representations or beliefs about one's health or illness; which are determinants of health behavior.	1. Report of motivation level to engage in pain management, as scored on a 0-10 Likert scale on the PSMEQ. 2. Importance of managing pain in relation to other major health conditions; Yes/no on PSMEQ.
Proximal Outcome	"...Short term outcomes that lead to attainment of distal outcomes... including engagement in activities/treatment regimens, symptom management, or use of recommended pharmacological therapies" (Ryan & Sawin, 2009, p. 255e5)	Short term outcome is stage of engagement in OA self-management behaviors.
<i>Stage of Engagement in Recommended OA Self-Management Behaviors</i>	Based on the 5 Stages of Change (i.e., pre-contemplation, contemplation, preparation, action, and maintenance; Arthur et al., 2009), an individual's level of involvement in OA and CJ pain self-management.	A continuum of engagement ranging from readiness to engage (e.g., pre-contemplation, contemplation, preparation) or actual engagement (e.g., action & maintenance) in each recommended OA self-management behavior as measured by the PSMEQ.

Summary

For older AAs, OA and CJ pain are major problems and self-management is essential for pain control. However, self-management is less than optimal in this population, and research has yet to go beyond describing self-management practices and evaluating the impact of self-management programs and to identify which factors support older AAs engagement in self-management with/without self-management programs. This dissertation used mixed-methods to elucidate and understand which contextual and process factors predict stage of engagement in OA and CJ pain self-management behaviors.

CHAPTER 2: LITERATURE REVIEW

Overview

Included in the literature review are studies addressing (1) epidemiology of OA and CJ pain, (2) patterns of OA and chronic pain self-management, (3) predictors of engagement, (4) barriers and facilitators, and (5) cultural preferences for self-management in diverse older adults, highlighting AAs. Integrative reviews assume various forms, but the overarching goal is to synthesize the research literature to develop a state of the science that informs practice, education, research, theory, and policy initiatives (Im & Chang, 2012).

Epidemiology of OA and CJ Pain in Older Adults

Overview

Chronic pain affects over 116 million Americans, disproportionately affecting older adults and represents an enormous public health burden in terms of disability, healthcare costs, and employment absenteeism (IOM, 2011). Chronic pain can be a chronic symptom of a pathological condition or it can be considered a chronic disease entity unto itself (IOM, 2011). The complex relationship between chronic pain and chronic disease can manifest in several ways (see Figure 2) and knowing the pathology of chronic pain is important for treatment and management. One of the most common conditions causing chronic pain in older adults is OA, which is the fourth most common cause of hospitalizations in the US (Murphy & Helmick, 2012). Studies indicate that “arthritis” is among the top chronic conditions reported by older AAs (Butler & Zakari,

2005; Lichtenberg, 2011), and is the predominant cause of chronic pain in older AAs (Bazargan et al., 2016a; Campbell, Carthron, Miles, & Brown, 2012).

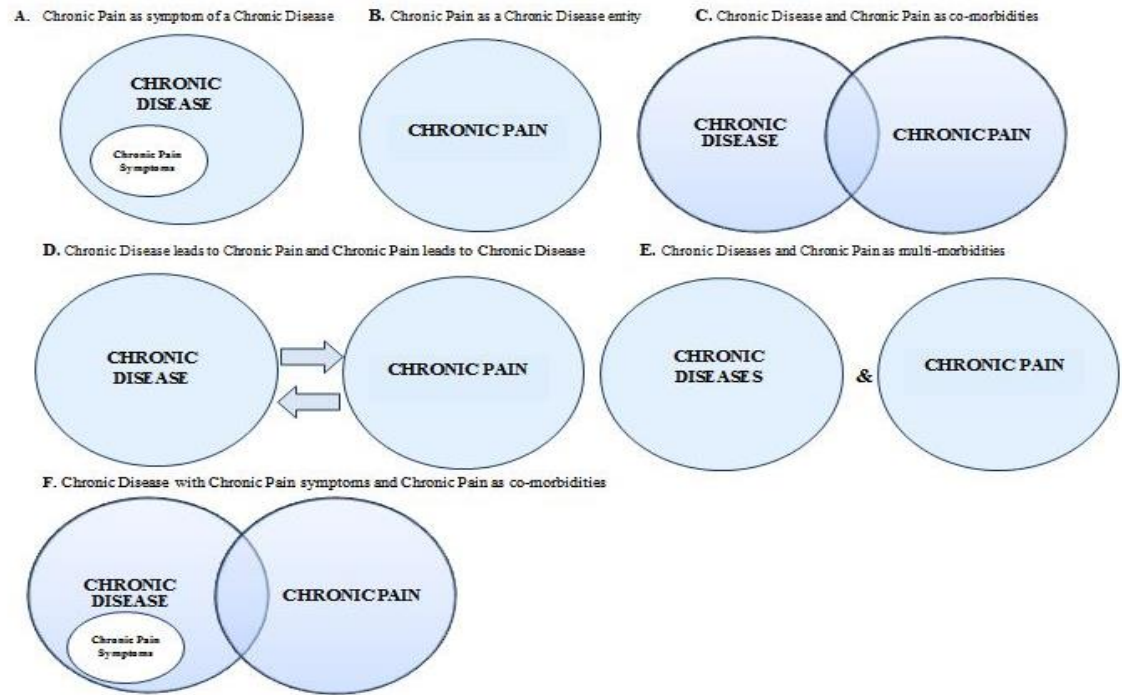


Figure 2- Chronic Pain-Disease Dyads. Modified and reproduced with permission from Booker & Baker (2015).

Epidemiology of OA in AAs

OA is the most common form of the 100 arthritis conditions. Approximately 52 million adults have a diagnosis of OA (CDC, 2014), and the lifetime risk of having OA by age 85 is 50% (Murphy et al., 2008). Of the 52 million, an estimated 6 million AAs currently have OA (CDC, 2013), and past projections suggested 7 million AAs will have some form of self-reported arthritis by 2020 (CDC, 1996). Among monozygotic and dizygotic AA twins, there is a respective 42% and 20% chance of both being diagnosed with OA (Baker, Whitfield, & Edwards, 2012).

Research consistently shows that AAs are disproportionately disadvantaged by OA and CJ problems when compared to other ethnicities (Bolen et al., 2010; Allen, 2010), but there is conflicting evidence on the actual population incidence and prevalence of OA and CJ pain in that AAs are characterized as having a lower (Bolen et al., 2010), near equal (Ibrahim, Siminoff, Burant, & Kwoh, 2001), or higher prevalence (Dillon, Rasch, Gu, & Hirsch, 2006; Handy, 1996; Jordan et al., 2007; Murphy et al., 2015). For example, in AAs, the incidence of hip and hand OA is typically lower while the incidence of knee OA is consistently greater (Kopec et al., 2013; Nelson et al., 2010; Nelson et al., 2013; see Table 2) because OA and CJ pain primarily affects weight-bearing joints in AAs (Baker et al., 2008; Bill-Harvey, Rippey, Abeles, & Pfeiffer, 1989). Among older AAs years, knee OA affects approximately 52% (Dillon et al., 2006) and knee joint pain affects 77% (Baker et al., 2008). Findings are discrepant because data were analyzed from different national survey data sets (e.g., National Health Interview Survey, Johnson County Osteoarthritis Project) with varying sample sizes of AAs and methods to measure presence of OA (e.g., self-report vs. doctor-diagnosed).

Table 2- *Comparative Summary of Radiographic and Clinical OA in AAs and CAs*

	AAs (%)	CAs (%)	Sample Size n = AAs, CAs (Total N= AA, CAs)	References
Hand	25.5	17.4	83, 88 (325, 506)	Sowers, Lachance, Hochberg, & Jamadar, 2000
	0.9	5.3	5, 59 (530, 1120)	Nelson et al., 2013

Table 2- continued

Hip	2.3	3.0	12, 33 (530, 1120)	Nelson et al., 2013
	11.1	8.0	11, 29 (108, 362)	Allen et al., 2009
	(mod/sev)			
	47.5	50.4	29, 71 (61, 141)	Golightly & Dominick, 2005
Knee	23.1	8.5	75, 43 (325, 506)	Sowers et al., 2000
	14.2	7.8	75, 87 (530, 1120)	Nelson et al., 2013
	68.5	53.1	148, 172 (216, 324)	Allen et al., 2009
	(mod/sev)			
	15.4	17.0	40, 57 (262, 334)	Ang, Ibrahim, Burant, & Kwoh, 2003
	(hip/knee)			
	78.7	86.5	48, 122 (61, 141)	Golightly & Dominick, 2005
	42.0	38.0	22, 53 (53, 138)	Riley et al., 2014
	23.4	32.3	22, 87 (94, 269)	Parmelee et al., 2012
	(1 knee)			
	76.6	67.7	72, 182 (94, 269)	Parmelee et al., 2012
	(both knees)			
Spine	11.1	12.1	59, 136 (530, 1120)	Nelson et al., 2013
	47.5	48.6	29, 69 (61, 141)	Golightly & Dominick, 2005
Ankle	29.5	44.0	18, 62 (61, 141)	Golightly & Dominick, 2005

OA and CJ Pain Manifestation in AAs

OA occurs when the cartilage between the bones wears away leaving the bones to rub against each other and muscles to be damaged and weakened. OA is defined one of three ways: radiographic, symptomatic, and clinical (Murphy & Helmick, 2012).

Radiographic OA is confirmed through x-rays and classification of severity using the

Kellgren-Lawrence scale, where grade 2 is mild (i.e., many osteophytes, joint space narrowing, sclerosis, and possible bone contour deformity) and grade 4 is severe (i.e., large osteophytes, significant joint narrowing, and bone deformity). A Kellgren-Lawrence grade of 2 is positive for OA. Symptomatic OA, on the other hand, is defined as radiographic OA in addition to symptoms, such as pain, stiffness, and swelling of the affected joint. Lastly, clinical OA exclusively uses clinical information like the patient's history and physical examination (Murphy & Helmick, 2012).

The progression of disease for both hip and knee OA is greater in AAs compared to CAs where AAs have more severe radiographic (i.e., more joint osteophytes and bone degeneration), clinical, and symptomatic OA (i.e., greater pain, aching, stiffness) (Braga et al., 2009; Goodin et al., 2014; Murphy et al., 2015; Nelson et al., 2010; 2013; Kopec et al., 2013; Sowers et al., 2000). A higher proportion of AAs fall into each Kellgren/Lawrence OA grade category for both knee and hip (Kopec et al., 2013). This explains why severe OA pain affects a higher proportion of AAs (38.7%) than any other racial population (i.e., 36.4% Hispanic Americans, 28.7% American Indians, 23.1% CAs, 18.5% Asian Americans) (Bolen et al., 2010). A newly published study further confirms that ethnic minorities (AAs and Hispanics) experience severe OA pain and are at higher risk for severe, high impact OA pain (Barbour, Boring, Helmick, Murphy, & Qin, 2016). It is no surprise then that AAs report significantly greater perceived arthritis-related stress than CAs (McIlvane, Baker, & Mingo, 2008a), which may limit ability to effectively and consistently manage OA pain.

Patterns of OA and CJ Pain Self-Management

Self-management refers to the daily tasks an individual uses to manage symptoms or the impact of disease (Brady, 2012). Although conceptually distinct, some studies used concepts of self-care (Albert et al., 2008a; Coulton, Milligan, Chow, & Huag, 1990; Ibrahim et al., 2001; Silverman et al., 1999; 2008), self-help care (Newman, 2001), coping (Golightly et al., 2015; Jones et al., 2008), self-treatment (Peat & Thomas, 2009), or treatments (Bill-Harvey et al., 1989) rather than self-management to describe the behaviors to manage pain. Barriers, facilitators, and cultural preferences lead to differential engagement in the types, frequency, and perceived helpfulness of OA and CJ pain self-management behaviors. For this dissertation, types of self-management behaviors are categorized as recommended and complementary. Describing the types and helpfulness of self-management behaviors are important components in older AAs' communication of OA pain, and when asked about their OA over 40% described the treatments used and 27% mentioned the helpfulness of treatment (Puia & McDonald, 2014). According to Silverman et al.'s (1999) study, both community-dwelling AA and CA elders used similar types of behaviors, such as OTC medications, home remedies, and hot and cold treatments. One strength of the study was their evaluation of both independent engagement and assisted engagement in self-care behaviors. This study, while seminal, had small sample sizes (AAs=55; CAs=37) and was unable to determine the effect of demographic and health predictors on self-care; they also failed to evaluate helpfulness or reasons for use of specific behaviors.

Frequency can be described in terms of occurrence (i.e., how often used either within a day or over a specified period), times of day used, and number of behaviors used

dependent upon the daily symptom trajectory. Often times, the type and frequency of self-management behaviors and treatment utilization depends on pain severity (Dobscha et al., 2009) and time of day (Silverman et al., 2008). Ability to adapt the treatment regimen is critical in OA and CJ pain self-management. Silverman and colleagues (2008) were instrumental in providing a snapshot of older AAs' and CAs' daily self-management, and Chiou and colleagues (2009) for Taiwanese older adults. Some suggest that older AA use fewer self-management behaviors unlike Hispanic and Caucasian Americans (Coulton et al. , 1990). During an average week, older AAs were using three of nine self-management behaviors, but after participating in an educational class, this increased to nearly five behaviors (Taylor, Kee, King, & Ford, 2004). Chinese middle-aged and older adults used a median of four pain self-management behaviors, with a majority using between 2-6 methods concurrently (Gong, Li, Li, & Mao, 2013). Although "race" and "ethnicity" are predictors of OA and CJ pain self-management practices (Katz & Lee, 2007; Quandt, Sandberg, Grzywacz, Altizer, & Arcury, 2012), research has not shown why it is a predictor or why older AAs use fewer self-management behaviors.

Helpfulness of treatment or self-management behaviors is an important component of self-management that was described by slightly less than one-third of older AAs in one study (Puia & McDonald, 2014). While helpfulness is a predictor of engagement in certain self-management behaviors, most studies did not investigate helpfulness in this way. Rather, it was used to describe helpfulness of current behaviors in reducing pain. The following sections discuss evidence-informed differences in types, frequency, and helpfulness of recommended and alternative OA and CJ pain self-management behaviors.

Recommended Behaviors

The ACR and OARSI recommend land-based exercise, water-based exercise, strength training, self-management education, analgesic medications, thermal modalities, and use of assistive and/or orthotic devices (Fibel, Hillstrom, & Halpern, 2015; Hochberg et al., 2012; McAlindon et al., 2014). According to Arthur and colleagues, over 50% of participants were in the maintenance phase for controlling pain, taking medications, and eating a healthy diet, while over a third of participants were in the preparation or maintenance phase for assistive device use and physical activity (i.e., exercise). Yet, many of the recommended self-management behaviors lack validation with AA populations. A major criticism of OA research is the under-representation of AAs and absence of treatment interventions evaluated in and appropriate for racial and ethnic minorities such as AAs (McIlvane et al., 2008b; Reid et al., 2008; Shengelia et al., 2013; Sperber et al., 2013). As a result, the recommended interventions may not be the most effective or culturally-appropriate interventions for older AAs.

Land- and water-based exercise and strength training. Physical activity and exercise are well-established pain management behaviors, but only 2% of AAs at high risk for or with knee OA met physical activity guidelines as compared to 13% of CAs (Song et al., 2013). Factors related to obesity, socioeconomic factors, and greater pain severity contributed to lower physical activity. An early study shows a slightly higher 16% of CAs engage in exercise as a pain management strategy (Austrian et al., 2005). In older CAs, 73% reported a high willingness to try the exercise program (Austrian et al., 2005), while investigation of readiness to exercise in a national sample of ethnically diverse women revealed that AA women were least likely to be in the active stages (i.e., action,

maintenance) of exercising (Bull, Eyler, King, & Brownson, 2001). This is consistent with reported lower rates of exercise utilization independent of pain intensity in older AAs (Grubert, Baker, McGreever, & Shaw, 2013). Others report a higher use of exercise and physical activity in older AAs for pain management (Parker et al., 2014), and exercise was the most frequently used pain management strategy among Taiwanese elders (Chiou et al., 2009).

Frequency. Several studies investigated the number of days spent exercising (Nour, Laforest, Gauvin, & Gignac, 2006; Parker et al., 2011; Reid et al., 2014). After participating in a chronic disease self-management program, post-intervention exercise behaviors increased in the number of days performing stretching, endurance training, and relaxation exercises in older AAs, CAs, and Hispanic Americans (Parker et al., 2011). Specifically, older AAs went from approximately 3.50 days to nearly 5.25 days, and their attitudes about exercising improved (Parker et al., 2011). However, sample size of the AAs was extremely small ($n = 29$). An earlier intervention study was unable to increase engagement in aerobic exercise (Rose et al., 2008). Similar to Parker et al. (2011), Canadian older adults increased 4.79 times per week (pre-intervention to 5.64 (post-intervention) in the control group, and the experimental group increased from 6.48 to 10.03 from pre-intervention to post-intervention (Nour, Laforest, Gauvin, & Gignac, 2007). In terms of time spent engaged, AAs in another study performed stretching and strength training an average of 7 minutes compared to 20 minutes for CAs (Lorig, Ritter, Moreland, & Laurent, 2015).

Decreased use of exercise could likely be due to older AAs' lack of knowledge about appropriate types, frequency, and amount of exercise (Park et al., 2013a), and older

AAs have even suggested adding time for guided practice (i.e., practice demonstrations) for various exercises during self-management program classes (Parker et al., 2012). Park and colleagues (2013a) found that among ethnically diverse older adults, embarrassment/self-consciousness (to participate in exercise programs) and fear of re-injury or exacerbating pain (in relation to exercise or chiropractic care) served as barriers. In fact, pain interference and depression limited physical activity and frequency of aerobic exercise in older AAs (Patil, Johnson, & Lichtenberg, 2008). Depression and lack of motivation are significant barriers to participation in physical activity and exercise for chronic pain management in ethnically diverse older adults (Park et al., 2013).

In terms of water-based exercise, such as water aerobics, fewer older AAs, Afro-Caribbeans and Hispanics have tried this method (Park, Manotas, & Hooyman, 2013b; Park et al., 2014). Only 8.7% of AA women participated in water activities for physical activity (Hall et al., 2013). In particular, many AAs are unable to swim, do not want to get their hair wet (Hall et al., 2013), or do not have access to a pool. Inability to afford fitness/health club memberships and living in unsafe neighborhoods are additional unique socioeconomic disparities that limit AAs participation in exercise (Ard, Durant, Edwards, & Svetkey, 2005). Facilitators of exercise in AAs include group-based, faith-based, and dance-based exercise programs (Park et al., 2013; Ard et al., 2005). Introducing dance as a pain management method may counter any negative attitudes toward exercise and physical activity, given that dance plays an important role in the cultural expression of AAs (Murrock & Gary, 2008), and is a form of acceptable physical activity among AAs (Alhassan, Greever, Nwaokelemeh, Mendoza, & Barr-Anderson, 2014).

Helpfulness. The Arthritis Foundation's Walking with Ease (exercise program) had long-term effects on pain and stiffness reduction in AAs, and this study was highly rated by AAs (Wyatt et al., 2014). Exercise was also rated as helpful for Taiwanese older adults (Chiou et al., 2009).

Summary: Strengths, limitations, and gaps. There are many issues that plague the exercise and physical activity literature with respect to older adults (Chase, 2013). One is that strength training are often lumped together with physical activity, making it difficult to understand these patterns independently. Moreover, there are varying definitions of what constitutes exercise and physical activity, most effective frequency and intensity, and best measurement. Measurement in the studies reviewed were mostly obtained from self-report versus direct observation of exercise or use of pedometers/accelerometers.

Most studies were cross-sectional or evaluated exercise over a short-period of time rather than longitudinally. This provides a limited picture of exercise behaviors and the factors that influence engagement and maintenance. Other variables such as physical functional ability to engage in exercise were rarely included as primary variables or co-variates; one study with AAs did consider performance of activities of daily living as a co-variate (Grubert et al., 2013). While longitudinal studies in older adults are needed, attrition is an issue and a higher mortality rate in AAs over a six-year study was observed (Song et al., 2013).

Also, studies comparing exercise in different ethnic groups did not perform sensitivity analyses to ensure that disparity issues (e.g., access) did not bias results. Also, because sample sizes (ranging from <100 to > 1,000) were not consistent across studies, frequency comparisons must be interpreted judiciously. Studies with smaller sample sizes

generally reported on original data whereas studies with large sample sizes used secondary data sources. This dissertation adds knowledge on stage of engagement and barriers and facilitators to exercise.

Self-management education. Individuals with chronic diseases are encouraged to seek self-management education in order to obtain the necessary self-efficacy and self-regulation skills to manage their conditions. Aside from online resources, standardized programs are the primary method of acquiring self-management education. However, only about 2% of older AAs report educating self about arthritis compared to 10% of CAs (Silverman et al., 1999). For CAs, this is consistent with other research that shows approximately 10% of people with arthritis have ever taken an educational arthritis self-management course (Allen et al., 2010b). Disparities in access to educational material are a major reason for these findings.

Frequency. No literature identified how often an older adult has participated in a single self-management program. However, a single self-management program generally includes multiple sessions, and some studies reported data on the number of sessions attended by participants. In Parker and colleagues' study (2011) Hispanic elders attended an average of 5.2 sessions, AAs 5 sessions, and CAs 4.9; their study was conducted in an inner-city which helps explain greater attendance by ethnic minorities. Completion rate for self-management education programs attended by ethnically diverse elders range from 61-91% (Parker et al., 2011; Reid et al., 2014; Sperber et al., 2013). Lack of interest, illness, death, lack of transportation are major reasons for attrition and drop-out of older adults in self-management programs (Parker et al., 2011).

Helpfulness. Because self-management programs are not widely accessible to older AAs (i.e., cost, transportation, timing of class) (Mingo et al., 2013; Townley et al., 2010), some may not even understand the benefits of participating in a chronic pain self-management program (Townley et al., 2010). Nevertheless, both AAs and CAs who participated in a telephone-based self-management program found it helpful in controlling OA and CJ pain (Sperber et al., 2012), and Taiwanese elders also had an improvement in pain outcomes after participation in a self-management program (Wu, Kao, Wu, Tsai, & Chang, 2011). This is consistent with other research indicating that pain self-management programs can be effective, although minimally, but the evidence on such programs are limited and inconsistent across studies and populations (Coster & Norman, 2009; Hadjistavropoulos, 2012; McGillion et al., 2010).

Summary: Strengths, limitations, and gaps. The Arthritis Self-Management Program (ASMP) was developed by Kate Lorig in 1978 at Stanford University, and is a derivation of the CPSMP that focuses specifically on OA. Many self-management programs are not informed by theory (Keogh et al., 2015) and are based solely on input from expert clinicians (McGillion et al., 2010). This was the case for the ASMP, whose early development was described as “bits and pieces taken from theory, accepted practice, and good intentions” (Lorig & González, 1992, p. 356). As the program evolved, Bandura’s Social Cognitive Theory, which emphasizes self-efficacy, became the theoretical foundation.

Statistics clearly demonstrate racial, gender, and age disparities in participation in the grant-funded CDSMPs. Of 89,861 participants, 56.3% self-identified as CA, 17.3% as AA, 5.0% as other/multi-racial, 3.2% as Asian/Asian Americans, 1.4% as American

Indian/Alaskans, and 0.8% as Native Hawaiian/Pacific Islanders. In addition, CAs and Asian Americans were older, while most participants were women (Korda et al., 2013). Approximately 86% of older AAs (N= 444) attended four or more of six sessions of a culturally-modified CDSMP (Gitlin et al., 2008). In one study where AAs comprised 14% of the sample size, it was concluded, “Unlike many studies where African Americans are underrepresented, in this study, they participated at a slightly higher rate than adult African Americans in the general population (14% vs. 13%)” (Lorig et al., 2015). While 14% may be a reasonable participation rate, when considering OA research participation in total, AAs remain underrepresented and Lorig’s conclusion may be over-reaching especially considering the mailed self-management kits were sent to a national sample. Consequent to disproportionate underrepresentation of AAs, Dennis and Neese ponder “whether...research is in danger of becoming "raceless" in its investigations and if so, what outcome can we expect (2000, p. 10)?”

Results from studies evaluating effect of self-management programs are less generalizable to older AAs because of a significant lack of racial and ethnic diversity in ASMP programs and studies (McIlvane et al., 2008b; Mingo et al., 2013; Nunez et al., 2009). Nevertheless, 90% of AAs believed there was a need for an arthritis self-help program (Mingo et al., 2013). AAs and CAs have stated they would participate in an arthritis self-management program only if recommended by a doctor (Mingo et al., 2013). Lack of physician support and greater value placed on complementary and alternative OA self-management options (Sperber et al., 2013) could support AAs’ need for other arthritis management options besides the doctor (Mingo et al., 2013).

Guidelines put forth by the OARSI and the National Institute for Health and Care Excellence (NICE) on OA and chronic low back pain (CLBP) recommend self-management and SME (McAlindon et al., 2014; NICE, 2014; Pillastrini et al., 2012). SME can be obtained through self-management programs. Chronic pain self-management programs are less accessible to older AA populations (Groupp et al., 2005; Townley et al., 2010), but 80% of older AAs, CAs, and Hispanics reported a willingness to participate in a chronic pain self-management (Townley et al., 2010). A chronic back pain program did not yield significant improvements in pain intensity or pain self-efficacy in older AAs or CAs, but Hispanic Americans did improve for these two variables along with functional ability and depressive symptoms (Beissner et al., 2012). Results such as this critically demand additional study.

Analgesic medications. The literature repeatedly shows that older AAs are more likely to use non-opioid medications rather than opioid medications for chronic pain (Park et al., 2013b), although there is evidence of limited prescribing of non-opioid medications like non-steroidal anti-inflammatory drugs (NSAIDs) (Albert et al., 2008a) and COX-2 selective drugs (Dominick et al., 2004) in older AAs. Over-the-counter (OTC) pain medications are used more often than prescription medications in older AAs (Albert et al., 2008a; Blake et al., 2002; Coulton et al., 1990), and may account for greater use of non-opioids. Specifically among a diverse sample of older adults, only three AAs were taking opioids, zero Afro-Caribbeans, two Hispanics, and fourteen CAs. Most AAs, Afro-Caribbeans, and Hispanics were taking acetaminophen, naproxen, aspirin and ibuprofen (Park et al., 2013).

Lack of knowledge on arthritis medications (Mingo et al., 2013) and limited access to commonly-prescribed opioids may partly explain greater use of non-opioids (Green & Prabhu, 2013). Some research has shown that AAs are less likely to have a prescription for NSAIDs and COX-2 inhibitors (Albert et al., 2008a), but others show AAs are more likely to have a prescription for and take NSAIDs (Dominick et al., 2003; Yang et al., 2012). These studies, however, were completed with individuals within the veterans' affairs system, where AAs have insurance and encounter less difficulty in receiving care (Lopez, Burant, Siminoff, Kwoh, & Ibrahim 2005).

Use of systemic NSAIDs for persistent pain is not strongly recommended for older adults due to high risks for adverse effects (American Geriatrics Society, 2009). Moreover, a large proportion of older AAs have co-morbid cardiovascular issues; thus, acetaminophen rather than NSAIDs is recommended for mild OA pain in this population (Johnson & Weinryb, 2006) despite research showing efficacy of celecoxib and naproxen in reducing OA pain in AAs (Essex, O'Connell, & Brown, 2012). AAs also had a shorter supply of medications (Dominick et al., 2004b), and this could clarify greater use of OTC and to some extent prescribed pain medications in AAs (Katz & Lee, 2007; Silverman et al., 1999; 2008; Yang et al., 2012).

In contrast, Taiwanese older adults used prescribed pain medications over OTC medications (Chiou et al., 2009). Among older adults taking opioids, they were 80% less likely to also be taking acetaminophen, and those on NSAIDs were 70% less likely to report taking acetaminophen (Fisher, Ballantyne, & Hawker, 2012), suggesting that older adults are relying on medication monotherapy versus recommended co-therapy (non-opioid plus opioid in moderate-severe pain). One study reported neither age nor sex

predicted opioid use for OA self-management; however age did predict NSAID and acetaminophen use wherein increasing age decreased use (Fisher et al., 2012).

Frequency. A greater number of older AAs report using pain medications throughout the day as opposed to when first getting out of bed for older AAs; the reverse is seen in CAs (Silverman et al., 2008). Studies generally identified whether older adults were using or had a prescription for medications (yes/no) or type of medication, but only Silverman et al. (2008) examined daily patterns of use.

Helpfulness. Older AAs were more likely to appraise Tylenol as helpful compared to CAs (Ibrahim et al., 2001). In general, however, medications and surgery are perceived as least helpful for older AAs (Bill-Harvey et al., 1989; Blake et al., 2002; Fiargo et al., 2005; Dominick, Bosworth, Hsieh, & Moser, 2004a). AAs in particular have a higher tendency to agree that pain medications cannot control pain (Green, Baker, & Ndao-Brumblay, 2004). This is different from findings showing that pharmacological behaviors are helpful for Taiwanese and Chinese seniors (Chiou et al., 2009; Gong et al., 2013). While aging AA veterans were more likely to report receiving treatment for chronic pain in the past year, they were less likely to rate the effectiveness of treatments as very good or excellent even after multivariate adjustment, including pain interference (Dobscha et al., 2009). Less-effective treatments being offered to AAs is another explanation for lower helpfulness ratings (Dobscha et al., 2009). Other research verifies that AAs have a greater incidence of mis- and under-treatment, receiving lower doses and less potent pain medications (Anderson, Green, & Payne, 2009). Difficulty accessing care could account for some disparities, but Lopez et al. (2005) did not find this to be an issue

in a sample of AA veterans' affairs patient. When access to care is available, management of pain disparities are lessened.

Summary: Strengths, limitations, and gaps. A large number of studies, particularly those comparing AAs and CAs were conducted from VA-based patients. These patients have fewer barriers to access to care compared to those non-VA patient who may not have insurance or access to a primary care provider. The studies reviewed are older, so the current policies and legislation limiting opioid prescribing in the VA system, as well as to patients with chronic non-cancer pain outside the VA, may not be relevant. However, we know from the literature that opioids are already under-prescribed to AAs, and current “anti-opioid” guidelines (Dowell, Haegerich, & Chou, 2016) may further limit their access to medications creating additional suffering and widening disparity in pain outcomes. This is an important issue because pain is more severe in older AAs, and current guidelines still recommend opioids for severe-moderate pain especially if function is severely impaired (American Geriatrics Society, 2009). Despite recruitment from Shreveport which houses a major military base, it was not anticipated that this study would include many VA patients; however, this data was collected but not analyzed due to small number of VA participants. Another bias is the geographic location of older adults surveyed in these studies. Research is clear in showing that predominantly-minority residential neighborhoods have decreased access to pain medications, particularly opioids (Gelfman & Morrison, 2013). Differences in patient preference and provider recommendation for medication should be acknowledged as variables impacting differential findings across studies. This study adds to the science: engagement/intent to use pain medications, types, frequency, helpfulness, and reason for

use of opioid and non-opioid medications, how many older AAs use medications, and barrier and facilitators to pain medication use.

Thermal modalities. Thermotherapy (warm/cool treatments) is especially effective for musculoskeletal pain. Use of warm/cool compress is one behavior preferred and used by older AAs (Coulton et al., 1990; Silverman et al., 1999; Quandt et al., 2012). Albert and colleagues (2008b) considered use of hot compresses as one criteria for optimal self-management, although some suggest that icing is better than heating (Oosterveld et al., 2009). Some AAs use warm water with Epsom salt to soak sore and swollen ankles and legs (Quandt, Sandberg, Grzywacz, Altizer, & Arcury, 2015). Use of thermal modalities ranged from hot showers, warm/cool compresses, to creams with capsaicin or menthol active ingredients.

Frequency. Approximately 27% of AAs and 23% of CAs in one study used topical treatments which included hot/cold treatments throughout the day (Silverman et al., 2008). Particularly for AAs, use was greatest in the morning and at night.

Helpfulness. Hot baths and heat therapy were helpful for Chinese (Gong et al., 2013) and CAs (Davis & White, 2008), and use of thermal behaviors by Asian populations may be a reflection of the principle of *yin* and *yang*. Use of heat was described as one the most effective behaviors for AAs (Bill-Harvey et al., 1989).

Summary: Strengths, limitations, and gaps. Despite recommendations and anecdotal stories emphasizing use of warm/cool therapies, few studies have evaluated thermal modalities in diverse older adults. Studies evaluating this therapy used basic methodologies.

Assistive and/or orthotic devices. Assistive devices, such as canes or walkers, and orthotic products such as braces and splints are explicitly recommended by the ACR (Hochberg et al., 2012). Among the recommended behaviors preferred and found helpful among older AAs, Hispanic Americans, and some Chinese are assistive devices (Bill-Harvey et al., 1989). Black race, along with factors such as knee pain severity, higher BMI, lower education, having Medicare only, was significantly associated with using assistive walking devices (AWDs); 75 aging AAs vs. 33 CAs with knee pain used AWDs (Carbone et al., 2013).

Frequency. Studies lacked descriptions of frequency of using assistive devices.

Summary: Strengths, limitations, and gap. Some suggest that clustering some self-care behaviors into one CAM category may overlook other routine behaviors (Silverman et al., 2008), perhaps like that of assistive/orthotic device use. Silverman and colleagues (2008) used the Lequesne Index (LI), which is a measure of OA severity by evaluating pain, stiffness, performance in activities of daily living, and the need for assistive devices. They reported that AAs had a higher LI, and a loose inference suggested that AAs' have a higher need for assistive devices.

Concluding summary: Strengths, limitations, and gaps. Strengths of the studies reviewed include a collective description of the self-management behaviors being used by ethnically diverse older adults. These studies have established with varying degrees of quality, the types, frequency, and perceived helpfulness of behaviors using both quantitative and qualitative methods. However, most studies only measured a single aspect of self-management (i.e., type of strategy or current use versus past use). No study evaluated types, frequency, perceived helpfulness, and reason for use, which makes the

HOPE study novel. AA participants were very different in terms of sampling behaviors (community-based, clinic-based, and VA-based), but across studies, demographics were quite consistent showing that older AAs have less education and income, poorer self-rated health, more severe OA and joint pain, and greater use of complementary and alternative behaviors.

Complementary Behaviors

While a combination of complementary and alternative and pharmacological behaviors is most effective for managing pain (Park et al., 2014), only 16% of AAs used complementary and alternative behaviors while 25% used either complementary and alternative behaviors with medications or medications exclusively, and 33% used neither medications or complementary and alternative medications (Yang et al., 2012). Similar findings were shown for CAs, except fewer (14%) used medications only. A couple of studies insist that AAs are less likely to have ever used complementary and alternative therapies relative to CAs (Mikuls et al., 2003; Yang et al., 2012). However, others show significantly greater use of complementary behaviors by AAs compared to Asian, Hispanic, and Caucasian Americans (Katz & Lee, 2007). Different operational definitions of complementary and alternative behaviors could impact these divergent results. There is no consensus what constitutes complementary and alternative behaviors or how to categorize these. Some studies evaluated non-Western therapies such as Ayurveda, Tai Chai, acupuncture, whereas other lists included traditional physical (exercise, massage, relaxation), nutritional/biological (herbs, diet change, glucosamine/chondroitin), thermal (warm/cool therapies), topical agents, and spiritual/energy-based (prayer, meditation).

Use of alternative behaviors is guided by culture, folklore, and beliefs in multipurpose use (Bill-Harvey et al., 1989; Coulton et al., 1990). A new study reported that older AAs have a rich tradition of home remedies for various types of ailments including arthritis and pain likely because of reduced access to care (Quandt et al., 2015) and preference for natural products. Honey, salts, and oils (including “healing oils [olive oil blessed by a pastor]”) were reported for musculoskeletal and joint pain. An example of using a product other than its intended use is WD-40, which is indicated for lubrication of squeaky or rusting door “joints” (Tamhane et al., 2014). Some older AAs believe this lubricant can help stiff and painful joints. Alternative therapies such as acupuncture and reflexology are used to a much lesser degree by AAs (Katz & Lee, 2007). This was not the case for Chinese older adults who use traditional Chinese medicine, balneotherapy methods, plaster, acupuncture, cupping, medicinal liquids, fumigation and washing, acupotomy, and Tui Na (Chinese massage) (Gong et al., 2013). In general, Asian Americans with arthritis used alternative medicine, body-manipulation, and dietary supplements (Katz & Lee, 2007). Regardless of the scenario, AAs still report needing resources on behaviors, including home remedies, to reduce pain (Mingo et al., 2013; Goeppinger et al., 2007).

Psychosocial and cognitive interventions. The ACR actually recommends that individuals with OA participate in self-management programs that include psychosocial interventions (Hochberg et al., 2012). However these programs are less accessible/available to the general population of older AAs. This is an issue because a review indicated that psychosocial therapies have positive effects on pain reduction and OA coping (Shin & Kolanowski, 2010).

Frequency. A primarily CA sample, although AAs accounted for one-quarter of the sample, found that almost all patients used relaxation and deep breathing at least once and almost 75% used it daily after participation in a cognitive-behavioral pain self-management program for chronic back pain (Bach, Beissner, Murtaugh, Trachtenberg, & Reid, 2013). In this same study, use of visual imagery, pleasant activity, sleep tips, muscle relaxation and activity pacing were used by a sizeable proportion at least once but daily use declined slightly.

Helpfulness. Guided imagery, specifically, appears to be one strategy that improves pain and even decreases use of pain medication in older CAs (Baird, Murawski, & Wu, 2010). However in Taiwanese elders, cognitive methods are used less frequently while pharmacological and physical methods were used more frequently (Chiou et al., 2009). Of 281 older adults representing several racial groups including AAs, only one older adult (CA) reported current use of cognitive behavioral therapy (Park et al., 2013).

Spirituality. Spirituality, social support and advice, and non-biomedical therapies are three culturally-essential factors for self-care in AAs (Becker, Gates, & Newsom, 2004). Older adults, specifically older AAs, use more emotion-focused coping behaviors such as praying/hoping CAs (Golightly et al., 2015). For many AAs, prayer is viewed as an active strategy rather than passive. The notion of prayer as an emotion-based strategy may be an incorrect characterization. For example, older AAs in the Arkansas delta region also noted the centrality of spirituality and faith and actively used spiritual behaviors (e.g., Bible reading, praying) to deal with problems associated with caregiving (Gerdner, Tripp-Reimer, & Simpson, 2007). Spiritual practices consist of prayer, reading the Bible, singing hymns and gospel songs, and going to church, and many older AAs use

“spiritual medicine” for various types of chronic pain (Booker, 2015). For example, one older AA with arthritis and other chronic conditions commented, “Girl, I do a lot of praying, go to church a lot. I try to stay calm as much as I can because when I – if I get over-exerted or upset, I have an asthma attack. And also, it makes me hurt more. ... I go to church and read my bible a lot” (Janevic et al., 2014, p. 249). Like many other cultures, mind-body harmony is a predominant belief in AA culture (Campinha-Bacote, 2012). That is why maintaining the spiritual self is important because it is believed to impact the physical self.

Intense use of prayer and spiritual mechanisms repeatedly emerged as a self-management strategy used by older AAs to manage and cope with OA pain (Golightly et al., 2015; Ibrahim et al., 2004; Jones et al., 2008; Katz & Lee, 2007; Quandt et al., 2012; Yang et al., 2012). One study, however, revealed that prayer was the most common self-management strategy among both older CAs and AAs (Quandt et al., 2012). A larger proportion of older AAs reported having tried prayer for knee or hip pain (Jones et al., 2008). Inclusion of a spirituality component to self-management programs has been suggested by AAs (Parker et al., 2012; Goeppinger et al., 2007).

Frequency. Prayer and meditation are consistently used at all three time periods (i.e., first out of bed, throughout the day, and night) by significantly more older AAs than CAs (Silverman et al., 2008). No data on how often prayers are prayed or length of prayers were provided.

Helpfulness. Prayer is considered one of the most effective behaviors endorsed by AAs and Hispanic Americans similarly perceived prayer as helpful (Bill-Harvey et al.,

1989; Ibrahim et al. 2001). Jones and partners (2008) show that 85% vs. 66% of AAs and CAs respectively believe prayer is helpful. Many believed prayer was an appropriate and effective strategy to manage OA pain and that only God could heal pain (Ibrahim et al., 2004). Prayer was also found to be helpful for Taiwanese elders (Chiou et al., 2009).

Physical modalities. Exercise (Coulton et al., 1990; Silverman et al., 1999; 2008), rest (Coulton et al., 1990; Ibrahim et al., 2001; Silverman et al., 2008), and reducing or changing activity are common in some ethnic older adults (Ibrahim et al., 2001; Quandt et al., 2012; Silverman et al., 2008). Particularly among AAs, rest, change of activity or pace, and self-massage are common responses to OA and CJ pain. Rest and exercise were two physical modalities used more frequently by Taiwanese older adults (Chiou et al., 2009). Physical manipulation using chiropractic therapy, physical therapy, massage, and acupuncture was used quite less among older adults (Ibrahim et al., 2001; Katz & Lee, 2007; Yang et al., 2012).

Frequency. Rates of self-massage were higher in the morning and at night with older AAs, who used the strategy with topical creams and lotions (Silverman et al., 2008). An inverse relationship between exercise and activity limitation was observed such that throughout the day exercise significantly decreased while rest and activity limitation starkly increased (Silverman et al., 2008). Massage, gentle activity, and range-of-motion increased significantly after self-management education in older AAs (Taylor et al., 2004).

Helpfulness. Massage was rated as one of the most helpful behaviors among Hispanics and AAs (Bill-Harvey et al., 1989; Ibrahim et al., 2001).

Topical products. Topicals used by older AAs included creams/salves or lotions, liquids (rubbing alcohol, grain alcohol, witch hazel, turpentine-kerosene-gasoline, WD-40), and oils (topical or oral) (Arcury et al., 1996; Fiargo et al., 2004; Ibrahim et al., 2001; Katz & Lee, 2007; Silverman et al., 2008; Yang et al., 2012). In addition, a larger number of older AAs use topical creams at night compared to CAs (Silverman et al., 2008). Topicals included both OTC and prescribed, primarily OTC.

Dietary modifications. As noted by some, it is seemingly contradictory that AAs with worse OA are less likely to make dietary changes (Katz & Lee, 2007; Silverman et al., 1999) or use dietary supplements, such as glucosamine and chondroitin (Albert et al., 2008a; Katz & Lee, 2007; Mikuls et al., 2003; Silverman et al., 2008; Yang et al., 2012). No older AAs reported using glucosamine for OA pain (Puia & McDonald, 2014). When asked about arthritis self-management needs, information on healthy eating is one topic that emerges in more than one study (Mingo et al., 2013; Goeppinger et al., 2007; Parker et al., 2012). Goeppinger et al. (2007) incorporated cultural dimensions of healthy eating to a self-management program, which was effective in improving pain outcomes.

Frequency. CAs were significantly more likely to use dietary interventions or changes throughout the day, upon first awakening, and at night compared to AAs or (Silverman et al., 2008). One change in AAs' diet (Coulton et al., 1990) was reflected by an increase in eating "green leafy" foods such as cabbage and kale (Katz & Lee, 2007). When considering the cultural implications, green leafy vegetables are a staple in AA cuisine and are associated with medicinal (e.g., helps blood clotting and provides strength) and mystic properties (e.g., associated with money and good luck).

Helpfulness. It is important to note that while nutritional supplements are not most common among older AAs (Albert et al., 2008a; Coulton et al., 1990), when used by AAs and Taiwanese they are perceived as effective (Ibrahim et al., 2001; Chiou et al., 2009). “There is reliable evidence that racial/ethnic minorities suffer disproportionately from unrelieved pain compared with Whites” (Shavers, Bakos, & Sheppard, 2010, p. 177) contributing to generally worse OA outcomes are in AAs. Hence, some suggest that AAs require more aggressive care (Golightly & Dominick, 2005), emphasizing weight management and psychosocial interventions (Allen, 2010), and may benefit more than CAs from self-management interventions (Sperber et al., 2013). Yet, none of the AA older adults interviewed in one study mentioned weight management when discussing management of OA pain (Puia & McDonald, 2014).

Concluding summary: Strengths, limitations, and gaps. Older AAs clearly prefer alternative therapies to many of the recommended behaviors, but a clear limitation of all the literature is that many of these studies are more than 5-10 years old. Also, the majority of the earlier descriptive studies did not use a validated measure to assess self-management behaviors. In a critical meta-analysis on self-management of arthritis, one of the issues cited was the variety in data collection methods, categorical surveys (validated and un-validated) versus qualitative interviews, considering each method will generate varying amounts and type of information depending if methods used open- or close-ended questions (Keysor et al., 2003). Missing from the literature on AAs is the safety and appropriateness of alternative therapies being used and clearer understanding of frequency, helpfulness, and reason for use. Silverman and others (2008) have even noted a need for further research on the motivations that influence choice for particular OA

self-care behaviors. Interestingly, among older AAs and other ethnic minority older adults, discrepancies between frequency of use and helpfulness were observed; several behaviors perceived as helpful were used less often. Cognitive dissonance (i.e., beliefs and resulting actions are antagonistic) may help explain this discordance (Booker, 2015). For example, several researchers found that among Taiwanese and Chinese elders, assistive devices were rated as being helpful, but these were used with much less frequency when compared to other pain management modalities (Chiou et al., 2009; Gong et al., 2013). Similarly, massage was used frequently, but the helpfulness rating was not comparable in Asian elders (Gong et al., 2013) unlike AAs and Hispanics who found massage to be helpful. This dissertation explored not only patterns of current use, but also past behaviors used that were not helpful as well as factors that predict use of the most frequently-used alternative behaviors. After reviewing the literature, one question unanswered is whether outcomes, such as more severe CJ pain in AAs, is due to differential use of behaviors and treatment, under-treatment of chronic pain, non-adherence to treatment, disproportionate differences in disease and symptom severity, or a perpetual cycle of these. This dissertation was concerned with the differential use of behaviors and treatment.

Predictors of Self-Management

Overview

A number of factors influence not only engagement in self-management behaviors but the intensity of engagement. Various types of chronic diseases and individual self-management behaviors have differing predictors, varying in strength and relationship.

The following sections review predictors of self-management for chronic disease (in general), arthritis, and chronic pain.

Predictors

Chronic disease. In general populations and older adults, predictors of chronic disease include *self-efficacy* (Clark & Dodge, 1999), *illness perceptions* (Abubakari, Cousins, Thomas, Sharma, & Naderali, 2015), *number of chronic diseases* (Rose et al., 2008), and *severity of symptoms or illness* (Hershey, Given, Given, Corser, & von Eye, 2014). Self-efficacy, perceived barriers, perceived susceptibility, necessity beliefs, and medication concerns were identified in a comprehensive literature review of 20 years of adherence research (Holmes, Hughes, & Morrison, 2014). Among older adults with hypertension, *stage of change*, self-rated health, and reading food labels predicted engagement in self-management. Specifically being in the action and maintenance phases predicted engagement in exercise (Douglas & Howard, 2015). It is important to note that studies typically attract a more highly motivated and/or engaged sample who are interested in improving their health, biasing results and limiting generalizability.

Arthritis. Similar factors as those identified in chronic disease and chronic pain self-management predict engagement in arthritis self-management. For example, severity of symptoms or illness (less severe), number of co-morbidities (fewer), and better functional ability predicted engagement in moderate-vigorous exercise in adults with arthritis (Baruth, Wilcox, Sharpe, Schoffman, & Becoskey, 2014).

Self-efficacy. Self-efficacy was identified as a key factor in the management of OA and coping with OA pain (Allegrante & Marks, 2001). Findings regarding pain

and/or OA self-efficacy in AAs are rather consistent, in which they have lower self-efficacy (Allen et al., 2010a). Standardized OA self-management programs are effective in reducing pain intensity and increasing knowledge and number of self-management behaviors used, although ineffective in improving self-efficacy (mainly confidence) (Parker et al. 2011; Beissner et al., 2012); a decrease in self-efficacy were noted in both studies. In contrast, others note both a small increase in self-efficacy in non-whites (i.e., predominantly AA) in the OA intervention group while decreases in self-efficacy were noted in the control and usual care groups (Sperber et al., 2013).

Without increased confidence in chronic pain self-management, older AAs may not sustain behaviors learned from these self-management programs, particularly during periods of stress. Low levels of self-efficacy are linked to several determinants of pain including education and pain interference. For example, having an education level greater than an associate's degree and better mental health were predictors of increased pain self-efficacy while greater OA symptom is associated with lower self-efficacy in older adults (Allen et al., 2010a; Newman, 2001); and while unfortunately fewer older AAs had an associate degree and more older AAs had greater symptom severity and worse mental health, race did not predict pain self-efficacy (Jones et al., 2008). Interestingly, however, while non-whites had lower baseline arthritis self-efficacy and decreases in arthritis self-efficacy from baseline to 12-month follow-up, pain still decreased (Sperber et al., 2013). In a recently published study with older AAs and CAs experiencing cancer pain, pain interference emerged as the single predictor of self-efficacy to cope with pain (Baker et al., 2013).

Age. Many older adults do not think of OA symptoms in terms of illness but as a sign of ‘normal aging’ (Peat & Thomas, 2009, p. 798), and consequently older adults believe they must accept OA as a natural aging process rather than treat it (Gignac et al., 2006; Goodwin et al., 1999). Indeed, older AAs were more likely to attribute OA to old age or work environment and to believe little could be done to make OA better or to improve the pain (Goodwin et al., 1999). An older AA demonstrates this reality by stating, “I can put up with all the pain because arthritis runs in my family and all of us get it when we get old” (Davis & McGadney, 1993, pp. 77-78). Their lack of knowledge about the development of arthritis prompts them to believe it is irreversible and irremediable and may play a great role in limiting active involvement in self-management (Fiargo et al., 2004; Goodwin et al., 1999). Such age-related expectations, along with knowledge deficits, reduced access to healthcare, and emotional distress, complicates OA pain management in older adults (Davis, Hiemenz, & White, 2002). Hadjistavropoulos (2012) asserts that after older adults acquire adequate knowledge on chronic pain self-management, then issues with limited access to healthcare services may be improved. Others have not shown age as a significant predictor of self-management among a sample of AAs and CAs (Arcury et al., 1996).

Chronic pain. Intriguingly, while chronic pain requires self-management, chronic pain in itself can make engagement in self-management difficult (Krein, Heisler, Piette, Butchart, & Kerr, 2007). AA women with chronic asthma reported how chronic pain due to arthritis or other chronic condition limited their self-management ability (Janevic et al., 2014). Several factors are shown to predict engagement in self-management and they

include pain intensity, pain interference, control over pain, spirituality, treatment effectiveness (or helpfulness), and number of chronic conditions.

Pain intensity. Pain intensity, location, and timing of pain are three qualities older AAs use to describe OA pain (Puia & McDonald, 2014). Mean pain intensity ratings are consistently higher for older AAs (Golightly et al., 2015; Park et al., 2015b), but pain intensity is an inconsistent predictor of use of self-care for chronic joint pain in a comparable diverse older sample (Coulton et al., 1990; Katz & Lee, 2007). Seemingly, more intense pain would require more intense self-management if reduction of pain and its' impact is the goal. According to one study, however, higher pain predicted fewer self-management behaviors in AAs (Coulton et al., 1990). Kawi's (2014) findings also did not support this assumption; pain intensity was not identified as a significant predictor of chronic pain self-management. This suggests that decreased pain intensity increases self-management. Adaptive coping and pain adjustment may explain why pain intensity is not statistically significant, but clinically, may be an important variable for older AAs. Persons with OA are shown to have greater levels of coping behaviors (Gignac et al., 2013).

Other studies discovered higher pain predicted any use of complementary and alternative (CAM) self-management behaviors only in AAs and not Asian, Hispanic, or Caucasian Americans (Katz & Lee, 2007; Park, Clement, Hooyman, Cavalie, & Ouslander, 2015a; Yang et al., 2012). More specifically, moderate or high pain intensity was associated with any CAM use and with specific mind-body interventions (Katz & Lee, 2007). A progression from mild pain to severe pain was characterized by an increase in oral opioid and topical analgesia use (Peat & Thomas, 2009). In stark contrast, joint

swelling emerged as the arthritis symptom that stimulated self-care behaviors in another study (Quandt et al., 2012).

Pain interference on function and illness perceptions. Worse functional status is an inconsistent predictor of self-management; in particular, it predicted greater mind-body interventions but lower dietary supplemental use in aging adults (Katz & Lee, 2007). AAs and persons of Hispanic ethnicity, in contrast to Asian Americans and CAs, had greater pain and stiffness and worse physical functioning (Katz & Lee, 2007), yet poorer function did not predict arthritis self-care in older AAs (Silverman et al., 1999). According to the premise of the common-sense model of health, "...actions taken to reduce health risks are guided by the actor's subjective or common-sense constructions of the health threat" (Meyer, Leventhal, & Gutmann, 1985, p. 115). When AAs perceive their OA and CJ pain as a threat to their health or functioning, then perhaps self-management is activated. This was confirmed when results showed older AAs used self-care behaviors not necessarily related to poorer function but for healthier lifestyles (Silverman et al., 1999). When OA self-management improved, so did general health (Goeppinger et al., 2007). Thus, "... cultural approaches to self-care formed the basis from which individuals developed behaviors specific to the particular parameters of their illnesses" (Becker et al., 2004; p. 2068).

Control over pain. According to Fishbein (2008), an individual's degree of perceived control over a specific behavior is a major contributing factor in whether they will engage in that behavior. Interestingly, while AAs reported greater control over health, it was not associated with optimal self-management unlike in CAs (Albert et al., 2008b; Baker et al., 2008). Others confirm lower abilities among older AAs and AA

adults to have control over pain (Green et al., 2003; Tan et al., 2005; Vallerand et al., 2005). Lower levels of perceived control over pain is likely due to their strong spiritual beliefs that permit them to relinquish external control to God, also known as God-mediated control (Booker, 2015; Fiargo Williams-Russo, & Allegrante, 2004; Ibrahim et al., 2004). Perceptions of pain control were significant predictors of being in the pre-contemplation stage of readiness to engage in pain self-management, and it was concluded that locus of pain control should be further explored in relation to motivation to self-manage pain (Hadjistavropoulos & Shymkiw, 2007).

Spirituality. Spirituality is likely to have a great impact on self-management, either as a mediator, moderator, or predictor. Indeed, religion and spirituality were significant predictors of self-management, in which low spirituality was reflected in lower back pain self-management (Kawi, 2014). Prominent researchers have shown that spirituality and religion in AAs serve as protective factor, but may also exacerbate adverse health outcomes (Levin, Chatters, & Taylor, 2005). One older AA, “I do not claim arthritis. God has not told me I have it. You have to claim it to have it” (Fiargo et al., 2004). Other chronic disease research with AAs also offer the same perspective about “claiming” a health condition (Spruill et al., 2015). As a spiritual mechanism, refrain from claiming OA is related to the scriptures found in Proverbs 23:7a (KJV) that says “For as he thinketh in his heart, so is he...”. Therefore by not speaking about or claiming OA, then, simply put, they won’t have OA or it will not be a problem. Yet if older AAs do not claim or believe they have OA, they may be less likely to participate in self-management and seek professional care and instead rely only on prayer and faith. Some, on the other hand, suggest using this deeply embedded cultural belief to improve self-

management rather than to stigmatize populations (Spruill et al., 2015). Still, as Levin et al. (2008) points out, reliance on prayer and faith may hinder AAs from seeking appropriate medical care. Greater prayer use was associated with decreased consideration of joint replacement for OA in AAs (Ang, Ibrahim, Burant, Siminoff, & Kwoh, 2002), but higher use of praying and hoping used by AAs as compared to CAs does not appear to increase pain self-efficacy (Jones et al., 2008). Jones and colleagues (2008) then concluded that “hoping and praying may not increase a patient’s ability to manage arthritis related pain...” (p. 345). Nonetheless, wishful thinking (McIlvane, 2007) and attitudinal changes are more common among AAs (Silverman et al., 1999).

Treatment expectations and effectiveness. Kawi (2014) found that greater perceived helpfulness of current management behaviors was a statistically significant predictor of pain self-management. Few studies have investigated intervention effectiveness in AAs (Goepfinger et al., 2007), but a common theme echoed by ethnically diverse older adults is the disbelief that non-pharmacological treatments would be effective in relieving pain (Park et al., 2013). When older adults believe various behaviors will not control pain or do not have/apply knowledge, skills and confidence, they are less likely to engage in or continue self-management (Park et al., 2013). It is suggested that treatment expectations may influence AAs’ perception of effectiveness (Dobscha et al., 2009). For example, older AAs do not believe that joint replacement will be effective in relieving pain (Fiargo et al., 2005), and data showing AAs undergo total joint replacements (TJR) at much lower rates than CAs (Cram et al., 2012; Fiargo et al., 2004; 2005; Ibrahim, 2010; Ibrahim et al., 2002a). When AAs’ expectations for a walking program were met, they demonstrated improved outcomes in OA pain, fatigue,

and stiffness (Wyatt et al., 2014). Treatment expectations are developed from learned cultural, social, and generational norms.

A similar concept, satisfaction with treatment, may also influence perceived helpfulness of chronic pain treatment. Studies have shown that AAs are less satisfied with pain care (Riley, Gilbert, & Heft, 2005). When studying cancer pain in older AAs and CAs, Baker and partners (2013) found discrimination was the only predictor of satisfaction with pain treatment such that lower perceived discrimination resulted in higher satisfaction with care. Although healthcare and social discrimination and physician bias did not explicitly emerge from this literature review as a factor linked to OA pain self-management, it is no less important. Discrimination is shown to be associated with greater pain in AAs (Burgess et al., 2009; Edwards, 2008) and lower pain tolerance (Goodin et al., 2013). Thus it is not surprising that discrimination is a known source of chronic life stress in AAs with arthritis, and racial discrimination is the major type reported by aging AAs whereas discrimination based on age is reported by CAs (McIlvane et al., 2008a; Baker et al., 2013). When assessing AAs' information needs related to OA self-management, information and resources on how to manage healthcare discrimination and communicate with physicians surfaced (Goeppinger et al., 2007). A recent study using virtual scenarios of OA patients found that physicians preferred to care for "White" patients over "Black" patients, and that Whites are more medically cooperative; however, race did not significantly impact their recommendation for total knee replacement (Oliver, Wells, Joy-Gaba, Hawkins, & Nosek, 2014) nor did race influence AAs' preference for a physician to help manage arthritis (Ibrahim et al., 2004).

Such biases may explicitly hinder AAs from seeking professional care and provides a stronger reason for AAs' need to engage in self-management.

Number of chronic conditions. Having and managing multiple co-morbidities is a barrier to self-management. Adults with a more favorable rating of their overall health were more likely to be self-managing their pain better (Kawi, 2014). Depending on the number and type of chronic conditions, some older adults do not feel pain self-management is a priority health issue although the impact of OA pain has a substantial impact on function and quality of life (Schoenberg et al., 2009). Having a higher number of chronic conditions was a predictor of lower self-care behaviors for CJ pain in older AAs, while CAs had less chronic conditions and self-care and Hispanics more conditions and more self-care (Coulton et al., 1990). Older AAs generally have at least three comorbidities (Baker et al., 2008; Rose et al., 2008). In Fisher and colleagues' (2012) study, aging adults with two or more chronic co-morbidities were nearly 30% less likely to use NSAIDs than those without co-morbidities; this is a positive finding because many with chronic conditions are urged not to take NSAIDs due to high risk for adverse health effects.

Barriers and Facilitators to Pain Self-Management Behaviors

Several investigators identify similar barriers and facilitators that impact older adults' engagement in chronic pain self-management behaviors (Austrian et al., 2005; Kawi, 2013; Park et al., 2013). In general, barriers are lack of motivation, unavailability/inaccessible treatments, decreased faith in the effectiveness of treatments, history of failed treatments, challenging patient-physician interactions, inadequate knowledge provided to them by providers, lack of self-efficacy and social support,

limited resources, depression, fear of pain or re-/injury, and anxiety (Kawi, 2013; Park et al., 2013).

Facilitators were adequate social support, available resources, and having a positive attitude (Park et al., 2013). In particular, social support, whether for physical help or emotional support, is repeatedly shown to be an important element for older adults with OA and CJ pain. Older AAs' social network is an integral facet of pain self-management reported in several studies as friends and families are regarded as sources of information regarding self-management behaviors and even joint replacement decisions (Blake et al., 2002; Fiargo et al., 2005; Ibrahim et al., 2001). One study of older AAs and CAs with OA revealed that social support was a source of emotional support to "help take mind off pain" (Martin, Schoster, Woodard, & Callahan, 2012, p. 668). Many with OA and CJ pain require the assistance of others to perform basic and instrumental activities of daily living. One AA elder respondent shared how her adult children help her walk when arthritis pain is intense (Silverman et al., 1999). When comparing cultural norms between AAs and CAs on social support and willingness to provide care, responses to vignettes revealed that AA young adult children were more willing to help a parent with arthritis than CA young adult children (Mingo, McIlvane, & Haley, 2006). This is consistent with the caregiving literature across chronic diseases that AAs have stronger familial values and positive attitudes about caregiving for elders (Epps, 2013).

Cultural Preferences

Self-Management Behaviors

There is an affinity to use home remedies for musculoskeletal pain, colds, and gastrointestinal and skin problems (Quandt et al., 2015). The literature review presented above show clear cultural differences in preferences of OA and CJ pain self-management behaviors. To summarize, older AAs prefer natural complementary therapies as opposed to biomedical or physical activity interventions. These preferences perhaps have a historical significance, in that older AAs during the days of segregation had to more often rely on natural remedies because medical care was not readily accessible (Shellman, 2004). Quandt et al. also noted this trend among AAs and CAs, that “when they were younger, one did not run to the doctor as much as is done today” (2015, p. 126).

Self-Management Education and Programs

Ibrahim and colleagues (2001) acknowledge the need “...for development of innovative programs that are culturally appropriate and congruent with patient values, attitudes, and beliefs as part of the national effort toward eliminating racial disparities in health care” (p. 343-344). Responding to the urgent need, research is beginning to explore cultural adaptation of OA self-management programs based on the needs and preferences of ethnically diverse older adults (Chen et al., 2013; Parker et al., 2012; Reid et al., 2014) and AAs (Goeppinger et al., 2007; Mingo et al., 2013). For example, the educational topics for the ASMP were tailored. Specific educational topics for OA self-management requested by AAs include: pain management education, cultural dimensions of healthy nutrition, faith and spirituality, cross-cultural patient-physician communication (Goeppinger et al., 2007). Other topical needs identified included how to deal with discrimination in healthcare, available medications, effective healthcare utilization, mutual support, and setting personal treatment goals and plans of action (Mingo et al.,

2013). Cultural modification of the CDSMP for AAs also included several of the same topics including cultural foods, communication with diverse physicians, and even changing the name of the program (Gitlin et al., 2008). In addition, cultural-adaptation of the CDSMP included a change in name to “Harvest Health”, including an introductory session, and adding content on culturally-relevant foods, stress reduction techniques, and how to communicate with racially diverse physicians (Gitlin et al., 2008). Prior to these seminal studies, acceptability of such programs to and needs of diverse groups were unknown. A number of suggestions and issues were cited by AA and other ethnic minorities which included method of delivery (i.e., face-to-face, internet, mailed; community-based vs. home-based; race of presenter), needed educational topics, and barriers to participation.

Studies are also examining the effect of culturally-tailoring of self-management programs (Goeppinger et al., 2007; Parker et al., 2012; Reid et al., 2014). Several of these same adaptations have been noted in other studies evaluating standardized self-management programs, revealing a common cultural thread on needs and preferences. Targeted self-management programming for older AAs did prove effective in improving pain intensity over a period of several months (Taylor et al., 2004), but one culturally-tailored chronic disease self-management program did not significantly reduce pain despite increasing knowledge and confidence (Goeppinger et al., 2007). Perhaps the level of or topics for cultural tailoring were not directly focused on pain management, as the topics desired by AAs included: cultural dimensions of healthy nutrition, faith and spirituality, cross-cultural patient-physician communication, and discrimination in healthcare (Goeppinger et al., 2007). Mingo and colleagues (2013) identified specific OA

content areas needed by AA to include pain management education, identifying available medications, and setting personal treatment goals and plans of action. Without these skills and knowledge, it is likely that older AAs' ability to engage in self-management is variable and inadequate, consequently resulting in lower capacity to improve pain.

Specific to delivery style, Lorig and colleagues (2015) recognized that not all individuals are willing or able to participate in face-to-face or internet self-management programs, thus they evaluated the impact of a mailed self-management kit. She concluded that a mailed chronic disease-self-management kit may be an acceptable method of SME delivery for AAs. Few have evaluated the effectiveness of various delivery styles of self-management education in older adults. Ersek and colleagues (2008) studying primarily CA older adults found that there were no significant differences between the two intervention groups (self-management education vs. a book), which led them to conclude that more research is needed to determine best delivery style for self-management education. A recently published study investigated preferences for location (i.e., delivery site) of CDSMPs, and found that CAs had a higher preference for healthcare organizations, faith-based organizations for AAs, Asian/Pacific Islander for community facilities, and American Indians/Alaska natives for healthcare organization (Smith et al., 2015). Older aged participants preferred residential facilities, while those with more chronic conditions preferred a healthcare organization; preferences for men were quite evenly spread across location types.

Summary

This chapter has reviewed the literature on OA and CJ pain self-management in diverse older adults, drawing attention to differences and disparities experienced by older AAs. There is a need to understand which factors predict self-management as well as cultural preferences for self-management. The following chapter details the methods to accomplish this.

CHAPTER 3: METHODS

Overview

In this chapter, a description of the quantitative and qualitative research methods used to explore engagement in OA and CJ pain self-management are presented. These include: (1) synopsis of mixed methodology, (2) study design, (3) sample and setting, (4) data collection procedures, (5) instrumentation, (6) data analysis plan, and (7) standards for rigor.

Mixed Methodology

According to Kuhn (1996) and Creswell and Plano Clark (2011), a paradigm can be conceptualized as a worldview or global lens, an epistemological standpoint, a set of shared beliefs, a model, or any combination of these. Mixed-methods are sometimes described as the “new” or “third” paradigm (Denscombe, 2008), wherein quantitative and qualitative research are the dueling first and second paradigms respectively. Mixed-methods can also be applied as a method (i.e., an approach to collecting and analyzing data), methodology (i.e., a method plus a worldview), or a research approach integrated within existing designs (Creswell & Tashakkori, 2007). The application of “mixed-methods” in this study is a combination of these conceptualizations.

Pragmatism is the epistemological stance that often informs mixed-methods research (Griffin & Museus, 2011; Onwuegbuzie, 2012). Two relevant philosophical features of a pragmatist worldview is its orientation toward understanding consequences of actions and real world practice. One of the pragmatic novelties of this study is that it reached individuals in the community who have pain, with or without a formal diagnosis

of OA diagnosis because in reality many will not have a diagnosis but are still self-managing joint pain.

Design

Health differences and disparities “are often embedded within an elusive cultural context which typically defies traditional quantitative methods” (Sullivan-Bolyai, Bova, & Harper, 2005, p. 129). Furthermore, Shin (2014) asserts that a combination of empiricism and interpretivism is needed to fully understand arthritis self-management in older adults. For these reasons, this study uses a convergent (also known as concurrent), parallel mixed-methods (see Figure 3) design integrating quantitative and qualitative data to understand contextual and process factors that are associated with OA and CJ pain self-management in older AAs. In general, a mixed-methods design is appropriate considering the aims of the study and the subjective nature of pain and the objective influence of various factors on chronic pain self-management.

The purpose of the convergent, parallel design was to obtain different but complementary types of data on the same topic to best understand the research problem (Morse, 1991). Creswell and Plano Clark (2011) suggest these data sources are quantitative and qualitative; thus, a mixed-methods design elucidates multiple perspectives via multiple methods, which offsets the weaknesses of each method and strengthens the validity and reliability of the findings (Tashakkori & Teddlie, 2010; Creswell & Plano Clark, 2011). This study used surveys to obtain quantitative data, while qualitative data was elucidated using open-ended survey questions and semi-structured, individual interviews with narrative undertone.

According to the mixed-methods typologies put forth by Leech and Onwuegbuzie (2009), this study has a fully mixed concurrent equal status design and is notated by QUAN (or QUANT) + QUAL. This means that the qualitative and quantitative research strands are collected at the same time, have equal priority (i.e., indicated by the uppercase letters), and are mixed across one or more areas such as the research objective and types of data, analysis, and inferences (Creswell & Plano Clark, 2011; Leech & Onwuegbuzie (2009).

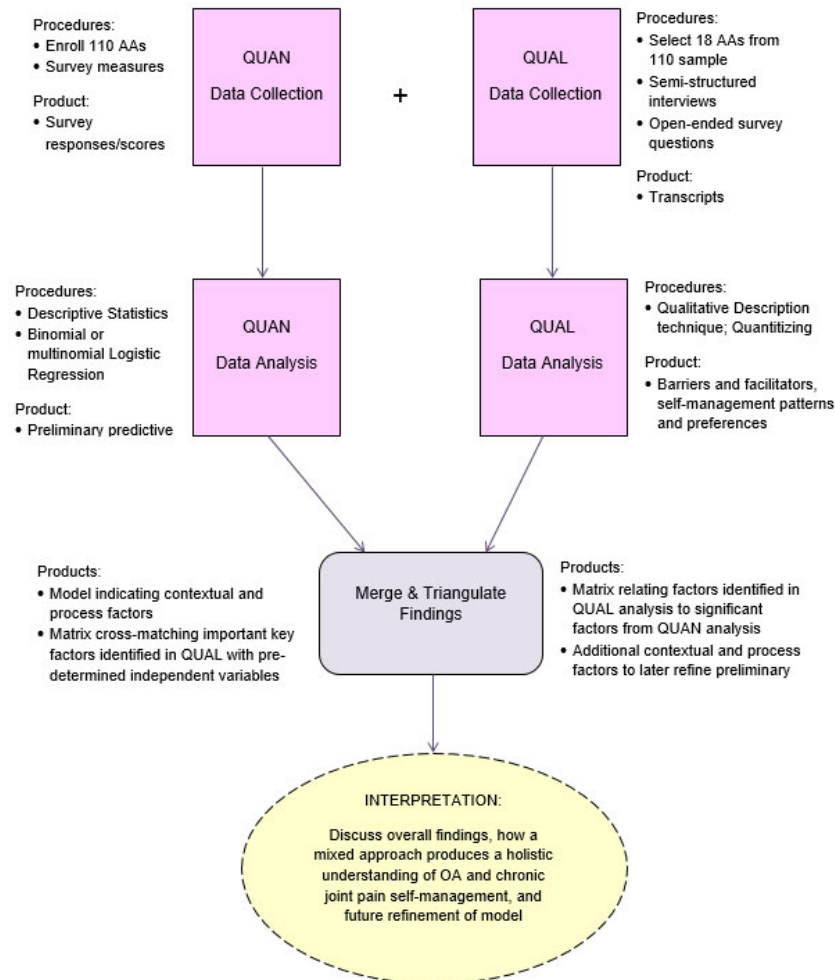


Figure 3- *Convergent Parallel Mixed-Methods Design.* Adapted from Wittink, Barg, & Gallo (2006).

Sample and Setting

Data show that 23% (N= 923,000) of Louisianans have a diagnosis of arthritis, but nearly 30% have chronic joint symptoms (CDC, 2013- Behavioral Risk Factor Surveillance System [BRFSS]). Those aged 45-64 account for 35% and aged 65 and older account for 54% with arthritis, most commonly OA (CDC, 2013). Overall, approximately 26% of AAs have arthritis in Louisiana (CDC, 2014). AAs, age 50 and older, will be recruited from Shreveport, Louisiana and surrounding communities within a 100-mile radius (including two other metropolitan areas- Ruston and Monroe). The AA population of the three major recruitment cities ranges from 43-65%. In Shreveport alone, the 50 and older population is 22,718 (US Census Bureau, 2011), allowing for a sufficient pool of older AAs.

Sampling and Recruitment

Traditional mixed-methods research sampling uses probability sampling for the quantitative component and purposeful sampling for the qualitative component (Palinkas et al., 2013). However, to accomplish the aims of this exploratory research, non-probability sampling using convenience methods was used for the quantitative strand and stratified purposive sampling using maximum variation techniques for the qualitative strand.

Quantitative strand. Non-probability sampling using a convenience sample of older AAs from churches, senior community centers, senior housing, and local Black sororities and fraternities served as the primary sampling strategy. Active approaches to garner interest and enhance recruitment included participating in community health fairs

and seminars and holding HOPE study informational meetings. A sign-up sheet gathered names of interested individuals at health fairs, seminars, and informational meetings. The PI followed up with these interested individuals and those referred by enrolled participants or family and friends. Self-selection bias, where highly interested and motivated participants seek out the study, must be considered; as a result, “In stages of change terminology, pre-contemplators are under-sampled” (Lee et al., 1997, p. 378).

Passive recruitment strategies included posting flyers (see Appendices A-C) at businesses and cultural events, churches, encouraging enrolled participants to pass along the HOPE study brochure (see Appendix D) included in their enrollment folder, and sending email blasts to local NAACP chapter members and alumni of Grambling State University (see Appendix E). Credibility and trust of the PI were enhanced through engagement with community cultural members by participating in health fairs in AA communities, attending church services, and lay discussions about OA with participating and non-participating AAs.

Snowball and referral sampling were also used. Although these are a type of passive, non-probability strategies typically used in qualitative research, they are especially effective in recruiting AAs (McLennon & Habermann, 2012) who are described as a “hard-to-reach” population (Altpeter, Houenou, Martin, Schoster, & Callahan, 2011; Vesey, 2003). Convenience and snowball sampling may result in homogenous groups of participants with low variation in demographics and self-management engagement between participants, and a high correlation on measures between participants may be seen. This could skew results and limit intra-race and inter-

geographic generalizability of inferences. Tracking participant residence (i.e., city) provides the ability to determine inter-geographic bias.

Qualitative strand. It is beyond the scope of this chapter to discuss all sixteen types of purposeful sampling (Patton, 1990), but two specific types were employed: stratified purposeful and maximum variation sampling. Stratified purposeful involves selecting certain cases varying on preselected parameters, usually of below average, average, and above average cases (Sandelowski, 2000; Patton, 1990). In this study, pain intensity (i.e., mild, moderate, severe) serves as the stratifying criteria.

Maximum variation sampling allows demographically varied cases to contribute sufficiently rich and relevant knowledge on the unique patterns of OA and CJ pain self-management. According to Patton (1990), “When selecting a small sample of great diversity, the data collection and analysis will yield two kinds of findings: (1) high-quality, detailed descriptions of each case, which are useful for documenting uniqueness, and (2) important shared patterns that cut across cases and derive their significance from having emerged out of heterogeneity” (p. 172). To maximize heterogeneity and representativeness, attention was paid to education and age as these are predictors of self-management in AAs, recruiting participants from various cities and community sites, and ensuring equal distribution by sex.

Maximum variation criteria (see Table 3):

1. Sex (Female, Male)
2. Education (\leq High school, = High school or trade, and = College or more)
3. Age (young-old [50-64], middle-old [65- 79], and old-old [80 +])

Table 3- Selection of Interviewees using Stratified Maximum Variation Sampling

Mild Pain	Moderate Pain	Severe Pain
1. Female, old-old, <HS <u>UI040 – Refused</u> Substitution: (moderate pain) <u>UI 030</u>	1. Female, middle-old, <HS <u>UI 008</u>	1. Female, young-old, =HS/trade <u>UI018</u>
2. Female, young-old, =College <u>UI060</u>	2. Female, old-old, =HS <u>UI075</u>	2. Female, old-old, =College <u>UI031</u>
3. Female, middle-old, =College <u>UI047 – Unable to contact</u> Substitution: (severe pain) <u>UI 093</u>	3. Female, young-old, =HS/trade <u>UI007</u>	3. Female, middle-old, =College <u>UI009</u>
4. Male, middle-old, <HS <u>None</u> Substitution: (moderate pain) <u>UI099</u>	4. Male, young-old, =HS <u>UI061</u>	4. Male, young-old, =HS <u>UI097</u>
5. Male, middle-old, =College <u>UI098</u>	5. Male, old-old, <HS <u>UI029</u>	5. Male, young-old, <HS <u>UI094</u>
6. Male, middle-old, =HS <u>None</u> Substitution: (severe pain) <u>UI108</u>	6. Male, middle-old, =HS <u>UI057</u>	6. Male, old-old, =HS/trade <u>UI081</u>

Sample Size and Power Analysis

Quantitative strand. Sample sizes in arthritis and chronic pain studies with exclusive or predominately AAs range from 90-500 participants. Determination of

sample size for this study used the conventional formula, $10 * \text{number of predictor variables}$. To obtain reliable and stable estimates of coefficients when fitting a model, a conservative estimate of 10-20 subjects per independent variable is needed (Polit, 2010); maximum likelihood estimation requires large samples. This ensures that "...the set of predictors, taken as a whole, are significantly better than chance in predicting the probability of the outcome event" (Polit, 2010, p. 317). Using the conventional formula of 10 participants per 11 predictor variables, it is estimated that 110 participants are needed. Fourteen variables were initially included in the conceptual model, but we expected several of these to drop from the final regression model. Post-hoc analysis to determine statistical power requires a significance level (α), a priori sample size, and an effect size (β) (Faul, Erdfelder, Buchner, & Lang, 2009). In contrast to a sample of size of 55 with an 80% power level, a sample size of 110 would provide 98% power to detect a true effect in engagement in self-management behaviors (G*Power © 2014).

Because this is a cross-sectional study in which participants may complete surveys onsite at churches or community centers, a low attrition rate was anticipated. Pilot testing determined 45 minutes was an acceptable length of time to complete surveys and interviews in order to minimize attrition. Response rate was monitored by keeping detailed records of the # of participants who expressed interest, how they learned of the study, city from which participants were screened and recruited, and reason for participation or refusal or termination.

Qualitative strand. Individual interviews, lasting between 45-90 minutes, were conducted with 18 of the 110 participants who satisfied the maximum variation criteria or until data saturation (i.e., when no new or relevant information emerges from

participants) was achieved. Maximum variation sampling is particularly useful with qualitative description (QD; see Data Analysis section) techniques, and studies using QD typically include moderate sample sizes (e.g., $N = 20-50$) (Sullivan-Bolyai et al., 2005; Sandelowski, 2000). Because pain intensity and OA severity are consistently shown to be greater, there is a possibility that six mild OA and CJ pain cases are not identified. However, studies show that approximately 30% of older AAs have mild OA according to the Lequesne Index (Albert et al., 2008b), which takes into account pain interference and duration. With this in mind, at least 33 participants were anticipated to report mild OA pain, providing an adequate pool from which to select 6 interviewees.

Timeline. Recruitment occurred over a seven month period following IRB approval. When sample size was not achieved by month three, recruitment strategies were re-evaluated and revised to improve recruitment: more targeted recruitment at senior housing, informal Facebook recruitment posts by members in the community, and recurrent email blasts to Grambling State University alumni.

Inclusion and Exclusion Criteria

Individuals interested in participation were screened for eligibility according to the following inclusion and exclusion criteria.

Inclusion criteria:

1. Race: self-identify as non-Hispanic African American or Black
2. Condition: self-report OA or CJ pain
3. Duration: self-report OA or CJ pain for \geq three months
4. Age: 50 years and older

5. Setting: community-based (i.e., individual homes, apartment complexes)

Exclusion criteria:

1. Condition: have rheumatoid, psoriatic, or inflammatory arthritis without osteoarthritis; other systemic rheumatic disease such as lupus or sickle cell disease
2. Evidence of cognitive impairment (see Instrumentation section)

Race. Participants must self-identify as non-Hispanic African American or Black.

The US Census Bureau (2011) defines African American, Black, or Negro as a person having origins in any of the Black racial groups of Africa. Based on this definition, approximately 40 million Americans identified as Black alone, representing 13% of the US population, while another 3 million identified as Black in combination with one or more races (US Census Bureau, 2011). The African diaspora represents many Black ethnicities with a common ancestral origin in Africa, and similarly the African/Black American diaspora has considerable variation (Agyemang, Bhopal, & Bruijnzeels, 2005; Aspinall, 2008).

Individuals of other Black ethnicities, such as Black Caribbean, foreign-born Blacks, or recently-immigrated Black *Africans*, will be excluded based on the assumption that the cultural orientation of these ethnicities are different than those who self-identify with the African *American* worldview. Although AA and Black are often used interchangeably, some participants, depending on age, social status, and educational level, may prefer a specific racial identifier. For example, those who are highly educated, younger, reside in large, urban cities or cities outside the Southern US, and attended racially diverse and integrated schools prefer AA whereas those whose characteristics

were opposite preferred Black (Aspinall, 2008). Fulton-Picot et al. (2002) found that older Black participants were offended when the correct racial/ethnic descriptor was not used, and some even refused to participate further in the study until the correct ethnic term was used; in fact, persons aged 65 and older in that study preferred Negro or colored, while those younger than 65 preferred AA. Today, ten years later, older AAs may not identify with Negro or colored, even though the 2010 US census still includes Negro as an option. Over the years, terms to identify AAs have evolved from the derogatory “N-word”, Negro/Negress (with the *Ns* capitalized and lower-cased; *Nigra* as the dialectic term), darkie, colored, Afro-American, Black (or Black American; capitalized and lower-cased), Brown, African American (hyphenated and unhyphenated), and person of color; utilization of preferred racial descriptor is important (Williams & Jackson, 2000). Only one participant in the HOPE study preferred the term Black to African American.

Limitations of self-report of race. There is no way to verify race considering that race is a social construct used to differentiate groups of people primarily based on color, physical features, language, and cultural practices. Some studies have instead resorted to using measures of ethnic identity and nativity either in place of or in combination with self-reported race (Rahim-Williams et al., 2007; Carlisle, 2015).

Condition. While verification of OA with radiographic imaging or chart review for official diagnosis is ideal, AAs have a disparately lower incidence and prevalence of physician-diagnosed OA (CDC, 2006); therefore, self-report of OA was used. The participant characteristics questionnaire assessed participants for common symptoms of OA and asked if their physician had informed them they have OA. These methods are

consistent with the CDC (2014) surveillance methods for self-reported arthritis and/or CJ symptoms.

Limitations of self-report of condition. No literature has examined the accuracy of self-report of a diagnosis of OA among older AAs, but others have found conflicting findings regarding accuracy of self-report with other populations. Sacks and colleagues (2005) determined that self-report of arthritis as chronic joint symptoms or doctor-diagnosed arthritis is a valid method among middle-aged and older adults, showcasing 83.6% sensitivity and 70.6% specificity for the older age group. More recent data reveal modest agreement between radiographic, clinical, and self-reported OA (Parsons et al., 2015). Other scholars similarly report that a significant number of participants are able to accurately identify their type of arthritis (Barlow, Turner, & Wright, 1998; McIlvane, 2007) with slightly higher specificity rates as Sacks and colleagues, 77% and 86% respectively (Ling et al., 2000; Wong et al., 2004). Among AA women with rheumatoid arthritis (RA), self-report was valid in identifying confirmed RA (Formica, McAlindon, Lash, Demissie, & Rosenberg, 2010). In contrast, there is disagreement between self-report and diagnostic confirmation for OA and RA (Oksanen et al., 2010; Simpson et al., 2004).

Because self-report is the primary method, there is a potential for misclassification bias of OA and CJ symptoms. To determine probable OA, participants were asked if they have ever been told by a physician they have OA. Those who answered no were assessed for common symptoms of OA: joint stiffness, pain with movement, swelling, and crepitus. Participants had the opportunity to share any documents showing a diagnosis of OA.

Duration. Chronic (or persistent) pain is defined as pain lasting three months or longer or beyond the time of expected healing (American Geriatrics Society, 2009). In one study, duration of OA symptoms for AA males was an average of nearly 136 months versus 131.8 for Caucasian males, and for AA females 119 months compared to 104 for Caucasian females (Parmelee et al., 2012). The duration of chronic pain of 37 older AAs, as reported by Parker and others (2011), was quite evenly distributed among the categories, < 5 years, 5-9 years, and ≥ 10 years.

Limitations of self-report of duration. Recall bias is a prospective issue, although it is not believed to be a significant issue. However, some older participants may have difficulty recalling when OA pain began, which is a major inclusion criterion, as well as any other key events related to OA and CJ pain self-management.

Age. This study defines older AA as an individual 50 years or older. While 65 is the traditional age used to categorize older adults, some suggest that AAs can be considered older adult at earlier ages (Tilley, Wisdom, Sadler, & Bradford, 2003). Genetic studies on telomere length show AA women are nearly 8 years older biologically than CA women counterpart (Geronimus et al., 2010), suggesting an accelerated aging process. In addition, the onset of OA and CJ pain in AA occurs at younger ages (see Chapter 2), which also disproportionately affects their functional and physiological health and predisposes them to premature aging. Several chronic pain and arthritis studies including older AAs set the minimum age criteria at 50 or 55 years (Baker et al., 2013; Burgess et al., 2009; Mingo et al., 2013), while others characterize older AAs as persons 45 years of age and older (Tilley et al., 2003).

Limitations of age. Moreover, while there were attempts to ensure variation in age of participants, it is anticipated that more young- and middle-old AAs will express interest in the study. Because younger age is associated with higher activation (Hibbard & Cunningham, 2008), a higher proportion of younger-old AAs could bias results; hence, analysis may adjust for age or analysis will be stratified by age (50-64, 65-79, and 80 and older, or older vs. younger).

Setting. Many AAs in the community have arthritis or chronic pain (Bazargan et al., 2016a; Butler & Zakari, 2005). While nursing homes have seen an increase in the number of AAs by 10% over the past decade (Feng, Fennell, Tyler, Clark, & Mor, 2011), many older AAs remain in the community either living with spouses, relatives, or alone (US Department of Health and Human Services, no date).

Limitation of setting. Limiting participants to the community is potentially excluding a moderate proportion of older AAs with arthritis who are institutionalized, including higher functioning older AAs residing in assisted living who may be self-managing their pain.

Data Collection

Procedures

The PI carried out all study protocols (i.e., initial contact, scheduling, consent, data collection, and tracking).

1. Flyers were distributed at informational meetings or posted in churches, businesses, and senior housing (see Appendices A-C).

2. Interested individuals contacted me via a study-designated cellular phone or secure University of Iowa email, or I contacted potential participants who have provided contact information at the recruitment sites or from snowball referrals.
3. An IRB-approved script (see Appendix F) was used during all on-site and telephone eligibility screening interviews. Screening took less than 5 minutes. If participants met eligibility criteria, a date was scheduled to administer surveys.
4. Prior to administration of surveys, participants were given a folder containing 1) an exempt information letter stating the purpose of the study and the PI's contact information (Appendix G), 2) PI's business card, 3) HOPE study brochure (see Appendix D), 4) a brochure from National Institute of Arthritis and Musculoskeletal and Skin Disease (NIAMS) (see Appendix H), and 5) a list of reputable online arthritis resources (see Appendix I). The list of online resources is in response to AAs' preference for an intervention that will teach you about internet sources focused on arthritis care (Mingo et al., 2013).

Although this is not an intervention study, this is one way to support older AAs need for education and resources and to show my appreciation for their participation in this study. After review of the enrollment folder, the PI asked participants if they had any questions prior to proceeding to surveys.
5. Surveys were completed at the participant's home (or other preferred, safe location such as the library, McDonald's® restaurant) and took approximately 45 minutes to complete. Based on informal feedback prior to initiation of

study, participants were given the option to complete the questionnaires independently (except the APSI) or to have each questionnaire read aloud by the PI and answers marked by the PI. “Younger” seniors preferred to complete questionnaires independently, while older seniors and those with vision impairment or lower reading abilities preferred to have the PI read questions. In order to maximize elicitation of data on specific self-management behaviors used within the past month, the PI used an open-ended question approach to administer the APSI to all participants.

6. At the completion of the surveys, participants received a \$15 gift card as research compensation.
7. During review of the exempt information letter, all participants were notified of a potential second in-depth interview. Participants were re-contacted anywhere from one week-to-one month following quantitative interviews to schedule a qualitative interview. Two women with mild pain were selected for qualitative interviews, but were not reached after three attempts to contact. They were replaced with two other women with the same maximum variation criteria. Because only 25 participants reported mild pain, it proved difficult to identify diverse participants who could provide a rich account of their experience with mild pain. Only two men had mild pain, but based on the quantitative interview, neither of these men were able to provide an in-depth qualitative interview. As a result, two men with moderate and severe pain having the same maximum variation criteria were selected.
8. Data entry and analysis.

Human Subjects Involvement

Protection against risks. This study is associated with minimal physical or emotional risks. All participants have the right to refuse to enroll or continue in the study in accordance with the Right to Self-determination Act. Participants were not be forced to respond to questions they feel uncomfortable answering. Participant burden is a concern if they choose to complete surveys and interview in one day; therefore, participants were offered breaks during the interview and were allowed to discontinue the interview at any time. When describing their pain experience, a few older participants became frustrated or emotional given that undermanaged pain frequently leads to depression, frustration, and anxiety. Participants who became visibly distressed (e.g., crying/tearing) were comforted and the interview paused at the participant's request. Also, if serious illness arose, un-treated serious illness was revealed, or experiencing severe pain during the interview, participants were promptly encouraged to seek urgent medical care at the nearest hospital or urgent care clinic. If they were receiving home health, they were also encouraged to contact their home health nurse immediately.

Informed consent. The University of Iowa's Institutional Review Board (IRB-02 [social sciences]) reviewed this study to ensure it met ethical standards and duly protects all participants. Approval from the IRB was obtained prior to recruitment and data collection. An exempt information letter given to all participants clearly explained the purpose of the study, benefits and risks, confidentiality, anonymity, and privacy agreements, compensation, voluntary nature of participation, and contact information for the PI and University of Iowa IRB office. Each participant was encouraged to contact the primary investigator if a question arises or s/he decides to discontinue with the study.

Confidentiality. There is a minimal risk for loss of confidentiality. Participants were asked minimal personal information; date of birth or social security number was not be asked. Surveys were anonymous and only a unique identification number was used. In addition, all survey responses were entered into database by the PI only to reduce any chances that a participant's unique handwriting could be identified or linked to their handwriting on the research compensation log. The statistician along with dissertation chair received a Microsoft Excel® sheet with de-identified data, and a second qualitative coder (Toni Tripp-Reimer [TTR]) received transcripts. A laptop designated for research only was used and electronic data and audio recordings were stored on a password protected, encrypted, and secure network drive provided by the University of Iowa. A central network administrator backs up electronic documents and files every 24 hours.

Potential benefits. Individual participants may not directly benefit from participating in this research study, but the study may indirectly increase knowledge of available pain self-management interventions. Participants may experience some personal benefit knowing that their story will contribute to the future improvement of pain self-management in other AAs. Scientific benefits of the study include increased knowledge of older AAs self-management practices and how to care for them in a culturally competent manner.

Instrumentation

Self-report surveys elicited information on participant characteristics and self-management. Any time self-report is used, there is a potential for self-report bias and socially-acceptable responses. Participants may want to demonstrate they are good self-

managers of their health and pain despite real limitations in their physical and cognitive ability; thus, they may inflate their responses specifically on socially-influenced behaviors such as exercise. To minimize this, participants were informed that there is no right or wrong response to questions. Copies of all quantitative instruments are provided in Appendices J-P in the order discussed below.

Eligibility screening questionnaire. This screening questionnaire comprises nine questions based on inclusion/exclusion criteria, which screened for race, Louisiana residence, arthritis, chronic pain duration, and cognitive status. Screening took no less than 3 minutes.

Animal naming test. To identify any cognitive impairment, participants completed the one-minute animal fluency test (Canning, Leach, Stuss, Ngo, & Black, 2004; Hanyu, Kume, Takada, Onuma, & Iwamoto, 2009); question #9 on questionnaire. In one minute, participants are asked to name as many animals as possible. The sensitivity and specificity of identifying those with dementia were 0.88 and 0.96 respectively (Canning et al., 2004). More recently, a study found the one-minute animal fluency test to have greater utility than the mini-mental status exam in identifying older adults who could reliably self-inject insulin (Yajima et al., 2014). Likewise, this screening test not only identifies those with cognitive impairment but also those who can likely engage in self-management. Naming 15 or less animals was 20 times more likely in persons with dementia (Canning et al., 2004). Others have used a cut-off of 13 animals with a sensitivity of 0.91 and specificity of 0.81 in identifying 87% with Alzheimer's disease; for mild cognitive impairment, 14 animals with 0.81 sensitivity and 0.69 specificity (Hanyu et al., 2009). Therefore, older AAs unable to name at least 15 animals

in one minute were excluded. Currently no research is available to show an income, educational, or cultural bias to this test.

Table 4- *Quantitative Instrumentation (DV= Dependent Variable, IV= Independent Variables)*

Instrument	Variable	DV	IV	Scoring
Pain Self-Management Engagement Questionnaire (PSMEQ)	Stages of Engagement (in seven OA behaviors)	X		Statements are scored 1-5; Each score indicates a different level of engagement (i.e., 1= pre-contemplation 2= contemplation, 3= preparation, 4= action, and 5= maintenance); higher score indicates higher engagement level.
	Motivation		X	0-10 Likert scale; higher score indicates higher engagement intensity in self-management
	Illness Perception (i.e., Importance)		X	1= Yes or 2= No
	Knowledge of each recommended OA behaviors		X	1= Yes or 2= No
Arthritis Pain Self-Management Inventory (APSI)	Complementary OA behaviors	X		Utilization: 1=Yes, 2= No Frequency: 1= Never, 2= Everyday, 3= Several days a week, 4= Once a week, 5= As needed, 6= Monthly Helpfulness: 1= Not helpful, 2= A little helpful, 3= Moderately helpful, 4= Very helpful

Table 4- continued

Instrument	Variable	DV	IV	Scoring
				Reason for use: 1= Helps with pain, 2= Just trying to see if it helps, 3= Prescribed by doctor or provider, 4= Recommended by family/friend, 5= All of the above
APSI	Spirituality		X	Use of any one of the 7 spiritual strategies listed on APSI; 1= Yes, 2= No
Participant Characteristics Questionnaire (PCQ)	Demographic and contextual factors		X	Varies depending on question
Brief Pain Inventory Short Form (BPI- SF)	Pain intensity and pain interference		X	Likert scale 0-10; higher scores indicate higher intensity and interference
Chronic Disease Self-Efficacy Scales (CDSSES)	Self-efficacy (i.e., Confidence)		X	Likert scale 0-10 on four symptom self-efficacy statements; scores are averaged; higher score = higher self-efficacy

PSMEQ. Developed by the primary investigator, this tool assesses stages of engagement in OA self-management behaviors, pain knowledge, confidence, skills, importance, motivation, and normative practice. For this dissertation, only stages of engagement and importance variables are used. Seven questions evaluate stage of engagement in land exercise, water exercise, strength training, pain medications, warm/cool compresses, assistive/orthotic devices, and participation in an arthritis or chronic pain self-management program. The Readiness to Manage Pain Questionnaire (RMAQ) provided the basis for responses and scoring for engagement (Arthur et al., 2009); this survey evaluated 11 arthritis behaviors which included using controlling pain, physical activity, eating a healthy diet, taking medications as prescribed, joint protection,

communicating effectively, managing stress, dealing with arthritis, learning about arthritis, managing fatigue, and getting restful sleep. Responses are derived from the Stages of Change framework- pre-contemplation (1), contemplation (2), preparation (3), action (4), and maintenance (5). Higher score indicate a higher level of engagement.

Intraclass correlation coefficients for test-retest reliability (baseline pre-intervention and 12 weeks post-intervention) was moderate for pain ($r = 0.52$), physical activity ($r = 0.66$), diet ($r = 0.58$), healthy diet ($r = 0.58$), medications ($r = 0.75$), and joint protection (0.67). There was low convergent validity between most of the behaviors, except the physical activity ($r = 0.43$) on the RMAQ when correlated with the Arthritis Self-Efficacy Scale (ASES); this is most likely because the ASES asks about efficacy to manage pain, control other symptoms, and physical function versus actual readiness/engagement in specific arthritis behaviors.

Using a 0-10 Likert scale, one question evaluates motivation level to engage in self-management. Higher scores indicate higher engagement in managing pain. Another question asks about illness perception (i.e., importance): Is managing your pain just as important as managing your other health conditions? Response options are yes or no. Open-ended questions on the PSMEQ asked about barriers and facilitators for each recommended behavior. These were coded as qualitative data.

APSI. The APSI asks about utilization, frequency of use, five levels of helpfulness (0= not at all helpful to 5= extremely helpful), and reason for use of 37 pharmacological and complementary behaviors. Participants were initially asked, “Tell me about the types of behaviors you use to help your arthritis and joint pain.” As the

participant responded, the primary investigator checked the strategy (and frequency, helpfulness, and reason for use) on the APSI. After participants reported their behaviors, they were given a list with all the APSI strategies to identify any other behaviors they may have failed to mention. Behaviors were used as descriptive data, and the two most common behaviors not captured in the PSMEQ were used to generate two regression models to determine factors that predict engagement in complementary OA behaviors. Engagement was coded as yes/no as opposed to stages of engagement in the PSMEQ. Also, a spirituality variable was created to identify those who used any one of the seven spiritual strategies listed on APSI. If participants selected one of the strategies, it was coded as yes; those not selecting any strategies were coded as no for being using spirituality. Spirituality was an independent variable included in the logistic regression models.

At the end of the APSI, five open-ended questions were asked related to self-management behaviors used in the past and being considered in the future. This data was also coded as qualitative data. From this measure several types of data can be obtained: number of, types (current and past), helpfulness, and frequency of behaviors used and reason for use.

The APSI questionnaire was derived from Davis and Atwood's (1996) 16-item PMI and Hampson (1993) et al.'s Summary of Arthritis Management Methods (SAMM) with additional items added from the self-management literature. The 16-item PMI assesses use of and helpfulness of arthritis pain self-management methods used in the past week. The PMI generates three separate scores/results: 1) an inventory of methods used, 2) total quantity of methods used, and 3) the helpfulness rating for each method

used. Content validity was evaluated by four randomly selected rheumatic specialists involved with the International Association for the Study of Pain organization. The readability of the PMI, according to the Fog formula, is 13.5 grade years.

The SAMM asks about frequency of use of 10 self-management behaviors used in the past seven days and on the day when arthritis was worse than usual. The behaviors included taking medications, low-impact activity, range of motion, joint protection, heat/cold applications, relaxation, rest, massage, splinting joints, and other behaviors (e.g., prayer, creams, etc.). Content validity stemmed from a review of the literature and consultation with medical providers (Hampson et al., 1993).

PCQ. Twenty-six questions prompted information on study response, demographic characteristics, health literacy, pain characteristics, and social support. For dissertation analysis, OA pain severity (1= mild, 2= moderate, 3= severe), number of chronic conditions, access to a provider (1= yes, 2= no), and family and social support (1= yes, 2= no) are included as predictor variables. Qualitative interviews elucidated more information on these characteristics, such as social support. Health literacy was screened using two different methods: Single Item Literacy Screener and REALM-SF. SILS is a single question tool asks “How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?” (Morris, MacLean, Chew, & Littenberg, 2006). Possible responses include: 1- never, 2- rarely, 3- sometimes, 4- often, and 5- always. Scores equal to or greater than 2 are considered positive, indicating some difficulty with reading printed health related material, with a sensitivity of 54% and a specificity of 83% (Morris et al., 2006). This cut-off captures patients who typically need help with written health material.

The REALM-SF is a 2-minute health literacy test assessing word recognition of common health terms (Arozullah et al., 2007). It asks participants to read aloud seven words: menopause, antibiotics, exercise, jaundice, rectal, anemia, and behaviors. Words pronounced correctly are marked. Scores were derived as the number of words correctly pronounced (0–7). The REALM-SF was validated in large ethnic minority and older adult populations. Results indicated that the REALM-SF and REALM instrument scores were highly correlated in development ($r = 0.95$, $p < 0.001$) and validation ($r = 0.94$, $p < 0.001$) (Arozullah et al., 2007).

BPI-SF. This nine-item multidimensional tool assesses current pain (yes/no), pain location(s), pain intensity, types and effectiveness of pain treatment, and interference with function. Two subscales are commonly used for scoring: pain intensity and interference. Worst, least, right now, and average pain intensity are measured using a 0–10 numeric rating scale (NRS; 0 = no pain and 10 = worst pain imaginable). Scoring can use a composite of worst, least, right now, and average pain intensity or “average” or “worst” pain can be used singularly to represent pain severity (Cleeland, 1991). Use of “average” or “worst” pain is supported by IMMPACT recommendations; however, the developers suggest a composite score as validation included all four pain intensity items (Cleeland, 1991). For this study’s statistical analysis, it makes sense to use a single score of average pain intensity to correlate with self-management behaviors used within the past 30 days.

This tool rates interference in seven functional areas associated with quality of life using a 0–10 Likert scale. These areas include: general activity, mood, walking ability, normal work, relations with other people, sleep, and enjoyment of life. Scores from each

functional area are averaged; sum of scores can range from 0-70. Higher scores reveal greater interference with function.

Originally developed for use with cancer patients, the BPI-SF is validated in people with OA (Kapstad, Rokne, & Stavem, 2010; Mendoza, Mayne, Rublee, & Cleeland, 2006) Cronbach's α for internal consistency of pain intensity scale ranged from 0.88-0.96 and test-retest reliability ranges from 0.67-0.87 for persons with OA. Cronbach's alpha 0.87 and there was high correlation ($r = 0.61$) with the Short Form McGill Pain Questionnaire in a racially diverse older adult sample (McDonald, Shea, Rose, & Fedo, 2009). The BPI is recommended by the Initiative on Methods, Measurement, and Pain Assessment in Clinical Trials (IMMPACT) to measure pain as a primary outcome in clinical trials (Dworkin et al., 2005), and the NRS is recommended by the NIH-affiliated Patient-Reported Outcome Measurement Information System (PROMIS). One study found the PROMIS pain intensity measure (0-10 NRS) to be a valid and reliable self-report measure in OA patients (Broderick, Schneider, Junghaenel, Schwartz, & Stone, 2013).

CDSES. Developed by Lorig and colleagues (1996) to measure multiple aspects of managing a chronic disease, the authors delineated three types of self-efficacy beliefs (to perform specific behaviors, to manage disease generally, and to achieve outcomes). The original CDSES has a total of ten subscales, each ranging from 1–10 items (Brady, 2011). Each subscale is scored separately. The managing symptoms subscale consisting of four self-efficacy statements was used. The word “disease” was replaced with “osteoarthritis” or “pain” as applicable. Each self-efficacy item is rated using a 0-10 Likert scale, range of 0-40. Ratings from the four items are averaged to result in a final

self-efficacy score. Higher scores reflect greater self-efficacy or confidence in managing OA pain symptoms. Internal consistency reliability for the managing symptoms subscale is $r = 0.91$ and 10-day test-retest reliability is $r = 0.89$.

Qualitative interview guide (see Appendix Q). To characterize patterns of OA and CJ pain self-management, 20 semi-structured, individual interviews were conducted by the PI. The interview guide was designed to elicit participant's beliefs on five content areas which were derived from a literature review (specifically identification of knowledge gaps): (1) perceptions/beliefs, (2) symptom experience, (3-4) daily and cultural self-management, and (5) self-management programs. A standardized interview guide helps ensure consistency and efficiency across interviews that can be easily analyzed and compared (McNamara, 2009). Pre-developed and response-based probing questions elicited additional contextual information for deeper understanding. The interviews concluded by asking participants if there were additional experiences, comments, or questions. Interviews lasted from 45 minutes to 90 minutes. In addition to audio-recorded interviews, field notes documenting participant behaviors and key responses and bracketing PI's reactions and thoughts were collected during each interview. Interview content was reviewed by a distinguished expert in qualitative methodology (TTR), and feedback was initially obtained from 10 participants resulting in significant reduction in number of questions.

Validity of PI-Developed Instruments: PSMEQ and APSI

Preliminary face and content validity of the PSMEQ and APSI were established with 10 AAs (50 years and older) with and without OA and CJ pain prior to

commencement of the study. Content for the qualitative interview guide and PSMEQ was reviewed by Drs. Tripp-Reimer and Wallace because of their expertise in self-efficacy and chronic disease self-management. To establish content validity, two pain experts (Drs. Herr and Rakel) reviewed the APSI. AA participants were asked about for clarity and ease of use, relevancy of content, language, overall readability of survey, and completion time. Based on comments received during the preliminary testing, the language of several questions was modified and some questions eliminated. A readability program (Readable.io; <https://readability-score.com/>) determined that the PSMEQ has a Flesch-Kincaide readability grade level of 0.6, a Gunning-Fog grade level score of 6.1, and Flesch-Kincaide reading ease of 100.2 (i.e., 5th grade reading level; very easy to read). This means the text can be read by those with at least a 6th grade education; the aim for health education questionnaires is generally between 6th-8th grade reading levels. This free readability program gave the PSMEQ an overall “A” rating. Because the APSI is a descriptive survey, test-retest reliability is not highly important.

Data Analysis Methods

Data Management

Data sources included completed surveys and recorded interviews; field notes provided additional data on participant interaction and observed behaviors as well as salient responses and initial impressions. Each data source was managed using appropriate quantitative and qualitative software.

Quantitative strand. All surveys were completed on paper by the participant or PI, and responses entered into a Microsoft Excel© spreadsheet in order to establish a

dataset for statistical analysis. Data entry verification consisted of randomly sampling 10% (n= 11) of each survey and comparing survey results to the excel database. Data were double-entered into the spreadsheet by primary investigator to ensure there were no missing data or unfeasible or numerical outliers. To minimize missing or incomplete data, responses were reviewed with participants after each survey administration. In cases of missing data, values were coded as “0” or left blank in the spreadsheet but coded “.” in Statistical Package for the Social Sciences® (SPSS, version 23.0, IBM®; Armonk, NY, USA). All excel spreadsheets were uploaded into SPSS statistical software for analyses.

Qualitative strand. There are two qualitative data sources. The first data source consists of in-depth, semi-structured interviews with a subset of participants (N= 18). The second data source include open-ended questions on the PSMEQ, asking about barriers and motivators to engagement in each of the seven recommended behaviors. All study participants were given the opportunity to report either barriers or motivators. Each qualitative interview was audio recorded with participant permission. After each interview, the PI typed up the field notes as a method to help identify when thematic saturation was achieved. Interviews were transcribed by Landmark Associates, Incorporated (Tempe, AZ; © 1987-2016), an IRB-approved transcription service for qualitative research. To verify accuracy of transcription, the PI who is AA and familiar with the Southern language used by participants, carefully compared the audio-recordings with each transcript. Each transcript was imported to HyperRESEARCH™ qualitative management software (© 1997-2016). This software was used to code and analyze data in the context of self-management. Responses from open-ended questions from the PSMEQ and APSI will also be uploaded into software. In the absence of a recorded

interview due to digital recording failure or interviewee refusal, detailed field notes will serve as the data source.

Data Analysis

Qualitative analysis. Qualitative description (QD) technique (Sandelowski, 2000; 2010) served as the primary approach to this content analysis. QD as an ‘epistemologically credible’ method was first described in detail by Sandelowski (2000), who differentiated this technique from similar analysis techniques such as interpretive descriptive. Although this method has been described as the “poor cousin” of qualitative research, it is particularly relevant to this study because it: 1) is useful for conducting mixed method studies with vulnerable populations, 2) supports culturally-appropriate and contextual-rich research, and 3) facilitates a needs assessment from the perspective of older AAs (Sullivan-Bolyai et al., 2005; Neergaard, Olesen, Andersen, & Sondergaard, 2009).

QD allows researchers to stay “close” to the data, without delving deep into interpretation of the abstract or engaging in great re-presentation of the data. Therefore, data are not over-analyzed or interpreted with a deep structure, but rather are interpreted from the participant’s point of view (known as manifest content), maintaining a high level of cultural congruency, interpretative accuracy, and emic concreteness. With QD, there is less opportunity for researcher biases to influence analysis, interpretation, and presentation of data.

Content analyses. QD analysis goes beyond simple classification (Sandelowski, 2000) and fits well with content analysis because it is more than “counting words” but

instead categorizes large amounts of data into meaningful units of knowledge and understanding of the phenomenon (Hsieh & Shannon, 2005). Qualitative content analysis uses a systematic coding scheme to identify common themes and patterns. A conventional content analysis is most appropriate as it is used when research on the phenomenon is limited, and allows the categories to emerge or flow from the data in order to either advance understanding or practice in addressing real world problems— a key outcome of pragmatic mixed-method health research. In this manner, the findings can inform an action plan to reduce health disparities, particularly those related to chronic pain self-management (Sullivan-Bolyai et al., 2005). This study, in particular, is concerned about identifying patterns of OA and CJ pain self-management in older AAs to help refine the predictive model which will provide a basis for intervention development.

Recorded interview data was the primary form of qualitative data. A systematic, multi-step approach guided coding. One of the goals is to generate new information about contextual processes impacting self-management.

Step 1: Line-by-line reading of transcripts to identify and extract meaning units of texts- any word, phrase, or paragraph with related content, context, and communication tone. Coding also looked for metaphors, analogies, indigenous terms, linguistic connectors, and repetitious terms (Ryan & Bernard, 2003).

Step 2a: A list of categories (open coding, *a posteriori*) from transcripts and field notes and closed codes (*a priori*) based on the literature and the coders' (SB & TTR) knowledge of the variables and facts about the phenomenon was initially developed.

Step 2b: A list of definitions for initial codes were developed to guide consistency in coding and reduce discrepancy in code meanings.

Step 3: Related categories were collapsed (axial coding) based on their relatedness.

Step 4: These categories were then sorted and grouped into meaningful clusters to derive textual description- the goal of QD. Some propose developing 10-15 clusters (Hsieh & Shannon, 2005). Care was taken to use participants' language in naming cluster themes in order to reduce imposing author bias on the data and maintain an emic description.

Step 5: Transcripts were re-read to choose appropriate exemplar statements for each final cluster.

Standards for rigor. Standards for qualitative research generally encompass ensuring credibility and trustworthiness of the data. Credibility was ensured through triangulation and member-checking that provided feedback on the cultural relevance and accuracy of interpretation of data. Using QD as the qualitative analytic method safeguards minimal re-presentation of participant's views (Sullivan-Bolyai et al., 2005), which attends to confirmability.

Trustworthiness in qualitative research (Lincoln & Guba, 1985) and legitimation (equivalent to trustworthiness, validity, and reliability) in mixed-methods research (Onwuegbuzie & Johnson, 2006) was established through iterative engagement with the data. A second expert, either secondary chair or outside expert on OA and pain in older AAs, randomly coded and reviewed 25% of transcripts ($N \approx 5$) to establish agreement or

inter-coder correlation. Discrepancies or disagreements were resolved through discussion until a consensus was reached.

Quantitative analyses. Descriptive statistics were also computed for Aim 1 and regression techniques were applied to Aim 4.

Descriptive analysis. Sample characteristics and study variables are summarized using descriptive statistics: mean (\bar{X}) and standard deviation (SD) for continuous variables, and frequency (N) and proportion (%) for categorical variables. Data were examined for integrity that includes linearity, outliers, and missing data (random or systematic).

Initial regression models revealed a large number of cells with zero frequencies given the distribution of categorical variables on some levels of the dependent variable. In an attempt to correct the issue, (1) the 5 stages of engagement were collapsed into 3 stages, (2) continuous variables were transformed into standardized z-scores, now each variable has a mean of 0 and standard deviation is 1, and (3) some categorical variables were dichotomized and dummy coded (e.g., education, employment). This technique allows for a more clear interpretation about individual values within the distribution of values and helps to stabilize the variance.

Bivariate analysis. Spearman (ordered variables) and Pearson (continuous variables) correlations between outcome and predictor variables show the nature or polarity of relationships (i.e., negative or positive), strength of the relationship, and significance. Correlation coefficients of 0.10-0.29 represent a small association, 0.30-

0.49 represent a medium association, and 0.50 and above represent a large association. Significance was considered at 0.05 and 0.01.

Multivariate analysis. Two methods were used to analyze predictors of engagement in pain self-management.

Method 1. Because the outcome variable is analyzed as categorical levels, generalized linear models (GLM) using multinomial logistic regression is appropriate. Multinomial logistic regression is a predictive analysis that describes the relationship of one dependent variable with one or more independent variables. The results determine the odds of an event occurring. Selection of predictors in any logistic regression model should be based on a theoretical framework or an evidence base (Polit, 2010). Predictor variables not reaching significance were not entered into the multivariate analyses. While $\alpha = 0.05$ is the default and traditional p-value used in research, there is a risk for Type I error (determining a finding as significant when it may have occurred by chance or systematic error). Conversely, conservative alphas below 0.01 increase the risk for a Type II error (concluding a finding as insignificant when in fact it may not be) (Jensen, Turner, Romano, & Lawler, 1994; Polit, 2010). We expected the final model for each recommended behavior would explain at least 30% of the variance in self-management engagement. The likelihood ratio test (i.e., chi-square goodness-of-fit) indicated the significance level of the overall model (i.e., whether all the predictors together better predict the probability of the outcome vs. chance), and the Wald statistic provides significance of each individual predictor in the model. Thus, reporting consisted of $\beta(\text{SE})$, overall model significance, Nagelkerke R^2 (a pseudo- R^2), goodness of fit, and classification summary percentage. An alpha of ≤ 0.05 is considered significant.

Method 2. Predictors of the two most frequently used complementary behaviors were determined using GLM, binomial logistic regression approach. Unlike multinomial logistic regression, binomial logistic regression dependent variable has only two categories. Statistical reporting was the same as Method 1 above.

Integration of Quantitative and Qualitative Analyses

Mixing of quantitative and qualitative data sources provides a mechanism to make meaningful inferences based on multiple perspectives of the data and to construct explanations based on convergence or divergence of data sources. Specifically, triangulation, or ‘across-methods’ technique (Bekhet & Zauszniewski, 2012), identified how the qualitative themes agree/support or converge/diverge with quantitative findings and vice versa. Thus triangulation was used as a cross-validation method and a construction approach to ensure comprehensive understanding. For example, qualitative interview responses provided more in-depth data on self-management practices and processes to support and explain results from the APSI and PSMEQ. Hence, a greater understanding of pain self-management is gained by “mixing” the statistical results with qualitative findings (Creswell & Plano Clark, 2011).

A mixed-method approach allows additional potentially key factors specific to AAs to emerge, and these factors were used to refine the predictive model. In addition, collecting both quantitative and qualitative data illuminates gaps that need further research, as well begin development of culturally-responsive symptom science. Then factors identified that limit and facilitate self-management can guide how the intervention is designed, implemented, and disseminated.

Innovation

The impetus for my inquiry is in response to the IOM's (2011) *Relieving Pain in America* report, (commissioned by the Affordable Care Act's *National Pain Care Policy Act* 2010), and the National Pain Strategy (Interagency Pain Research Coordinating Committee, 2016) calls to improve pain care and reduce disparities in diverse populations. The proposed research also supports the National Institute for Nursing Research's strategic mission to improve self-management and clinical outcomes for older adults. The results of this study are set to improve understanding of chronic pain self-management in older AAs, a population that is under-researched. This study has the potential to identify within-group disparity patterns related to older AAs' self-management and to guide future symptom science and comparative effectiveness research between tailored self-management interventions, usual self-management care, and standard of care. Tailored self-management can also reduce morbidity and patients' and taxpayers' dollars.

Summary

A convergent, parallel mixed-methods study explored factors associated with OA and CJ pain self-management engagement in a population of community-dwelling older AAs. As a mixed-methods study, careful attention to both quantitative and qualitative methods is critical. A predictive model using regression analyses and a descriptive content analysis are presented in the next chapter.

CHAPTER 4: RESULTS

The purpose of the mixed-methods research investigation was to understand real-life contextual patterns, preferences, and predictors of self-management in older African Americans with OA and CJ pain. For reader recall, the four aims are presented below:

1. Describe current patterns of OA and CJ pain self-management in a sample of older AAs.
2. Determine which model variables (contextual and process) predict stage of engagement in (1) seven recommended self-management behaviors that provide immediate and long-term relief for OA and CJ pain and (2) two most commonly-used complementary self-management behaviors for OA and CJ pain.
3. Describe barriers and facilitators to engagement in the recommended behaviors for OA.
4. Discover older AAs' preferences for culturally tailoring interventions to promote engagement in OA and CJ pain behaviors.

This chapter is dedicated to reporting the findings from quantitative and qualitative analyses. Two data sets were used: quantitative survey data (N= 110) and qualitative interview data (N= 18); qualitative interviewees were sampled from the quantitative participants. Aims 1, 3, and 4 use both quantitative and qualitative data sets, and aim 2 uses the quantitative data set. First the sample characteristics for each quantitative and qualitative strand are presented followed by the results of each aim.

Demographic Characteristics

Quantitative Sample Characteristics

Over the course of nine months, 153 African Americans expressed interest in the study, but 43 were excluded due to ineligibility, declination, or inability to contact by phone or in person. Data were collected on 110 African Americans (see Table 5) who ranged in age from 50-94 years, where the average was 68.44 years ($SD= 12.37$). Participants were mainly from Jonesboro/Hodge ($n= 45$, 40.9%; rural) and Shreveport ($n= 39$, 35.5%; urban) Louisiana, and the remaining 26 (23.6%) resided in surrounding areas. Women ($n= 90$; 81.8%) were an overwhelming majority, with only 20 (18.2%) men participating. Sixty percent of African Americans ($n= 67$) were not married. Unlike previous studies' samples, 50% ($n= 55$) of AAs in our sample had a high school education with/without some college while 39% ($n= 43$) had a college or graduate degree and only 12 (10.9%) did not complete high school. Over 70% ($n= 79$) were unemployed due to disability or retirement, and 28.2% ($n= 31$) were currently employed. Most participants reported their income was just enough to pay bills and buy necessities ($n= 71$, 64.5%), while only 21.8 and 12.7% reported their income was not enough or more than enough respectively. However, nearly all ($n= 106$, 96.4%) had access to a provider and some form of health insurance coverage, many having Medicare. While it is expected that most older AAs have Medicare and/or Medicaid, the literature is replete with evidence that many AAs typically lack health insurance. Greater availability to private health insurance through the Affordable Care Act's Marketplace and expansion of Medicaid in participating states, such as Louisiana, may help explain the high proportion of AAs with health insurance.

Table 5- Demographic Characteristics

Demographic Characteristic	Frequency	%
Gender		
Women	90	81.8
Men	20	18.2
Education		
< High School	12	10.9
= High School/GED	31	28.2
= Some college	24	21.8
= College degree	25	22.7
= Graduate degree	18	16.4
Health Literacy (REALM-SF)		
0/7 words pronounced/did not complete	2	1.8
2/7 words...	3	2.7
3/7 words...	6	5.5
4/7 words...	8	7.3
5/7 words...	15	13.6
6/7 words...	15	13.6
7/7 words...	61	55.5

Table 5- continued

Demographic Characteristic	Frequency	%
Income		
Not enough to pay bills and buy necessities	14	12.7
Just enough...	71	64.5
More than enough...	24	21.8
Marital status		
Married	43	39.1
Not married	67	60.9
Employed		
Yes	31	28.2
No	79	71.8
Residence		
Jonesboro-Hodge	45	40.9
Shreveport	39	35.5
Other	26	23.6
Health Insurance		
Yes	106	96.4
No	4	3.6

Pain Characteristics

Table 6 provides an overview of pain characteristics in AA seniors. Most participants rated OA pain severity as moderate, with an equal split for mild and severe.

According to the BPI-SF, “average” pain intensity was 5.47 ($SD = 2.02$), with “worst” pain intensity an average of 6.85 ($SD = 9.35$) and “least” pain intensity 3.07 ($SD = 2.32$). Eighty-nine (79.1%) reported experiencing pain “today” (i.e., day of interview), for a mean pain “now” of 3.77 ($SD = 3.02$). On average, participants reported having pain 12.19 years. The majority of older AAs had multi-joint OA ($n = 88, 80.0\%$), while only 22 (20.0%) reported OA in a single joint. The most common sites for multi-joint OA were hands, shoulders, knees, and low back. Single-joint OA mainly affected hands only, knees only, and shoulder only. Although the majority had OA in multiple joints, average pain interference score was relatively low for this sample ($\bar{x} = 3.53, SD = 2.58$), likely because many participants rated items such as interference with mood, social interaction, and normal work as 0. Slightly less than half had other pain conditions such as carpal tunnel, rheumatoid arthritis, gout, fibromyalgia, acid reflux, and sciatica.

Table 6- Pain Characteristics

Pain Characteristic (N =110)	Frequency	%
OA pain severity		
Mild	25	22.7
Moderate	66	60.0
Severe	19	17.3
Pain persistence		
Constant	40	36.4
Intermittent	70	63.6

Table 6- continued

Pain Characteristic (N =110)	Frequency	%
Pain today		
Yes	87	79.1
No	23	20.9
Pain location		
Single joint	22	20.0
Multi-joint	88	80.0
Number of other pain conditions		
0	66	60.0
1	25	22.7
2	11	10.0
3+	8	7.3
	Mean	SD
BPI-SF		
Average pain	5.47	2.02
Worst pain	6.85	9.35
Least pain (N= 108)	3.07	2.32
Pain now	3.77	3.02
Pain interference	3.53	2.58
Pain duration (years)	12.19	11.71

Qualitative Sample Characteristics

A total of 18 participants, 9 women and 9 men, took part in semi-structured interviews, each lasting between 38-107 minutes. Participants ranged in age from 50-85, and average age was 67.9 years. Because participants were matched on maximum variation criteria, age, education, and pain severity did not differ between men and women. Table 7 provides additional demographic information on the interviewees.

Table 7- Additional Interview Participant Characteristics

Participant	Residence		Pain Persistence		Time of Interview	
	Rural	Urban	Constant	Intermittent	AM	PM
UI007		X		X	X	
UI008	X			X		X
UI009	X		X			X
UI018	X		X		X	
UI029	X			X		X
UI030	X			X		X
UI031		X		X		X
UI057	X			X	X	
UI060	X			X		X
UI061	X			X		X
UI075		X	X			X
UI081	X			X	X	
UI093		X	X			X

Table 7- continued

Participant	Residence		Pain Persistence		Time of Interview	
	Rural	Urban	Constant	Intermittent	AM	PM
UI094		X	X			X
UI097		X	X			X
UI098		X		X		X
UI099		X	X			X
UI108	X		X		X	

Aim 1: Describe current patterns of OA and CJ pain self-management in a sample of older AAs.

Qualitative and quantitative data were used to explore this aim. Qualitative results are presented first, then quantitative results. Data were analyzed using an inductive, conventional content analysis with a qualitative descriptive overtone by two researchers (PI and Dissertation chair [TTR]). Older AAs shared their experience with OA and CJ pain by focusing on their perceptions, daily symptom experience, personal self-management practices, cultural self-management, and support needs for a self-management program. Responses to questions within each of these a priori meaning units guided open coding. The process began by open coding two transcripts to develop a general hierarchical coding scheme- the major categories. Coding areas of disagreement were discussed until consensus was achieved. Observations and content linkages between participant responses were coded to form sub-categories. Similar sub-categories were sorted and clustered under major categories. As additional transcripts were read and

coded, the scheme was revised until no new major categories and sub-categories emerged. Based on the major categories, patterns of OA and CJ pain self-management were derived. The thematic overtone of each pattern was summarized with a representative phrase from the participants' narratives and was used as a heading. Care was taken to present 'themes' from an emic (insider) perspective. Multiple readings of the transcripts were performed to identify exemplar texts for each major category.

“Dealin’ with It”: Patterns of OA and CJ Pain Self-Management (Qualitative)

An overall theme of “dealing with it [pain]” characterized the total experience of pain self-management in older AAs. Participants repeatedly spoke about “dealin’ with pain” on their own, typically with comments such as *“I deal with it myself”* (UI008) or as *“...somethin’ you gonna have to learn, anybody, to do on your own”* (UI007). “Dealin’ with pain” was viewed as a personal activity, and as a perceptual process, encompassed cognitive-evaluative and affective-motivational dimensions. The subjectivity was entirely dependent on the individuals’ experience as well as how they communicated this experience in their narratives. Major sub-categories for “dealin’ with it” are (1) bearing the pain, (2) understand OA pain, and (3) experiencing pain. “Bearing the pain” exemplified ways older AAs expressed and experienced pain. “Bearing the pain” had three minor sub-categories: revealing pain, tolerating the pain, and accepting pain. Participants dealt with OA and CJ pain as they understood the nature of OA, and “understanding OA pain” was the second major sub-category, and had three minor sub-categories: nature of OA, perceived causes and risk factors for OA, and causes of pain. The third major sub-category, “experiencing pain,” was best depicted through minor categories: development and progression of OA pain, coping, and others’ perceptions of

their pain. Living with pain also involved controlling the pain, whereby participants described not only personal self-management practices, but also what it meant to engage providers in professional management. Figure 4 provides a schematic of major and minor categories.

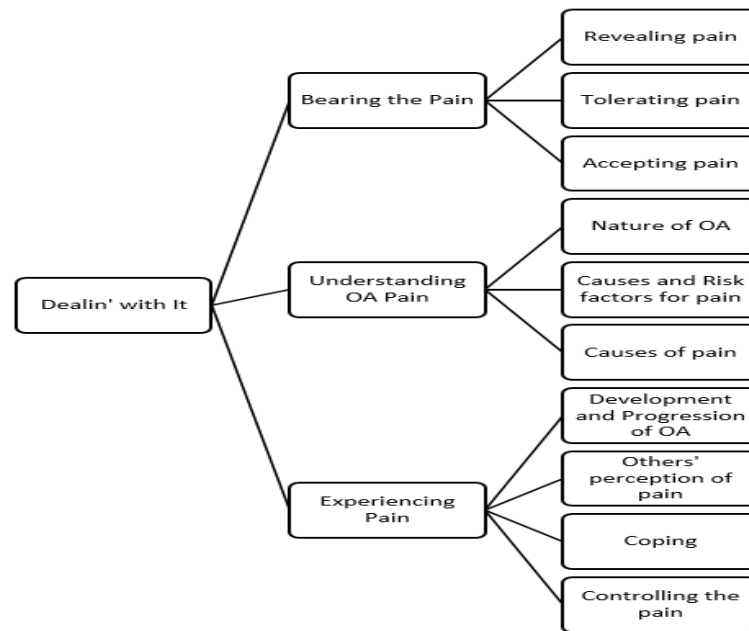


Figure 4- Major and Minor Qualitative Categories

“...Just bear it and go on”: Bearing the Pain

There were several ways in which AA older adults expressed bearing the pain. Bearing the pain was fueled by the prohibitive norm of not revealing pain, tolerating the pain, and accepting/un-accepting pain. The extent to which AAs “*put up with it [pain]*” (UI081) was different and influenced by their capacity to tolerate or accept the chronicity of their condition.

Not revealing/Not disclosing pain. One notation of bearing the pain meant keeping pain to oneself since some did not feel comfortable talking to others about their

pain and suffering through it. It was common to hear older adults discuss their personal silence as they hid pain from others. One man commented,

Interviewee: *Yes. We just don't like people to know we in pain—*

Interviewer: *Yeah.*

Interviewee: *- or suffering.*

Interviewer: *Yeah. Yeah.*

Interviewee: *I just deal with it and go on. (UI108)*

Most men did not share their pain with others, not even their wives who also suffered with OA (UI057, UI081, UI108): *“That's just normal. A man has a way of not goin' to—it's a man thing. He don't want people to know he in pain, or he's sufferin' in any kind of way, so he just bear it and go on. I try to hide it from my wife this year. [laughter]”* (UI081). They viewed this as complaining or a sign of weakness. This was evident as one participant spoke about her boyfriend who also suffers with chronic pain: *“That tickles me when people come. It tickles me that it don't tickles me how people come. ‘Oh, I got this pain. This hurtin’. That hurtin’.’ I just be wantin’ to look at them like—if you was in my body, you would want yours back...”* (UI018). When participants spoke about their pain to their significant others, it was viewed negatively as complaining. Yet when the significant others mentioned their pain, the significant other did not view it as complaining (UI018, UI009). Inferred from participants' statements, there was a double-standard: women complain and men simply express their feelings.

However, there was still this underlying belief among both men and women that pain is not a topic for conversation. One man in particular found it acceptable to share his pain, but also noted that his male friends did not share his same belief. For women, they didn't mind if others, such as close family or friends, knew they were in pain. In fact, they mentioned that if others knew they were having pain, then they could help in some way, either by praying or offering treatment recommendations. Some felt that discussing pain "*wouldn't make them hurt any less*" (UI009) or "*feel better*" (UI094), and that they would "*still be hurting...*" (UI081) if they shared their pain with others. They did not find talking about pain to be a helpful emotional outlet.

This distinct cognitive dissonance between not caring if others knew they were in pain, but not talking about pain per se' was illustrated in a typical response. Instead of mentioning pain, participants might say, "*I don't feel good today.*" (UI031, UI075). "*I got to the point when people say, 'How you feeling? How you doin'? I'm in pain all the time, but I don't let them know*" (UI097). Most AA women felt it was important to let their friends know how they felt so that friends would not believe they didn't want to be bothered or acting different or "funny." Nevertheless, older AAs were compelled to say, "I feel alright," "I feel okay," or "I'm fine."

Participants recalled how relatives no longer living modeled this norm by suffering in silence, never talking about pain or visiting provider about arthritis (UI108). In particular, one participant discussed the historical origin behind hiding pain:

"I think a lot of us Black, African Americans, I think a lot of ours is pride. A lot of ours is pride. We don't want no one to know. We can't blame that on self, though. It was instilled in us, cuz if you think about it, back in the slavery, they had to do

what they had to do. They had to hold it in in order to survive. That's what a lot of ours is. We can be in 99—we can be in pain, but we know we got to get this job. We got to do the job so we can take care of our family. We gonna suffer through this pain. We ain't gonna let nobody know it" (UI018).

Another participant similarly discussed how his grandmother dealt with pain.

"She didn't mention it. My grandma, oooh—because she saw it as weakness She was dragging everything, dragging that cotton sack with two childrens on it. "Yeah, I seen you dragging them children with that cotton sack?" Well, whoo! We got arthritis from our folks. ... It's genetic. They shouldn't have kept us in the dark" (UI099).

Tolerating the pain. Others had no choice but to bear pain especially when treatment resources are limited. Lack of financial resources or challenges with insurance were clear barriers in access to care. When lack of money prevented purchase of medications, creams, or other treatments such as physical therapy or surgery, older AAs were forced to “deal with pain” with the resources they had.

"As a matter of fact, I told you I had a bottle of that Tylenol PM. I was talkin' to this brother that is right over here. He's right here on the first floor. I was tellin' him, "Man, I was in so much pain the other night, I didn't know what to do. I didn't have anything to take." He said, "What did you take?" I said, "Tylenol PM." He said, "Sit right where you are." He went and got me a whole bottle. I told him, "Man, I don't know how to tell you how much I appreciate." I says, "Cause I ain't

got no money." [Laughter] Okay? If I got pay, it's just somebody got to deal with it. It's that simple." (UI098)

Bearing pain is not the ideal method to manage pain, but was either a voluntary choice or involuntary outcome. Some chose to just suffer through the pain without medications, and this sentiment was reflected by other HOPE participants not interviewed. Others, due to disparities in access and other limiting factors, were sometimes forced to suffer with pain.

Accepting pain. Thirdly, "dealin' with pain" involved learning "...to accept it and try to deal with it the best way they can" (UI008). Because most had lived with pain for a number of years, they've accepted that they have pain and typically expect pain on a daily basis. As one man exclaims, "...Cuz when the good Lord say, "Well, I'm gonna give him a little peace today," and then that peace'll scare you because you don't feel that pain. You think something else wrong now because like you said earlier, I done dealt with it so long that I've adjusted myself to the pain" (UI094).

Accepting arthritis and pain can be viewed as a positive or negative coping mechanism. It is positive when an individual accepts they have a chronic condition, and actively engages in behaviors to manage and prevent the progression. On the other hand, a maladaptive form of accepting arthritis leads people to believe that it can't be prevented or controlled. Participants frequently mentioned past family members who had arthritis, specifically parents, and because of the genetic link, they expected they too would develop arthritis. One older woman beautifully characterized this as "disbelief" (UI075). She says, "I think it's those. I think, number one, I think it's the knowledge, no motivation, and number three, just really disbelief. ... Disbelief in that, since the father

had it, the cousin had it, and everybody in the family had it, now it's my turn. ...There's nothing I can do about it. That's the worst kinda thought. I just do believe that a person could have, because technology and medicine and everything is so changed. ... I think, for us, it's hard getting out of our comfort zone, because other people say it's not gonna bother you. Your mama had it. This is something we have to learn to care for, you know. Then, we just get comfortable with it, and don't know that the comfortableness of it can kill us, too, and make us cripple. Make us cripple. It's different. It really is, because I think that there are times when we just accept bad things, even if it's about our health. We just accept it..." (UI075). As a result, the negative sense of accepting arthritis is detrimental to the health of AAs in general because these individuals often are not proactive or active in self-management

On the contrary, a few participants reported how some in the Black community have not accepted that they have arthritis, which also is harmful in its own way. *"Some people are not in the place where they want to admit that they have— [are having problems]"* (UI057). One participant explains, *"A lot of times, a lot of people, I just—they amazes me. People actually, especially us Africans. Now White folks, they gonna own up to this. They just keep on goin'. They gonna own up to theirs and keep on goin' and do what they gotta do to—I think a lot of us Black, African Americans, I think a lot of ours is pride. A lot of ours is pride. We don't want no one to know"* (UI018). This gives credence to the AA-specific colloquial term of "not claiming" a disease or condition (UI007, UI018).

Because everything that I confess in him is what comes to pass. When I was ignorant of some things and I confess what they told me, that's what happened to

me. When I started to confessin' the word of God, when I go in and talk to doctors, I don't tell them I have this. They think I'm crazy. I'm diagnosed with it, but I don't have it. They look at me and they say, 'What do you mean?' I say, 'I'm a child of God. I believe in healin'” (UI007).

As demonstrated by participant UI007, “not claiming” OA took on a spiritual meaning, but another participant credited this belief to pride (UI018). *“Even if they can accept it or not. It's [pain] definitely real”* (UI099). In either circumstance, this sentiment of accepting/not accepting arthritis is a major part of how older AAs deal with pain.

Learning to accept pain did not mean dwelling on the pain. When asked “Is it something that's always in the back of your mind?”, one woman responded, *“No, no, no. I got it. I gotta deal with it.”* (UI018). There was an implied relationship between dwelling on pain, by thinking or talking about it, and pain severity. It was suggested that dwelling on pain actually intensifies the pain severity because you are giving power to the pain. Thus, it is important to get your mind off pain by continuing to be active and not letting the pain “stop them” in any aspect.

“...Usually, once I get up and get busy, I mean it just—the next thing you know, the pain is gone. I don't dwell on it. I don't dwell on it... Of course, keeping up, not falling behind in that walking, that particular kind of activity, and doing something, keeping my mind alert and active. I think all of that works well. I belong to about three or four groups, doing something three times a month with them. And so I think, if you're active, you don't focus—I don't focus on the arthritis. I don't focus on my high blood pressure. I know I have it, so I take my

medicine, do the blood pressure checks, do the glucose checks, but I don't just like "oh, I can't go today cuz I'm gonna get sick". No, I'm not gonna get sick. I'm gonna go because I'm well. I keep saying that. I think, the more I say it, I think the better it will be for me." (UI075)

Interviewer: *"Then, not talkin' about it, you just don't wanna dwell on it, or—"*

Interviewee: *"No. You know sometimes, when you don't think about something, it doesn't bother you as bad"* (UI081).

Distraction from OA pain was attempted by trying *"to take off my thinkin..."* (UI018) or ignore pain (UI099), they acknowledged the thought was still there because *"you're so used to having it, it's a thought in mind... pain is in the mind and brain"* (UI094). Learning to get their minds off pain is a complex coping skill that significantly influences older AAs ability to be in control over pain. Accepting or not accepting pain is contingent upon how older AAs understand the nature and progression of OA as a chronic condition.

"It's a Down Syndrome": Understanding of OA Pain

The second dimension of "dealin' with pain" involved understanding the OA pain. While some believed arthritis was just *"something that people have"* (UI018), others recognized it as a *"down syndrome"* (UI094) impacting their physical and mental performance. A few older AAs did reveal a lack of a good understanding, but this was not representative of the majority. Most had some understanding of OA, typically acquired from their personal experience rather than formal education. As a result, they dealt with arthritis as they understood and interpreted the chronic condition. By speaking about their

immediate thoughts about pain and their beliefs about OA and CJ pain, “dealin’ with pain” was uniquely revealed in their understanding of the nature of OA, causes of and risk factors for OA, and causes of pain.

Nature of OA. Participants discussed the nature of OA and CJ pain from a personal and global perspective. Older AAs’ understanding of the nature of OA can be grouped into three categories: demographic association, disease characteristics, and functional impact. Each of these categories were described by participants in more detail.

Demographic association. In terms of demographic impact, a prevalent belief that emerged was that pain is pain, no matter your race or age. They believed that pain can affect anybody. Based on participants’ response, a definition for OA pain is a natural pain that is race-less and age-less and is caused by joint degeneration, inflammation, and nerve irritation.

“Because, to me, you need to understand that it just doesn’t afflict you. You need to understand that it afflicts all people. It don’t have no color barrier. Cuz anytime babies are born with RA, have you ever seen a two-year-old on a walker tryin’ to learn how to walk?” (UI007)

Participants believed pain is pain no matter your race, but in the same breath recognized racial variation in pain experiences, such as development of OA pain and disparities in its treatment and self-management. The universality of pain divergently represents the cultural diversity of pain.

Interviewer: *Basically, cuz you said something that somebody else had also told me. Was that basically when it comes to, I guess, arthritis pain, we're all the same, because pain is pain.*

Interviewee: *Pain is pain.*

Interviewer: *Yeah.*

Interviewee: *To me, I feel like it's not a culture. Pain is pain. Only reason why us as a culture suffer from it worser is because we have to work harder. That some of us back then, say our age, we had to work physical labor. It's gonna carry on back, cuz we was on our feet more than they was. You got some of them that was, too, now. I'm not knockin' them neither... Basically really and truly, like I say, we all the same. We all have arthritis just like they have arthritis. It's no difference. Arthritis to me, arthritis is arthritis. Pain is pain. It don't matter what color your skin. Only reason we have more of it is because what we had to go through"*
(UI018).

Disease characteristics. Another way older AAs demonstrated their understanding of OA was to describe the disease-specific characteristics of OA. These included chronic, incurable, irreversible, varying levels of severity, progressive, painful, unpredictable/sudden pain onset, and location non-specific. *"Well, to me, it's a down syndrome cause it ain't no cure. There ain't no reversibility to. It's a lot of suffering. ...so it feel like I'm being abused"* (UI094). Because there is no cure for OA, *"once you get it, I think it'd always kind of be with you, but you can do things to make it ease up on you sometime"* (UI029). The chronicity and severity often becomes problematic, both physically and mentally.

Functional impact. Particularly, older AAs discussed their understanding in the context of how it affects them physically and mentally. As one participant put it plainly, *“it takes hold of the body and gives you problems, no matter where it’s located on in the body”* (UI081). In all sense of the word, OA was problematic for AAs- causing issues with mobility, range of motion, sleep, activities of daily living, and work. *“I know it affects you, especially your movement. Even affects you physically and emotionally because you be in so much, you be in pain. Then it restricts you from doin’ the things that you like to do and you used to do and that can cause problems. It’ll make you cranky, irritable. [Laughter] That’s basically the only thing I really know about arthritis, that it affects you a lot”* (UI018). Having OA resulted in changes in functional status and ability perform basic and instrumental activities of living. Participants described not being able to *“function quite like you ordinarily would”* (UI108), making certain tasks challenging (UI098, UI097). Limited range of motion and mobility often created concerns about safety.

Participants even found it difficult to engage in leisure and pleasurable activities. As one older woman said, *“I sit and look back over my life and wonder. I didn’t think this day would come when I was younger, but I say now, just look at me now. Things I used to could do, can’t do ‘em now. Yeah, I used to have a garden, beautiful garden”* (UI030). Similar statements were echoed by others (UI093).

Changes in function were not limited to physical ability, as some discussed the impact of pain on mental function, their attitudes, and mood. *“You’re already dealin’ with enough emotionally, mentally when your whole life has been flipped upside down and you don’t know and it’s somethin’ you know is uncureable...”* (UI007). AAs reported

feeling irritable, not wanting to be bothered, or depressed. Two female participants specifically mentioned feeling self-conscious about their gait, walking with bowed legs and a limp (UI009, UI057). Though none mentioned that they personally have considered suicide, they did discuss how pain may initiate suicidal thoughts in others, especially those without strong faith (UI007, UI061, UI094). It was noted that suicide was an option but not for them. This “othering” or third person reference may be a way in which participants reminded themselves of how blessed they are to be alive even though they have persistent pain. When the PI mentioned the relationship between depression and suicide, one man quickly responded, *“You ain’t really got to be depressed to think of suicide”* (UI094).

These changes in physical and mental function elevated the level of the seriousness, causing an underlying fear of losing independence and some dispiritedness. The corollary between maintaining physical function and independence was strong (UI007, UI075). In the words of one woman, *“It’s very serious because it determines whether I do take care of myself and life I would have. I mean it’s a difference between bein’ able to walk, bein’ able to do things on your own”* (UI007). Overall, having OA affected their quality of life. Not only were social relationships compromised, but also personal relationships. A lady recalled how as a young women that she was engaged to a minister, but his lack of compassion for her physical limitations ultimately caused their split. *“You’re already dealin’ with enough emotionally, mentally when your whole life has been flipped upside down and you don’t know and it’s somethin’ you know is uncureable and supposed to be. People are just not there”* (UI007). Despite the mental

consequences associated with living with chronic OA pain, several described the need to be strong and maintain a positive attitude.

Causes of and risk factors for OA. Participants named 10 causes of OA: aging, cause and risk factors are unknown, degenerative joint disease, fat accumulation, genetics/family history, inflammation of joint, lifestyles, spiritual attributions, surgery, and wear-and-tear/stress on joints. The two most common causes were lifestyles and wear-and-tear.

Lifestyles. The most common response was the effect of lifestyles (15/18 participants); that is, occupation/hard labor, neglecting health, stress and adversity, overweight, and injury. Diet was the most commonly attributed, eating red meat, salt and fat intake, and less water. One man identified several lifestyle factors, *“Maybe working on the railroad and in the oil field, in all different types of weather, and probably not eating a good diet, especially a diet that had a lot of fruits and vegetables and stuff like that. Yeah, I’m like a carnivore. That’s what I’m trying not to be so much of now”* (UI061). Some who were unable to identify a cause of pain were able to identify risk factors. For example, one gentleman commented, *“Now the cause is unknown because you got so many different types,”* but later mentioned genetics, types of food, not exercising, and chronic illnesses as risk factors for arthritis (UI094).

Wear-and-tear. Wear-and-tear/stress on the joints was the second most common response (10/18 participants), and this category is closely related to lifestyles. The wear-and-tear was a result of hard physical labor (e.g., construction, housekeeping, nurse’s aide), standing on concrete for extended periods of time, work- and sports-related

injuries. Often this type of overexertion was summed up as “overworking” and “overdoing ‘it’ or the ‘body’s capacity.’”

Causes of pain. The causes of pain are those things which trigger the development or onset of pain. The range of causes attributed to pain were quite similar to those ascribed to OA. Additions were that pain was caused by nerve irritation, an irritant in the body, and a natural bodily process. In total, participants named 7 sub-categories of causes: inflammation, irritant in/to the body, nerve irritation, pain comes naturally, stress, wear-and-tear on joints, and weather and temperature changes. A few were unable to pinpoint a cause, and wear-and-tear on joints, weather and temperature changes, and nerve irritation and damage were the most frequently conveyed causes.

Wear-and-tear on joints. Wear-and-tear took on a similar mechanism for cause of pain as did for cause of OA. Participants noted that mechanical stress from over-working the joints and muscles led to pain. “*Tak[ing] my body a little beyond what it’s capable of doing*” (UI061) through excessive activities such as over-exercising and physical labor, and being overweight contributed to pain.

Weather and temperature changes. Several older AAs were convinced weather impacted their pain, “*I truly believe too that weather plays a part. I’ve always heard that, and I believe that*” (UI009). From the example quote, the perception of the weather’s effect on pain was formed either through personal experience and/or from the social influences. On the other hand, others did believe weather played a part in their OA pain, but the strength of their belief was not as strong.

Interviewer: *Today it was raining outside. Does that affect you at all?*

Interviewee: *Sometime I think it do.*

Interviewer: *Yeah.*

Interviewee: *Sometime I think I do. I'm not sure. (UI057)*

Particularly, cold weather and rain were considered triggers for inducing pain. Interestingly, they used the onset of their pain to determine if it was going to rain or drop in temperature. This lay ethnomedical belief is common in AA culture- using changes in health status or severity of symptoms to predict weather changes. Of the participants responding, only one felt that warmer weather made the arthritis worse.

Nerve irritation. Three participants were knowledgeable about the involvement of nerves in pain transmission and perceptions.

Interviewer: *What do you think actually causes the pain?*

Interviewee: *Well, nerves.*

Interviewer: *Damage to your nerves?*

Interviewee: *Yeah. Well, no. Nerves, pain goes through nerves, and nerves go through from the brain.*

Interviewer: *Oh, I see what you're saying.*

Interviewee: *"They come out of the brain which kicks on the pain. Cuz if you can block pain in the brain, then you won't feel it in the body. That why they give you more of this narcotic type medication to cover the pain up." (UI094)*

They further demonstrated some mechanistic knowledge by discussing the use of anesthetics and nerves. In particular, they talked about how some OTC creams and medications are now infused with lidocaine (UI009, UI093). Fewer people may understand the role of nerves in pain perception because they believe pain comes naturally. Understanding the causes of OA and CJ pain intricately influenced their daily living with pain.

“Something you have to live with...”: Experiencing Pain

The third theme of “dealin’ with it” was “experiencing pain.” Participants described OA and CJ pain as “...*something you have to live with, I guess*” (UI030) whether it is intermittent or persistent. Such statements highlight older AAs’ nuanced perceptions of chronicity. By accepting this as ‘something you have to live with’, they shape their own experience either in a positive or negative manner. Although living with pain has commonalities across people, older AAs were quick to suggest that every person’s experience and pain is different and unique. Though many recognized the reality of mental health consequences, maintaining a positive attitude was important. Their experience of “living with pain” included rich descriptions of development and progression of OA pain, coping, and others’ perceptions of their pain.

Development and progression of pain. Developing pain was a pre-cursor to living with pain. The progression of pain was viewed in terms of the level of worsening of pain or temporal transition from acute OA pain to persistent OA pain. Individual’s symptom progression of OA manifested in one of three ways: is getting worse (12 participants), hasn’t worsened at this point (5 participants), or has reached its’ ultimate

severity because joint is bone-on-bone (1 participant); the latter being an uncommon observation.

Getting worse. Several older AAs used a temporal description to describe the ‘progressively getting worse’ phase. Some even mentioned how they first began to experience pain in their youth, but age served as a protective factor. During this semi-prodromal period, they were able to “handle the pain.” But generally, the progression occurred over a period of time, such as months-to-years. Pain was intermittent in the beginning stages but as time passed, it became more persistent especially when provider treatment was delayed. In addition, pain began as mild, then became more intense. One woman in particular also described her OA as getting worse, but she also characterized her progression in a slightly different manner. She believed her pain couldn’t get any worse because the joint space is “*bone on bone*” (UI009).

Hasn’t gotten worse. Five participants reported that their OA pain had not gotten any worse, mainly due to effective provider management, surgical replacement, and proactive self-management. An older female shared a unique perspective, “*The pain now, I don’t know that it’s worse than it was in the beginning. I think they’re just more sites where it is. When you have more than one place hurting at the same time, it might seem like it’s worse, but it really isn’t*” (UI093). Each individual’s perception of advancing OA was personal, but other people were unable to fully recognize and understand how their condition was progressing.

Others’ perceptions of pain. A part of “living with pain” is dealin’ with other’s perceptions of pain. Other people don’t tend to believe the severity of OA and CJ pain because pain is not a visible symptom. This minimization was apparent when one

participant spoke about a family member's response to her arthritis: *"Cuz it's been my experience that people that try to give you advice that have no business trying to give you any advice about somethin' because they don't even know what you're dealin' with cuz people was tellin' me, 'You can't walk because you don't wanna get up.' ... Just like other people in my life because they couldn't see the symptoms. Cuz I still looked the same at the time. I even had people that told me I was faking. Finally, you'd be surprised what family, not my immediate family, but family relatives and members were all tellin' me. They were saying, 'She can do this. She can do that.' I really was getting to where I couldn't walk. When I actually ended up on canes or walkers and then gradually to a wheelchair, then they saw the destruction of how all of it was happenin'" (UI007).*

Other participants also spoke about other's treatment of people with OA (UI018, UI098), and one person said, *"Right, right, right. Then you do have some people that actually belittles you because of it, cuz I've had someone come to me and say, 'Well, I don't want you, because you do this, do that, do this'" (UI018).* Several felt that they had no support from their family and friends because they didn't take the time to provide physical help or emotional support, nor did providers educate or recommend strategies that may help control the pain. The latter was evident in one gentleman's comparison, *"...for example, like if you in prison, and you complain about pain all the time, they think you trying to get out of work. Out in a free world, you complain about pain, they think you're trying to get some drugs cuz they can't see pain. They can't feel your pain... Oh, 'he don't act like he ain't in no pain', but I'm painin' like hell. Like I said, the doctors can't see no pain, they can't feel no pain... All they can do is just take what you say and*

analyze it to their own ability” (UI094). Therefore, participants had no choice but to find things on their own to help with pain, alluding to strategies for self-help.

Dealing with others’ minimization of pain did not exclude participants themselves and their former perceptions. In fact, several participants themselves reported that they didn’t believe someone could be hurting that bad until they personally developed OA (UI009, UI081, UI030). *“Well, my grandfather used to have us rubbing him with liniment and all that stuff. You know I thought they was just puttin’ on, but [laughter] I know now he was not puttin’ on”* (UI030). This led some to reminisce about their childhood and their observations on how family members dealt with arthritis and rheumatism (UI081). Often times, participants mentioned that they didn’t understand what their relatives were experiencing. *“I did a lot of that, too, for my uncle [rubbing with liniment]. Back during that time, I didn’t even know about arthritis”* (UI029). How older AAs deal with others’ perceptions and judgement of their condition is part of their daily coping strategies.

Coping. Although AAs did not use the word “cope” or “coping” very often, they did discuss the importance and ways of *“handl[ing] it [pain]”* to reduce the physical and mental impact and know how to go on with life even when they are havin’ severe pain. They were clear that *“If you don’t [adapt to it], it’s gonna take it out somewhere else in your life, I mean if you don’t know how to deal with it. You need to search every avenue you can to find out emotionally, mentally, just whatever you can do”* (UI007). This meant having to *“...to learn emotionally, it don’t affect me anymore”* (UI097). It was the wisdom gain through life experiences that taught them how to accept and adapt to the pain (UI007). This is likely why *“African Americans are probably more capable or better able to accept and deal with pain than others... because African Americans have*

had to deal with so many adverse situations all through life on down through the years” (UI009). In doing so, participants had to be strong; *“You got to be the strong person. Yep. No, it’s not easy. You know?”* (UI018).

Having OA was considered another one of life’s challenges in which they correlated their temporary suffering with Jesus’ suffering. Still they believed that *“...he [God] wouldn’t put more on us than we could bear”* (UI007), *“‘Cuz sometime I could say, ‘I refuse to let arthritis stop me.’ That’s my attitude toward—I’m not gonna let this just get me completely down! That’s why I bought my car, so I could keep movin’, at least on wheels, if not on my legs!’”* (UI031). While OA did result in varying levels of disablement, participants were determined not to allow pain to stop them from moving, doing activities (leisure and household), and partaking in life. *“...If I stop every time I was hurting, I wouldn’t get much done”* (UI009). It did however slow them down, but they were okay with this if that meant ensuring safety (UI031, UI093). Even though they experienced changes in mobility and functional ability, their mindset reflected the concurrent role of cognitive reframing, positivity, and resilience. For the most part, “handling pain” signified seeking and using spirituality.

Spirituality. Spirituality was used more as a coping mechanism than an actual pain management strategy. In fact, one gentleman pointed out that the Bible is a like a medical guide to help people when ill. *“The Israelites were God’s chosen people, and God had given them certain laws about this, as far as sanitation, health, disease. In fact, our latest Awake! is all about disease prevention”* (UI061). This same gentleman was the first person to explicitly say: *“Like I said, in certain places, it mentions little things about stuff that’s good for you, if you search through the Bible. I don’t think the Bible has*

helped me a lot with pain management, but it's helped my attitude toward pain because we believe that—Revelation 21:3 and 4 says, 'There'll be no more pain'” (UI061).

“We're having pain here, but on the other side, won't be no more pain” (UI030).

Spiritual practices are a major part of Black people's lives as evident by this one older woman, *“I really think it plays—I think it plays a big part. For Black people, I think it plays 90 percent, probably. I really do believe that it does” (UI075).* In some cases, this was directly related to pain and arthritis, and other times to life itself. In this manner, participants recognized how blessed they were despite their pain and other health conditions. Most of interview participants discussed the importance and helpfulness of prayer, faith, trusting as God as healer, and being a Christian. Praying and trusting God as healer were central themes across cases.

Power of prayer. AAs strongly believed in the importance and power of prayer, and 15 participants spoke explicitly about prayer. They prayed on a daily basis, and for some this was *“number one!” (UI031).* In fact, after one interview, an older woman asked me (PI) to have a word of prayer with her. AAs viewed prayer as a way *“...for the Lord to help you be able to manage or deal with your pain” (UI009).* In their prayers, participants would ask God to either (1) remove the pain, (2) ease the pain, (3) help bear the pain, or (4) give them strength in their body. *“To where I'd have to call out to Him in the middle of the night. When I'm layin' there, my legs will be so bad, just before I had finally got the surgery. ...I find myself callin' up out to Him, because it was difficult for me to sleep. I said, “Lord, all I want, if you don't take it away, just allow me to go to sleep. I'd go to sleep. I'd get up in the morning, and I'm much better. I didn't even ask Him to take away the pain, I just wanted to go to sleep [laughter], and He would do that*

for me. I'm really dependent on that, on many a time, to bring me through whatever it was" (UI060). Some would pray in the morning or throughout the day depending on the severity of their pain. They might combine prayer with Bible reading, gospel music, or meditation.

Prayer is an activity embedded within AA culture, whether they consider themselves religious or not. That's where the element of faith comes in, believing that whatever you have prayed for that God can do it. *"Prayer help heal the pain"* (UI097). They relied on faith to help them make it through, and any pain (physical or emotional) incurred could be overcome by having faith that God could and would heal them from their affliction.

Trusting God as healer. Because older AAs knew their OA was chronic, they found it necessary to trust God as healer. This was noted by 11 participants. As one man stated, *"I do understand that God is in the healin' business, and if I'm suffering, then I feel He can heal me, whatever goin' on. That's the reason why I say all the time that you just got to trust God"* (UI108). Healing was considered a miracle, and people believed God was still working miracles. It is commonly said in the AA church that God is a miracle-working God. *"If you truly know God and Jesus Christ and what they did for you, it's gonna help you, havin' faith that you know God's gonna heal you, and he gonna give you the strength that you need. That's the way I look at it. That's who I depend on as my healer. Well, he is my healer. It's just point blank. [Laughter]"* (UI018). Although they believed God could heal, many found themselves not even asking God to heal the pain or remove the pain. For example, *"Instead of sayin', 'Oh, God. Take the pain away.' I usually offer it up for my sins and sins of the whole world. Jesus didn't die in vain, but I*

want him to know that I realize how much he suffered for my sins. I'm gonna offer my pain instead of complainin' about it. I offer it up to him for my sins and of the whole world" (UI093). Not asking for pain to be removed seemed to negate their trust that God can heal. When contextualized, being thankful, humble, and cognizant of Jesus' suffering, mediated this gap between praying and trusting God.

Trusting God involved an element of praise and thankfulness to still be alive. *"Through God I know all things are possible. That's what I believe, baby. I wouldn't be walkin'. They don't understand to this day how blessed I am... So I'm trusting God. I think if they had not been for him, darlin', I would be dead. I know I would"* (UI007). Some acknowledged that they were thankful that their OA was not as worse as others or as worse as it could be (UI029). Prayer and trust were not used in isolation, but typically were combined a self-management practice to control pain. The centrality of faith, reliance on God as healer, and divine intervention through healing was evident. AAs used a holistic approach, mind-body-spirit to manage pain on a daily basis.

Controlling the pain. Controlling the pain was associated with the strategies and behaviors used to manage pain on a daily basis, as well as seeking information and concurrent management of other chronic conditions. Participants were engaged at varying degrees to *"...trying to get some control over the pain"* (UI075) through physical, spiritual, and pharmacological methods. This specific notion of "dealin' with pain" manifested in several ways, each highlighting an aspect of personal self-management: daily self-management practices, actions to limit disease progression, and provider engagement and interactions.

Daily self-management practices. AAs listed 10 strategies to control pain: medications, creams and rubs, exercise, diet and weight control (e.g., eating fresh foods, drinking water), rest and activity limitation, joint procedures (e.g., arthroplasty, joint injections, arthroscopes), thermal modalities (e.g., ice/heat), aquatic therapies (e.g., hot showers and baths), rehabilitative therapy (e.g., physical and occupational therapy), and prayer. Patterns of use, how and when these strategies are used, were altered and adapted over time according to their changing arthritis needs. Pain intensity and impact on function guided self-management response. Using creams and rubs, taking medications, rest and activity limitation, and exercise and physical activity featured prominently in their daily self-management programs.

Creams and rubs. When in pain, AAs first choice was to use a cream or rub. They tried to avoid using oral analgesic medications as a first response. Instead they resorted to creams and muscle rubs that they grew up seeing family member use, those recommended by family and friends, or creams prescribed by providers. This was confirmed by responses to “What do Black people do to manage pain?”: *“I’ve heard a lot of people say that they use different kinds of rubs and creams and even the pain relief patches, ointment”* (UI009). Examples include: IcyHot, Aspercreme, Watkins liniment, Australian Dream, and various types of rubbing alcohol. Typically rubbing alcohol was rubbed directly on the joints or poured in their bath water. One woman was even recommended WD-40, but never used it because of safety concerns.

Creams and rubs were sometimes helpful, and usage became a habitual practice in hopes of obtaining some pain relief. Other topical modalities included OTC pain relief patches and ice/heat.

Oral medications. Oral medications (i.e., pain pills) were not preferred first-line treatment. In fact, several did not like to take medications in general or pain medications. Sometimes AAs had to take oral medications, especially when the pain was severe. Participants made comments such as, “...if I’m hurting bad, I got somethin’ to do, that’s when I take a pain pill” (UI018) or “on a bad day I have to stop and find something to take” (UI009). Nevertheless, taking medications was a temporary solution to “subdue the pain” (UI018) because “after that [pain pills] wear off, you gotta deal with your pain” (UI008). Others believed taking their diuretics helped reduce knee swelling and subsequently helped their pain (UI061; quantitative participant UI053).

Participants made lay evaluations of oral medications’ effectiveness and safety before considering use. Safety concerns included the negative effect of medications such as addiction and dependence, effect on kidneys and heart, and bleeding. Certain medication classes such as corticosteroids increased blood glucose and weight gain. When taking medications, some used self-monitoring techniques such as listening to or knowing one’s body or keeping a health diary.

When perceived as helpful, they were more to open to taking pain medication consistently, but one issue was that AAs would not take prescribed medications long enough to determine its helpfulness because they reserved these medications for severe pain. “The things I use the most to control my pain, ‘cuz I’m a be honest. I’m not good at—I don’t take the medicine like they tell me I should take it. I don’t like pain meds. I really wasn’t takin’ it when they first came. I just found out that I made things worse for myself, because I shoulda been takin’ it, and the pain wouldn’t be so bad” (UI0093).

The types of oral pain medications were OTC and prescribed- some took both or either. Common medication classes included: anti-inflammatories (e.g., meloxicam, naproxen), opioids (e.g., tramadol, Lortab), anticonvulsants (e.g., gabapentin), corticosteroids (e.g., prednisone), and muscle relaxers (e.g., cyclobenzaprine). At times, medications were taken with adjuvant pain medications. Nonetheless, there was no consistent medication regimen. Some either stopped medication use because they believed it was not effective or they modified it in some way, usually taking only when hurting or not taking it when using alcohol.

Rest and relaxation. Twelve participants mentioned some aspect of resting and relaxing. Rest and relaxation were perceived as being both good and bad depending on how and when it was used. Rest was good when AAs believed they had done too much, but was bad when used as an excuse to neglect personal responsibility to self-manage pain. On bad days or during times of very severe pain, rest was common. *“On a bad day, when I’m hurting bad, I’ll just slow it down and do less. On a worst day, I don’t do anything. I just relax”* (UI018). Rest included bedrest, elevating legs, relaxing in chair, or just limiting activities. Along with rest and activity limitation, AAs equally noted the importance of exercise and physical activity.

Exercise and physical activity. AAs recognized the value of exercise and physical activity, even if they were not currently engaged in regular exercise. They were in agreement that exercise was helpful in controlling the pain. The issues were finding the time and becoming motivated. Most times, exercises and stretching were done in the morning after waking or in the evening. *“Okay, what I normally do, I get up in the morning, and to get me goin’... I’ll do exercise. I do my—someone taught me to do that in*

the morning, get my legs goin'. ...Walkin' is very good. Good for me. Now that my daughter and I have gotten into this contest, we exercise in the evenin'. I'm doin' pretty good. The exercisin', is good for me in the mornin', just the arthritis..." (UI060). For AAs, exercise and physical activity included: walking, chair exercises, range-of-motion, stretching, completing household chores, and lifting light weights.

Although rest was used frequently, it was important to keep doing regular activities, including physical activities. They couldn't let the pain stop them from doing what they needed to do. "Staying active" was important for controlling pain and limiting the progression of OA.

Actions to limit disease progression. Actions to limit progression of OA pain included strategies to reduce the worsening of OA and impact on physical function. Participants noted eight strategies for limiting progression: exercise and physical activity, maintaining functional safety, healthy diet/weight control, rest, prayer, proactive pain relief, being more/less active, and rehabilitative therapy. There was overlap between daily self-management strategies and strategies to limit the progression of OA and CJ pain. Engagement in progression-reducing activities was hindered by doing nothing and lack of motivation.

Doing nothing. It was an interesting and disheartening to some that others did nothing to slow the advancement of OA, either because they didn't know what to do or had no motivation. They asked themselves, "*How did I get here?*" *You know what I mean? Those thoughts run through my mind. "How did I get here?" ... "So how did I get here? How did I allow myself to get to this point?"* (UI060). Their hindsight revealed a need to be more physically active through exercise, better diet, and even greater self-

education; *“Just like I heard this man say, ‘If I knew I was gonna live as long as I have lived, I’d of took better care of myself than what I did.’”* [Laughter] (UI029). In retrospect, participants realized they should have been or should be more proactive and active in managing their OA. Such reflection was a mechanism for increasing motivation.

Increasing motivation. Participants were asked, “What could we do to motivate our [Black] people to better manage their pain?” This was a complex and convoluted question for many, and participants spoke of five distinct, almost systematic, ways to do this: acknowledge their lack of motivation (5 participants), modify negative attitudes and keeping a positive attitude (8 participants), become disciplined (5 participants), and talking to someone who cares (5 participants). What was clear for some was their need to “get motivated.”

Acknowledge lack of motivation. First, they noted a need to acknowledge their lack of motivation and the role of self-motivation. As one lady puts it, *“It’s got to be self. To me, I think a lot of it’s got to be self. If you want it. If you wanna manage that pain, it’s got to be up here. I can do this. I’m gonna manage this”* (UI018). Taking responsibility for caring for oneself and health was a corollary topic, but it was noted that *“...as American Black folks, they just really say they don’t give a damn because there ain’t nothing they can do”* (UI094). Consider one man’s perspective,

“Ain’t nothin’ you can do. Anything you can do bout that—you can’t do nothin’ about that. See, if a person is not going to look out for their own arse [ass] when they in pain, ain’t nothin’ you can do about that. You just might as well just step back and say, “Hey, did you do what you know you supposed to do?” “No.”

“Guess what, this should be a bulletin for you.” Okay, and you ain’t no different

than nobody else. Okay? It's your arse. [Laughter] Now, you ain't gonna do nothin' about it, it's on you. It ain't on nobody else” (UI098).

Though seemingly a simple issue to “know your body” and take care of your health, some of the responsibility was placed on the provider. Wisely stated, one of the older women said in reference to the patient-provider collaboration, *“I found that a lot of people, they don’t like that. I said, well, if you’re not gonna—if you don’t know nothing about this body that you live in—you gotta know. I can’t come to you and say you the doctor, you find out. He might take everything out” (UI075).*

Modify negative attitudes. Mitigating these laissez faire beliefs and negative conceptions about pain, health, and life was the third major motivational process. *“What I realized, I should have been watching what I eat. I should have been exercising more. I should have been reading and educating myself on things I need to do. Then, I finally said, ‘That’s behind me now.’ ...That’s when I started concentrating on... Now I wanna do more. Do something better...because I don’t wanna ever get that way again” (UI060).* Transitioning from a victim perspective to a victor perspective was indicated by AAs need to change their ways of thinking. *“Like I said, I just try to keep a positive attitude about life and your health, and don’t think, just because you’ve got some issues that you gotta sit down. You can work on it and make it better. ...Especially in my older years, I think about still just making lifestyle changes. Just because I’m old, that don’t mean I can’t change the way I do certain things” (UI061).*

Become disciplined. However, becoming self-motivated and engaging in health behavior change was not easy, required some to be sporadic in changing their physical activity patterns. *“They tell everybody exercise. Yeah, I know that, but I just*

couldn't get motivated. One day, one night, I was like, 'I just feel like dancing or somethin'.' I went to one of them line-dancing that you can do" (UI060). It was similar acts of becoming disciplined, whether with exercise or using medications that older AAs lacked.

Talking to someone who cares. Older AAs appreciated talking to someone who cares about their condition and experiences. On multiple occasions they mentioned that talking to the PI actually motivated them. It was likely the act of having someone listen to their issues and make simple, unpretentious recommendations facilitated their view. This shows a need for social support in managing any chronic condition including OA and CJ pain. Characteristics such as caring, empathy, and genuineness are key qualities older AAs look for in researchers and providers. Overall, increasing motivation is a multifaceted issue involving improved access to treatment and education, reducing stigma and maladaptive cultural norms, belief/attitude modification (i.e., changing negative attitudes), and having social and moral support.

While they knew there is no cure for OA, older AAs had expectations or a desire for their provider to find a permanent or long-term solution. This was a primary reason for seeking care from a provider. Yet, overwhelmingly there were more negative issues than positives in regards to providers' care. AAs' engagement and interactions with providers were an integral part of "dealin' with it" and are discussed next.

Provider engagement and interactions. Another way to "deal with the pain" was to engage providers in treatments. Participants often delayed initially seeking the help of a provider until the pain became persistent and severe; subsequent visits occurred during acute pain flares. This trend was reflected in an older man's statement, "*Here, lately, I've*

been in a lot of pain. One to ten, it's on a scale of ten all the time. That's reason why I'm—that's reason why I'm gonna go to the doctor and see what he can do" (UI108).

Participants discussed the positive and negative things about providers' misperceptions, communication style, disposition, and management approach.

Provider misperceptions. One of the more common misperceptions providers hold is that AAs are uninformed; *"Baby, that why, when I go in, doctors be so surprised that I don't want anything for pain. It just act like it throw them for a loop that you're informed"* (UI007). *"They don't want you to have no knowledge of what's wrong with you. Now, isn't that sad? That is sad."* (UI075). This is one form of power and privilege (occupational and racial), and a way to keep patients (and "Blacks") in their place. *"...I think sometime doctors get full of themselves"* (UI061).

Providers need to have a *"direct conversation"* to better understand AAs needs and lifestyles (UI098). In fact, AAs wanted providers to know about their lifestyle including the health habits, environment in which they live, and the stress they experience; how AAs are treated in the healthcare system; their religious beliefs (e.g., faith; refuse blood products); and that some AAs are less comfortable reporting pain to a provider. There were a few AAs that did not have an idea on what providers should know about AAs or Black culture.

Provider communication style. Through communication, providers learn how to effectively interact with older AA patients. *"The patient and the doctor should be able to communicate together so therefore we both have an understanding, right"* (UI097).

Having an open communication style is valued by AAs, and is one way trust is built.

However, it was providers' communication, or lack thereof, that AAs took issue with.

Most providers did not provide education or explain their approach to pain management. For example, AAs remarked that providers (1) didn't explain medications (UI007), surgical procedures (UI009), or medical diagnoses thoroughly (UI061), (2) needed educational material in their clinic (UI008), and (3) to spend more time with patients (UI009, UI075). AAs identified a need for greater education and shared-decision making. One man pointed out,

"I see a lot more proactive counselling with diabetes, than I do with arthritis. It's got a lot to do with the fact that, especially rheumatoid arthritis, can hit you anytime. You can be 21 and have it. Okay! That's why I sayin', when they get it, they need to be just as proactive as they are when you get diabetes. They sit you down, and they tell you. "Now, unless you wanna come up with foot short, or with a leg short, this is what you need to do. Okay?" It is what it is" (UI098).

It was difficult to manage pain with misinformation or no information. The lack of educational material on arthritis and other chronic conditions in the clinic was eye-opening, and revealed a significant gap in care. Moreover, the lack of emphasis on patient education framed participants' perceptions that having information or being informed is not valued. Nonetheless, some of the older AAs asserted their patient right to information and communication, and would take a list of topics to talk about with the provider. That way providers had to take the time and communicate.

Provider disposition. Along with having an open communication style, providers' disposition played a critical role in the extent to which older AAs' engage and interact with providers. Some participants did not feel their provider cared for or about them (UI008, UI018). Providers' disposition and tone of communication was sometimes

perceived as defensive. For example, when “...*I did talk to my regular doctor about it and tell him about it. Then, I told him—I said, ‘Well, maybe I need to go get a second opinion.’ He says, ‘Well, maybe so.’ [Laughter] So I don’t even fool with goin’ back to the doctor about my pain anymore*” (UI081). This was a time for the provider to display care and empathy, as this clearly affects whether participants would engage in the treatments prescribed and recommended.

Provider management. Providers had varying management approaches ranging from provider-centric to patient-centered. Provider-centric management consisted of providers simply prescribing pain medications without developing a comprehensive pain management plan. “*When I went to Dr. [name deleted], ‘Oh, you just got arthritis here and gave me some inflammatory pills and sent me on out the door and said, ‘No, you’re too young for surgery’ ... Oh, you be all right...I literally had to go in there the same way. In tears. All that he did was took x-rays and, okay. Here. Take these pain pills and go home. That’s it. That’s all they do*” (UI018).

In other cases, providers wouldn’t prescribed pain medications or recommended discontinuation of certain analgesic medications. Conversation with one woman who was still employed revealed an unfortunate issue in professional care:

Interviewee: *I was taking pain medication, but when I went to the doctor last time he told me to stop ‘cause with the medicine I take, it might interact with it and it’s not good for you know what I take. Told me to deal with it. ...*

Interviewer: *What pain medicine was it? What was the name of it? Can you remember?*

Interviewee: *Mobic?*

Interviewer: *Oh, Mobic, okay. Oh, okay.*

Interviewee: *I said, "Okay." Then he told me. I said, 'Well, I take Advil every night.' He told me don't do that either 'cause there's all that in the same category. ...He said that's all. I said, 'Well okay. I'll manage it best that I can, but when it get to the point where it's too, mm-mmm.' I had to take something.*

Interviewer: *He didn't give you anything in like place of the Mobic?*

Interviewee: *Mm-mmm [no]. It's whatever I had to deal with it unless I decide to go buy me some Advil and don't listen to him (UI008).*

When providers perceived there was nothing else they could do for OA, they left management up to the participant (UI029). Thus, some did not have full support of their providers as one woman reported that her doctor *"told me to deal with it"* (UI008). As a result, participants were generally unsatisfied with this level of care. AAs much rather preferred to find natural or OTC remedies to control the pain as opposed to going to the doctor (UI008, UI018, UI094, UI108).

In patient-centered models, AAs participated in shared decision-making, often collaborating with the provider to determine best approach and medications to manage pain. Management was a two-way street. AAs believed their role was to report their symptoms to the provider. First, AAs *"...have to explain your feelings to him... 'Hey, I'm having this.' Okay now, I express my feelings, let him know how I feel..."* (UI097). Then the provider's role was to use their expertise and professional judgment to determine a prognosis and plan a course of treatment (UI007, UI075, UI097). Second, providers

should share their “*opinion about what should I do. ... The only thing the doctor’s here for is to help us relieve our pain, ‘cause the doctor don’t know what’s hurting me you know what I’m saying unless you tell them. Then, he can give you his opinion on what to do or how to do it to ease your pain and stuff*” (UI097). Then ultimately it was up to the participant to decide if they would follow the recommended plan. This process was powerfully illustrated through one woman’s response,

“Doctors are really shocked when you’re informed and you know your—see if you don’t know your own body—see I’m not gonna let you tell me what I’m gonna be on. I’m gonna tell you what I choose to be on. See when I go into a doctor my thing is you tell me what you think the prognosis is, plan a treatment, then I’m gonna be the one to choose which way I’m gonna go. I’m coming to you for your expertise, but this is my body, and what I put in it is up to me. That’s the way I view things. Some doctors don’t want you to have a say in treatment. They become abrasive and wanna throw around they’re the doctor. You couldn’t be a doctor without a person like me. Because what’s the use of being a doctor if you don’t have anybody to treat. The only way, like I’ve had to tell some that you learn about this is because of people such as myself. If it wasn’t for people like us, they wouldn’t know about, especially disease they know there’s no cure for. They need us. It’s important you know when you go in there, don’t let him tell you about your body. You know your body before you go in there. That way, because a lot of times how they treat you depends on what info come from you, and you knowin’ yourself” (UI007).

Patients had to have faith in their provider that the treatment plan would work, but providers also need to follow-up with patients sooner rather than later:

“...A lot of times...doctors give you medicine. They don’t check on you soon enough to see whether or not it’s workin’ for you. If you give me a medication today and say, “This is a pain medication. This is gonna help your arthritis pain,” what happens in the three months til I see you again if it’s not workin’? That’s the problem I have. That’s why I don’t like to take that stuff, cuz I know if it make me sick or somethin’, I can’t see nobody until three months or go in and sit in a waitin’ room. I don’t wanna do that. But I have to say my arthritis doctor, Dr. [name deleted], she’s givin’ me four or five numbers to get her when something goes wrong” (UI093).

In summary, although pain management is a personal activity, providers play a key part in older AAs’ pain management. “Dealin’ with pain” was a strong cultural theme, and it had several dimensions: “bearing the pain,” “understanding OA pain,” and “experiencing pain. In each of these categories, caring for the mind, body, and spirit was significant, and influenced their engagement in complementary and recommended OA behaviors.

Patterns of OA and CJ Pain Self-Management (Quantitative)

One hundred ten older AAs were surveyed about their self-management practices. First, the PI posed an open-ended statement, “Tell me what you did to care for your arthritis over the past month.” After recording their responses, older AAs were shown a

list of common medications, complementary, and spiritual practices and asked if there were other things they have done in the past month to manage their arthritis pain. The top 10 strategies used are presented from highest to lowest frequency (see Table 8): creams- OTC, warm baths, exercise, rubs- OTC, NSAIDS- OTC, warm/cool compress, prayer, Tylenol- OTC, NSAIDS- prescribed, and orthotic devices.

It is not surprising that the primary reason for use of the top 10 behaviors was due to its helpfulness in reducing with pain. Older AAs developed their own regimen for using creams and taking medications and with regards to frequency and dosage. The common types of creams and rubs used and medications currently taking are available in Tables 9-10, respectively. Creams and rubs were used as needed, a lot of times at night and when the pain was becoming severe. Many poured rubbing alcohol, arthritis rubs, or Epsom salt into their warm bath water to help with joint achiness and soreness. Taking warm baths/showers was also highly perceived as helpful in easing the pain. On average, creams and rubs were rated as moderately helpful. Aside from medications, creams and rubs were their “go-to” strategy.

AAs were more likely to use OTC medications at any given time, compared to prescribed medications. OTC medications were generally taken as needed, only taken when the pain became severe or when they ran out of their prescribed medications. Older AAs were more adherent to taking prescribed NSAIDs every day or several days a week, but this was not the case for prescribed opioids which were used as needed. As needed could consist of once per day, once a week, or every other week. Participants used opioids as needed because (1) their provider said to use as needed versus around the clock, or (2) of concerns about addiction, dependence, and side effects. They rated OTC

NSAIDs as moderately helpful and OTC Tylenol® and prescribed NSAIDs only as somewhat helpful. Naproxen (Aleve®) was typically more helpful than ibuprofen or Tylenol®.

While only half of the sample used prayer, it was the only behavior with an average rating as very helpful (3.83). Prayer was one of seven spiritual strategies used. Some had never considered using prayer as a direct strategy to control or reduce pain, but did acknowledge that they used prayer frequently just not for pain per se'. Others used it to cope with pain, and of all the complementary and recommended behaviors, prayer was the only option most used daily (n= 35, ~32%)

Understanding the behaviors most used and why they are used are essential to inform future self-management interventions that are culturally-sensitive to older AAs. Later in this chapter, we will provide both quantitative and qualitative evidence of specific cultural preferences for self-management and self-management education.

Table 8- Frequencies and Means for Top Complementary OA Behaviors

Behavior	Using N (%)	Frequency N (%)				Helpfulness [†] \bar{x} (SD)	Primary Reason for Use
		<i>Everyday</i>	<i>Several days/week</i>	<i>Once/week</i>	<i>As needed</i>		
Creams- OTC	63 (57.3)	11 (10.0)	7 (6.4)	1 (0.9)	43 (39.1)	3.03 (1.09)	Helps with pain
Warm baths ^{1,2}	62 (56.4)	24 (21.8)	21 (19.1)	2 (1.8)	11 (10.0)	3.53 (0.94)	Helps with pain
Exercise ³	58 (52.7)	18 (16.4)	26 (23.6)	6 (5.5)	8 (7.3)	3.34 (1.09)	Helps with pain (stiffness)
Rubs- OTC	57 (51.8)	12 (10.9)	7 (6.4)	0	37 (33.6)	2.70 (1.04)	Helps with pain; Trying to see if helps
NSAIDs- OTC	53 (48.2)	11 (10.0)	6 (5.5)	2 (1.8)	34 (30.9)	3.19 (1.19)	Helps with pain
Warm/cool compress	47 (42.7)	6 (5.5)	5 (4.5)	1 (0.9)	35 (31.8)	3.32 (1.09)	Helps with pain
Prayer	46 (41.8)	35 (31.8)	5 (4.5)	0	6 (5.5)	3.83 (0.68)	Helps with pain
Tylenol- OTC	38 (34.5)	2 (1.8)	3 (2.7)	1 (0.9)	32 (29.1)	2.22 (1.21)	Helps with pain

Table 8- continued

Behavior	Using N (%)	Frequency N (%)				Helpfulness [†] \bar{x} (SD)	Primary Reason for Use
		<i>Everyday</i>	<i>Several days/week</i>	<i>Once/week</i>	<i>As needed</i>		
NSAIDs- Prescribed ¹	36 (32.7)	24 (21.8)	2 (1.8)	0	9 (8.2)	2.58 (1.54)	Prescribed; Helps with pain
Orthotic device ^{1,4}	36 (32.7)	7 (6.4)	7 (6.4)	2 (1.8)	18 (16.4)	3.21 (1.39)	Helps with pain (stability)

[†] 0-4 scale: Not helpful, a little helpful, moderately helpful, very helpful

¹ Missing data: NSAIDs- Prescribed, n=1 (0.9%); Orthotic device, n= 2 (1.8%)

³ Exercise may include the same recommended behaviors (land- and water-based exercise)

² Additional data: Warm baths: Monthly- (3, 2.7%)

⁴ Assistive devices and opioids had similar rates as orthotic devices, and were the next two most common strategies.

Table 9- Common Types of Creams and Rubs

Prescribed Creams	OTC Creams	OTC Liquid Rubs
MN-CMPDI (TN) compound cream (gabapentin, lidocaine, prilocaine, nalfon)	Absorbine Jr. Aspercreme®	Rubbing alcohol (wintergreen, clear)
AL-CMPDI compound cream (gabapentin, acetaminophen, butalbital, lidocaine, prilocaine)	Arthritis Hot muscle rub Australian Dream Arthritis Cream Capsaicin BenGay® Biofreeze® IcyHot® JointFlex® Two Old Goats Thera-Gesic® Salonpas® pain relief patch	Dr. Fred Summit® Arthritis & Sports Rub - with Epsom salt (green) - penetrating heat rub (red) - cool blue ice (blue) Watkins liniment™ Witch hazel
Lidocaine cream		
Lidocaine patch		
Voltaren® gel		

Table 10- Common Types of Medications

Opioids	acetaminophen/codeine (Tylenol® with codeine [Tylenol® 3]), acetaminophen/hydrocodone (Norco®, Lortab®), acetaminophen/oxycodone (Percocet®), codeine, hydrocodone, oxycodone, tramadol (Ultram®)
NSAIDs - Prescribed	celecoxib (Celebrex®), sulindac (clinoril®), diclofenac, diclofenac/misoprostol (Arthrotec®), ibuprofen/famotidine (Duexis), fenoprofen (Nalfon), indomethacin, meloxicam (Mobic®), naproxen, naproxen/esmoprazole (Vimovo®), nabumetone (Relafen®)
NSAIDs - OTC	aspirin, aspirin/caffeine (BC Powder Original® & Arthritis Strength®), ibuprofen (Advil®, Motrin®), naproxen (Aleve®)
Muscle Relaxers	cyclobenzaprine (Flexeril®), methocarbamol (Robaxin®), tizanidine (Zanaflex®)
Anti-Depressants	amitriptyline (Elavil), citalopram (Celexa®), trazodone, venlafaxine (Effexor®)
Analgesics - OTC	acetaminophen (Tylenol®)

Aim 2: Determine which model variables (contextual and process) predict stage of engagement in (1) seven recommended self-management behaviors that provide immediate and long-term relief for OA and CJ pain and (2) two most commonly-used complementary self-management behaviors for OA and CJ pain.

Predictors of Self-Management

The aim of these analyses was to identify predictors of stage engagement in recommended behaviors and the two most commonly-used complementary behaviors. Although a conceptual model guided predictive testing, there were no formal hypotheses for this descriptive exploration. First, descriptive statistics of independent and dependent variables are described. Second, consideration was given to correlations between the independent variables and each dependent variable. Only significant ($p \leq 0.05$) independent variables were included in multinomial regression models. Next, the overall test of relationship was examined to identify which correlates were significant predictors for each recommended behavior.

Independent Variables Descriptive Data

The proposed independent variables in this study were average pain intensity, pain interference, OA pain severity, age, education, employment, spirituality, number of chronic conditions, access to a primary care provider, social support, confidence, knowledge of OA self-management behavior recommendations, motivation, and illness perception (see Table 11).

Table 11- Frequencies and Means of Independent Variables

Categorical Variables (N= 110)	Frequency	%
Education		
< High School	12	10.9
= High School/GED	31	28.2
= Some college	24	21.8
= College degree	25	22.7
= Graduate degree	18	16.4
Spirituality		
Yes	58	52.7
No	52	47.3
Employed		
Yes	31	28.2
No	79	71.8
OA pain severity		
Mild	25	22.7
Moderate	66	60.0
Severe	19	17.3
Illness perception (i.e., Importance)		
Yes	93	84.5
No	11	10.0
Missing	6	5.5

Table 11- continued

Categorical Variables (N= 110)	Frequency	%
Chronic conditions		
0	5	4.5
1-3	73	66.4
4-10	32	29.1
Access to a provider		
Yes	103	93.6
No	7	6.4
Social Support		
Yes	25	22.7
No	85	77.3
Knowledge of land-based exercise recommendation		
Yes	98	89.1
No	12	10.9
Knowledge of water-based exercise recommendation		
Yes	85	77.3
No	24	21.8
Missing	1	0.9
Knowledge of strength training recommendation		
Yes	99	90.0
No	11	10.0

Table 11- continued

Categorical Variables (N= 110)	Frequency	%
Knowledge of self-management education recommendation		
Yes	50	45.5
No	59	53.6
Missing	1	0.9
Knowledge of medication use recommendation		
Yes	109	99.1
No	1	0.9
Knowledge of thermal modalities use recommendation		
Yes	104	94.5
No	6	5.5
Knowledge of assistive and/or orthotic device use recommendation		
Yes	102	92.7
No	8	7.3
Continuous Variables	Mean	SD
Age	68.44	12.37
Average pain	5.47	2.02
Pain interference	3.53	2.57
Confidence (symptom management)	7.07	2.52
Motivation (N= 109)	8.30	2.26

Dependent Variables Descriptive Data

The distribution of each dependent variable was examined visually with a histogram. Skewness, a measure assessing whether a distribution of participants' responses clusters at one end and trails off in one direction or another was examined. A second measure, kurtosis, examined how pointed or flat the distribution is at its peak. As indicated, all but self-management education were skewed to the right or left. Skewness and kurtosis scores for each dependent variable are presented below:

- Land-based exercise: negative skewness (-0.82, SE 0.23), kurtosis (-0.688, SE 0.46)
- Water-based exercise: skewness (0.84, SE 0.23), kurtosis (-0.346, SE .46)
- Strength training: skewness (-1.420, SE 0.23), kurtosis (0.571, SE 0.46)
- Self-management education: skewness (-0.04, SE 0.23), kurtosis (0.395, SE 0.46)
- Analgesic medications: skewness (-2.09, SE 0.23), kurtosis (2.541, SE 0.46)
- Thermal modalities: skewness (-0.61, SE 0.23), kurtosis (-1.358, SE 0.46)
- Assistive and/or orthotic device: skewness (-0.07, SE 0.23), kurtosis (-1.97, SE 0.46)

Table 12 provides descriptive data on stage of engagement in each recommended behavior. Over half of older AAs (55.5%) reported engaging in some kind of land-based exercise, typically walking, for at least 6 months or longer. Another third reported making plans to begin an exercise routine, and less than 15% had no intentions or interest in land-based exercising. The number of individuals not engaged in water-based exercised was the exact opposite of those engaged in land-based exercise. Although 77%

acknowledge their awareness of water-based exercise for OA pain, 55% were not engaged in water-based exercise and only 8% were involved in this behavior. However, an astounding 36% were interested and responded they would like to participate in water-based exercises at some point. The majority of AA seniors (71%) were engaged in some type of strength training such as resistance stretching at least once per day, and the remaining 29% were not. In regards to participation in a chronic pain or arthritis self-management education program, 18% were staged at pre-contemplation, roughly 12% were situation in action and 70% were in preparation to attend at some point.

Nearly all AAs (93%) were taking either prescribed or OTC medications. Use of thermal modalities for some also included warm/cool compresses, hot showers/baths as well as temperature-adjusting creams like IcyHot. Approximately 55% percent reported using thermal modalities. Other AAs had no plans to use thermal modalities (26%), but there was a moderate group, 20% (N= 21), willing to begin use. Lastly, the use of assistive and/or orthotic devices, had a near even split between no use and use, 45% and 49% respectively. There are specific barriers and motivators that help explain many of these findings, and this is discussed later.

Table 12- Frequencies for Stages of Engagement for Recommended OA Behaviors

Recommended Behavior	Pre-contemplation (No, don't plan to)	Preparation (No, but at some point)	Action (Yes, < or > 6 months)
Land-based exercise	16 (14.5%)	33 (30.0%)	61 (55.5%)
Water-based exercise	61 (55.5%)	40 (36.4)	9 (8.2%)

Table 12- continued

Strength training	13 (11.8%)	19 (17.3%)	78 (70.9%)
Self-Management education	20 (18.2%)	77 (70.0%)	13 (11.8%)
Analgesic medication	14 (12.7%)	3 (2.7%)	93 (84.5%)
Thermal modalities ¹	28 (25.5%)	21 (19.1%)	60 (54.4%)
Assistive and/or orthotic device	50 (45.5%)	6 (5.5%)	54 (49.1%)

¹ Missing: n= 1 (0.9%)

Correlates of Recommended OA Behaviors

Spearman rank correlations were calculated to investigate the relationship between potential predictors and each dependent variable; a correlation matrix is shown in Table 13. There was a significant, weak, and positive association between confidence (0.251, $p = 0.008$) and land-based exercise. As confidence increased, engagement in exercise increased. No independent variables were associated with water-based exercise. Related to strength training, motivation (0.1942, $p = 0.045$) and confidence (0.247, $p = 0.009$) were weakly associated. As motivation and confidence minimally increased, so did engagement of strength training. There was also a weak, negative relationship between strength training and spirituality (-0.203, $p = 0.034$), pain interference (-0.195, $p = 0.042$), and knowledge of strength training recommendation (-0.253, $p = 0.008$). Strength training decreased when spirituality, pain interference, and having knowledge of this recommendation increased.

Engagement in self-management education was inversely related to having knowledge of the self-management education recommendation ($-0.238, p= 0.013$). Pain interference ($0.227, p= 0.017$) was positively associated with taking analgesic medications, while confidence ($-0.180, p= 0.048$) and knowledge of medication recommendation ($-0.190, p= 0.047$) were negatively related with taking analgesic medications. This suggests that lower levels of confidence is associated with greater analgesic medication use, whereas higher levels of knowledge of recommendation are associated with lower levels of medication use. Both pain interference ($0.203, p= 0.035$) and chronic conditions ($0.192, p= 0.045$) were positively and significantly correlated with engagement in thermal modalities. Having higher pain interference and chronic conditions increased use of thermal modalities. Lastly, being unemployed ($0.232, p=0.015$), having worse OA pain severity ($0.267, p= 0.005$), and experiencing greater pain interference ($0.406, p= 0.000$) are positively associated with using an assistive and/or orthotic device. In particular, pain interference had a strong moderate correlation with assistive and/or orthotic device use. There are several ways to interpret this complex correlation. For one, the moderate relationship between social support ($-0.337, p= 0.000$) and assistive and/or orthotic device was inverse which means as social support decreases, use of assistive and/or orthotic devices increases. Another interpretation may be as use of assistive devices increases (the condition is worsening and function is decreasing), social support decreases. Thirdly, as pain interference and OA pain severity worsens, function decreases and leads to disability in which AAs may have greater reliance on assistive devices, become unemployed, and have decreased social support due to less social engagement.

Table 13- *Correlations between Independent Variables and Recommended Behaviors*

N= 110	Land-based Exercise	Water-based Exercise	Strength Training	Self-Management Education	Analgesic Medications	Thermal Modalities¹	Assistive and/or Orthotic Device
Age	-0.093	-0.177	-0.097	-0.117	-0.112	-0.044	0.082
Average pain	-0.169	-0.101	-0.072	-0.070	0.171	0.096	0.169
Access to a provider	0.008	-0.094	-0.096	-0.176	0.006	0.001	0.182
Chronic conditions	0.072	-0.061	-0.046	-0.049	.000	0.192*	0.183
Confidence	0.251**	0.012	0.247**	0.042	-0.189*	0.139	-0.112
Education	0.178	0.112	0.118	0.112	-0.120	-0.087	-0.162
Employment	-0.050	-0.057	-0.012**	-0.011	-0.032	-0.014	0.232*
Illness perception	-0.133	-0.085	0.060	-0.058	-0.088	-0.045	-0.064
Knowledge of recommended behavior	-0.135	-0.130	-0.253**	-0.238*	-0.190*	-0.183	-0.012
Motivation	0.116	-0.007	0.192*	0.079	-0.068	-0.099	0.124
OA pain severity	-0.124	0.011	-0.054	0.048	0.116	0.161	0.267**
Pain interference	-0.091	0.168	-0.195*	0.039	0.227*	0.203*	0.406**
Social support	0.166	0.026	0.003	0.055	-0.047	0.003	-0.337**
Spirituality	-0.046	-0.075	-0.203*	0.011	0.102	-0.011	-0.056

** $p \leq 0.01$; * $p \leq 0.05$

¹ Missing data: n= 1

Regression Models of Recommended OA Behaviors

Regression models were generated based on three levels of the dependent variable (pre-contemplation, preparation, and action). The same predictors were assumed for each stage, and a significance level was <0.05 was used throughout. Reference categories were selected based on distribution of responses. The goal was to compare those who were engaged (i.e., action) vs. not engaged (pre-contemplation, preparation) in a particular behavior. Thus, the interpretation would be, compared to those actively engaged in “x” behavior, “x” predictors were indicative of no engagement. Results for each regression model for recommended OA behaviors are presented.

Land-based exercise. The overall model shows pain interference is a significant predictor of engagement in land-based exercise ($p= 0.24$). When compared to those in the action stage, pain interference was predictive of being in the pre-contemplation stage but not the preparation stage. Because the Pearson chi-square was not significant, the model is a good fit with the data. Table 14 supplies additional statistics.

Table 14- Predictors of Land-based Exercise

Stage ¹	Variable	β	SE	Significance
Pre-contemplation	Intercept	-1.474	.314	0.000
	Pain interference	-0.753	.285	0.008**
Preparation	Intercept	-0.597	0.218	0.006
	Pain interference	-0.260	0.227	0.252

Table 14- continued

Model Fitting	
Overall Model Sig.	p= 0.024*
Nagelkerke R^2	0.076
Goodness of fit	$\chi^2= 60.377$, p= 0.672
Classification Summary Percentage ²	Pre-contemplation= 6.3% Preparation= 0.0% Action= 98.4%

** p ≤ 0.01; * p≤ 0.05

¹ Reference category: Action

² Percentage of correct classifications (predicted vs. observed) of three stages

Strength training. The overall model containing confidence, knowledge of strength training recommendation, motivation, pain interference, and spirituality was significant (p= 0.005). This was confirmed by the Pearson chi-square which indicated the model has a good fit. However, when the independent factors are considered separately, only knowledge of strength training recommendation in the pre-contemplation stage and confidence and knowledge in the preparation stage were significant. Having used a spiritual strategy trended towards significance in the pre-contemplation stage (see Table 15).

Table 15- Predictors of Strength Training

Stage¹	Variable	β	SE	Significance
Pre-contemplation	Intercept	0.284	0.863	0.742
	Confidence	-0.263	0.372	0.324

Table 15- continued

	Knowledge of strength training recommendation (yes)	-1.1789	0.904	0.048*
	Motivation	-0.290	0.294	0.971
	Pain interference	0.159	0.346	0.646
	Spirituality (yes)	-1.139	0.670	0.089
Preparation	Intercept	0.247	0.834	0.768
	Confidence	-0.633	0.312	0.042*
	Knowledge of strength training recommendation (yes)	-1.836	0.866	0.034*
	Motivation	-0.376	0.270	0.686
	Pain interference	0.453	0.313	0.149
	Spirituality (yes)	-0.587	0.577	0.309
Model Fitting				
Overall Model Sig.		p= 0.005**		
Nagelkerke R^2		0.256		
Goodness of fit		$\chi^2 = 200.621$, p= 0.514		
Classification Summary Percentage ²		Pre-contemplation= 0%		
		Preparation= 26.3%		
		Action= 93.5%		

** p ≤ 0.01; * p ≤ 0.05

¹ Reference category: Action

² Percentage of correct classifications (predicted vs. observed) of three stages

Self-Management education. As presented in Table 16, knowledge of self-management education was the only factor included in this model and was significant ($p=0.007$). Because the Beta coefficient is negative, if the participant indicated they were not knowledgeable of a self-management education, then they were more likely to be in the pre-contemplation and preparation stages.

Table 16- Predictors of Self-Management Education

Stage ¹	Variable	β	SE	Significance
Pre-contemplation	Intercept	1.872	0.760	0.014
	Knowledge of self-management education (yes)	-2.324	0.900	0.010**
Preparation	Intercept	3.091	0.723	0.000
	Knowledge of self-management education	-2.023	0.803	0.012*
Model Fitting				
Overall Model Sig.		$p= 0.007^{**}$		
Nagelkerke R^2		0.107		
Goodness of fit		$\chi^2= 0.000$, $p= \text{none}$		
Classification Summary Percentage ²		Pre-contemplation= 0% Preparation= 100% Action= 0%		

** $p \leq 0.01$; * $p \leq 0.05$

¹ Reference category: Action

² Percentage of correct classifications (predicted vs. observed) of three stages

Analgesic medication. The overall model was significant ($p=0.019$) (see Table 17); however, none of the independent variables was significant for the pre-contemplation and preparation stages. This is most likely due to the fact that nearly all AAs were in the action stage. Thus, when compared to the action stage, confidence and knowledge are not as relevant for those in the pre-contemplation and preparation stages.

Table 17- *Predictors of Analgesic Medication*

Stage ¹	Variable	β	SE	Significance
Pre-contemplation	Intercept	-2.623	0.315	0.000
	Confidence	0.397	0.349	0.256
	Knowledge of analgesic medication recommendation (yes)	0.737	0.000	None
	Pain interference	0.737	0.333	0.115
Preparation	Intercept	33.411	0.718	0.000
	Confidence	0.189	0.709	0.790
	Knowledge of analgesic medication recommendation (yes)	-37.183	0.000	None
	Pain interference	0.258	0.696	0.711
Model Fitting				
Overall Model Sig.		$p=0.019^*$		
Nagelkerke R^2		0.203		
Goodness of fit		$\chi^2=170.782$, $p=0.903$		

Table 17- continued

Classification Summary Percentage ²	Pre-contemplation= 0% Preparation= 33.3% Action= 100%
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** $p \leq 0.01$; * $p \leq 0.05$

¹ Reference category: Action

² Percentage of correct classifications (predicted vs. observed) of three stages

Thermal modalities. Unlike previous models, this model was not statistically significant ($p = 0.127$), but the goodness of fit index indicates the model fits the data well. Alone, neither pain interference nor the number of chronic conditions predicts being in the pre-contemplation or preparation phase. Table 18 provides statistical results.

Table 18- Predictors of Thermal Modalities

Stage ¹	Variable	β	SE	Significance
Pre-contemplation	Intercept	-1.422	0.500	.004
	Pain interference	-0.303	0.248	0.221
	Number of chronic conditions1 ^a	1.530	1.514	0.312
	Number of chronic conditions2 ^a	0.878	0.570	0.123
Preparation	Intercept	-1.449	0.507	0.004
	Pain interference	-0.531	0.284	0.062
	Number of chronic conditions1 ^a	2.229	1.374	0.105
	Number of chronic conditions2 ^a	0.389	0.599	0.516

Table 18- continued

Model Fitting	
Overall Model Sig.	p= 0.127
Nagelkerke R^2	0.101
Goodness of fit	$\chi^2= 138.938$, p= 0.367
Classification Summary Percentage ²	Pre-contemplation= 0% Preparation= 9.5% Action= 98.3%

** p ≤ 0.01; * p≤ 0.05

¹ Reference category: Action

² Percentage of correct classifications (predicted vs. observed) of three stages

^a Reference category: Number of chronic conditions³ (i.e., having 7 or more chronic conditions)

Assistive and/or orthotic device (see Table 19). Together, employment, OA pain severity, pain interference, and social support were statistically significant predictors in the overall model (p= 0.000). This was validated by the Pearson chi-square goodness of fit (p= 0.382). Although the Nagelkerke R^2 is a pseudo-measure of variance, it was able to show that almost 40% of the “variance” was due to employment status, OA pain severity, pain interference, and social support. If you are employed compared to unemployed, AA older adults are less likely to use an assistive and/or orthotic device. If you have social support compared to no social support, you are more likely to use an assistive and/or orthotic device. Also, pain interference was a predictor of being in the action stage compared to the preparation stage.

Table 19- Predictors of Assistive and/or Orthotic Device

Stage ¹	Variable	β	SE	Significance
Preparation	Intercept	-1.938	1.326	0.144
	Employment (yes)	1.295	0.983	0.187
	OA pain severity1 (mild)	-1.171	1.637	0.474
	OA pain severity2 (moderate)	-0.984	1.308	0.452
	Pain interference	0.340	0.545	0.533
	Social support (yes)	1.269	1.289	0.325
Action	Intercept	0.881	0.747	0.238
	Employment (yes)	-1.203	0.571	0.035*
	OA pain severity1 (mild)	-0.737	0.910	0.418
	OA pain severity2 (moderate)	-0.952	0.784	0.225
	Pain interference	1.129	0.310	0.000**
	Social support (yes)	1.866	0.680	0.006**
Model Fitting				
Overall Model Sig.		p= 0.000**		
Nagelkerke R^2		0.396		
Goodness of fit		$\chi^2= 185.075$, p= 0.382		
Classification Summary Percentage ²		Pre-contemplation= 76%		
		Preparation= 0%		
		Action= 75.9%		

** $p \leq 0.01$; * $p \leq 0.05$

¹ Reference category: Pre-contemplation

² Percentage of correct classifications (predicted vs. observed) of three stages

It was apparent that pain interference is a key factor for stage of engagement in recommended behaviors. It was the only factor to be significant in multiple models. This is important to know because depending on how high or low older AAs score on pain interference will determine whether they engage or disengage in key recommended behaviors known to reduce pain intensity. Knowledge of a specific recommended behavior was also another factor that was significant in two models. Although, confidence was significant in one model, it was moderately correlated with several behaviors. As proposed in our conceptual model and in the self-management literature, these three factors, pain interference, knowledge, and confidence are important for self-management.

Correlates and Regression Models of Complementary OA Behaviors

The two most-commonly used behaviors, not represented as a recommended behavior, were examined to identify predictors of use. The complementary behaviors tested were use of rubs and prayer.

Rubs. Using the same 14 predictors as in the recommended behaviors models, pain interference (-0.322, $p=0.001$) and OA pain severity (-0.233, $p=0.014$) were the only two factors correlated with use of rubs. There was an inverse relationship between these two factors and rubs wherein older AAs with higher pain interference and OA pain severity prefer to use rubs. A binomial logistic regression was performed to ascertain the effects of pain interference and OA pain severity on the likelihood of using rubs. The

overall model was significant ($p= 0.006$) with pain interference and OA pain severity as predictors (see Table 20).

Table 20- Predictors of Rubs

Behavior	Variable	β	SE	Significance
Rubs	Constant	-0.671	0.549	0.222
	Pain interference	-0.549	0.230	0.017*
	OA pain severity1 (mild) ^a	0.954	0.727	0.190
	OA pain severity2 ^a (moderate)	0.602	0.606	0.320
Model Fitting				
Overall Model Sig.		$p= 0.006^{**}$		
Nagelkerke R^2		0.142		
Homer and Lemeshow Test: Goodness of fit		$\chi^2= 8.455$, $p= 0.390$		
Classification Summary Percentage ²		Yes: 68.4%		
		No: 64.2%		

** $p \leq 0.01$; * $p \leq 0.05$

^a Reference category: OA pain severity 3 (severe)

Prayer. For prayer use, the use of spiritual strategies was the one factor positively associated (0.803, $p= 0.000$). From the large correlation, there is a high level of multicollinearity given that prayer is also included in the spiritual strategies variable. To develop a binomial logistic regression with only this variable would be tautological; therefore, no regression model was run.

Aim 3: Describe barriers and facilitators to engagement in the recommended behaviors for OA.

Barriers and Facilitators to Pain Self-Management Behaviors

As illustrated, each recommended OA behavior was associated with its own set of predictors. Some variables proposed to correlate with each behavior were in fact not related nor predictive of engagement. To further understand engagement in each in OA behavior, we investigated barriers and motivators. Based on participant response to engagement (i.e., yes or no) in a particular behavior, they were asked, (1) “If you selected no, what things prevent you from [recommended strategy]?” or (2) “If you selected yes, what things help/motivate you to [recommended strategy]?”. Because these were open-ended, optional survey questions, response rate for each behavior varied. Nonetheless, each recommended behavior had a distinctive set of barriers and motivators. Response rates varied for each question. Because only the most salient (as evidenced by frequencies) barriers and facilitators for each recommended behavior are presented in the following paragraphs, the number of sources reported may not equal the response rate.

Land-based Exercise

Of the 69 (62.7%) who answered this question, nearly half ($n = 29$, 26.4%) reported barriers to engagement in land-based exercise, these being both physical and cognitive barriers. The lead barriers included pain ($n = 9$), lack of time ($n = 6$), lack of motivation ($n = 6$), physical environmental safety ($n = 3$), and mobility limitations ($n = 3$). Pain was equally a barrier and motivator to land-based exercise. Experiencing pain or inducing pain from exercise prevented engagement. One participant who wanted to

exercise commented, *“ain't no sense in getting up to hurt.”* When pain was an issue, one older AA adapted by doing chair exercises. Lack of time was most attributed to work schedule and family responsibilities. The third barrier was lack of motivation to get involved. Although participants knew exercise would be helpful, they reported “laziness” as an impediment. An interesting barrier was an unsafe physical environment, and combined with existing mobility issues, limited participation in land-based exercise. Participants mentioned issues such as uneven surfaces such as pavement and fear of dogs in the neighborhood. Other less critical barriers were having had a recent joint procedure, lack of information about exercise, and arthritis only affecting their shoulder alluding to no need to engage in land-based exercise.

The most influential motivators were opposite conditions of the barriers. For example, the two most common motivators were finding exercise helpful for pain relief (n= 9) and to maintain mobility and good health (n= 8). Other important facilitators for exercising included working out with a group (n= 4), having exercise equipment (n= 2), and to help with other chronic conditions (n= 2; e.g., hypertension and diabetes). Only a few participants mentioned because their provider recommended, having time, exercise as relaxing, and sporadic motivation.

Water-based Exercise

Water-based exercise is a recommendation shown to be effective and safe workout that relieves pain because it provides a zero-gravity/pressure on the joints. However, water-based exercise was associated with major barriers in older AAs. Of the seven recommended behaviors, water-based exercise received the second highest response rate (n = 61, 55.5%) in providing barriers and facilitators. The two greatest

barriers were lack of access to a pool (n= 22) and inability to swim/dislike of water (n= 18). The inability to swim was translated as a fear of drowning, in which one participant commented that she was afraid of water and that she doesn't even fill her bathtub too full. There were a few who although unable to swim, would be willing to learn in order to participate in this exercise because they heard it was helpful. In many of the communities, there was no pool or no pool close by. Some had to drive 30 minutes away if they wanted to attend a water aerobics class. One participant noted that insurance wouldn't pay for a water-aerobics class.

Some mentioned that they had participated in the past and liked it, but personal and environmental safety (n= 7), lack of motivation and time (n= 7 and n= 4, respectively), and health problems (n= 5) prevented engagement. Participants were concerned about their mobility and falling or not being able to get in and out of pool safely. While there were those who simply were not interested or motivated in water-based exercise as a pain-relief strategy, only two participants mentioned pain as a barrier. Interesting enough, there were five participants who said nothing prevented them from engaging in water-based exercise. The remaining barriers cited include lack of information, needing an exercise partner, and personal beliefs. One personal belief reported that symbolizes a generational and cultural belief is *"I don't want to get a cold"* which was shared by an 83-year-old woman. Despite the barriers, several made mention of purchasing a walk-in tub with jets, swim spa, or pool.

Given the preponderance of barriers, there were fewer motivators. Having access to a pool (n= 6) and finding water exercise enjoyable (n= 3) were the main motivators. Having a provider recommendation prompted two people to try water-based exercise.

Only a few older AAs recounted water-exercise as helpful with pain and joint mobility, with one saying *“It’s very beneficial because I really can move without hurting myself as opposed to doing land aerobics.”* Another participant made a similar statement, but pointed out the effect of pain, *“did before and it helped in the water but as soon as got out of care, started to feel the pain.”* It appears the barriers significantly outweigh the benefits to potential users.

Strength Training

This particular behavior had the lowest response rate with only 35 (38.1%) reporting either a barrier or motivator. Several conveyed that there were no barriers (n= 4). Barriers found included not taking the time (n= 3), pain (n= 3), no motivation (n= 2), and health problems (n= 1). On the other hand, there were more motivators described. The primary motivators for stretching, in particular, were relief of pain (n= 9), to strengthen joints and improve flexibility for safe mobility (n= 7), exercising either as a group or individually (n= 6), having exercise equipment (n= 3), and for relaxation (n= 3). By strengthening joints, participants believed their stiffness was reduced and balance was improved. There was agreement that stretching helped with joint pain. When participants exercised in group settings, this behavior was viewed more positively. *“Aerobics is fun and stimulating, in that it is a group activity”* as stated by one person. Some of these group exercises took place at the senior center, church, and during physical/occupational therapy. Of course, having exercise equipment at home, such as simple stretch bands or using soup cans as weights, was a motivator. Lastly, some found stretching as relaxing and as a preparatory step to exercise.

Self-Management Education

Response rates (n = 61, 55.5%) and barriers for participation in a chronic pain or arthritis self-management program mirrored similarities to water-based exercise. A lack of access to a self-management program was the predominant barrier (n= 8). This access was either physical or cognitive, meaning that a program was not available in the area or that participants were not knowledgeable of any programs or of this as a recommendation for OA. Having no knowledge of programs in their area is a potential resource barrier which holds significant implications for self-management and “resourcefulness” may be another key factor in self-management engagement for AAs; this requires future probing. Additional critical barriers related to lack of time (n= 6), information (n= 6), transportation (n= 5), and motivation (n= 2); health problems (n= 3); the belief that such a program would not be helpful (n= 4), and cost (n= 1). In fact, one older gentleman acknowledged, that he didn’t see a reason to take such a class because he didn’t have much time left (number of years); he believed that since he’s lived this long with OA pain that there was no need for this option. Another commented that the program facilitators/teachers “*probably can't teach me nothing... I would teach them.*”

In contrast, the top facilitator included wanting to learn skills to manage OA pain (n= 12). Example skills included learning about pain, medications, types of exercises, best strategies for pain relief, natural remedies, and coping skills (or how to control the mind). Having participated in health-related classes and programs in the past was also motivating factor (n= 5): “*It [self-management program] gives the tools that promotes a healthier life. Learn things for pain modification as well as things to help emotionally*” (UI007). One woman noted an interesting feature of a program she had taken, which was the ability to take various devices home and trial them to see if they help with pain. To

further motivate participation, the program would need to be inexpensive and accessible (i.e., have transportation or be located in the community or home-based). In thinking about how to culturally-tailor a self-management program, these barriers and facilitators must be considered to maximize the program's appeal and effectiveness.

Analgesic Medication

Thirty-six (32.7%) older AAs responded to this question. Surprisingly, there were fewer barriers cited than anticipated. Older AAs had concerns about the negative side effects on organs and health (n= 4), and some resorted to natural remedies or *“trying not to take pain medications.”* Others cited provider reluctance to prescribe (n= 2), high tolerance for pain (n= 1), and fear of addiction and dependence (n= 1). One person distinctly commented that taking hypertension medications helped because it reduced swelling in joints. No doubt the main motivator for using medications, either over-the-counter or prescribed, was because of the pain (n= 18). Participants were seeking pain relief even if temporary. Some had a (1) proactive approach, taking medications to prevent pain, (2) reactive approach, waiting until pain started, or (3) a delayed approach, waiting until pain was severe or unbearable. Medication usage was related to having a provider prescribe the medication or a physical therapist or friend recommend a certain medication (n= 6) and improving physical function (n= 2). As also noted in the quantitative analyses, analgesic medications fell within three drug categories: acetaminophen (Tylenol®), anti-inflammatories (e.g., naproxen [Aleve®], meloxicam [Mobic]), and opioids (e.g., acetaminophen/hydrocodone [Lortab]).

Thermal Modalities

The fifth recommended behavior is use of thermal modalities, and response rate was 34.5% (n = 38). Helpfulness was equally the driving force for use or non-use of warm or cool modalities. As a barrier, when participants felt warm or cool was not helpful or having the “desired effects”, they were more likely to report not using it (n= 10). Some had not thought of this as a pain-relieving strategy. Participants spoke of issues about heat more than cold. For example, one person noted that heat made the pain worse and another person was advised not to use heat due to diabetes. One person mentioned cost as a factor, and had not “made the sacrifice to purchase a heating pad.”

Not unlike other behaviors, pain was the leading motivator for using a warm or cool compress of some sort (n= 15). Heat or cold worked to relieve or ease the pain, as well as help with stiffness and inflammation. A couple of seniors mentioned using heat at night to help relieve pain and relax so they could sleep. A recommendation by a provider or physical therapist facilitated use in a small proportion of participants.

Assistive and/or Orthotic Device

The response rate for this question (n = 32, 29.1%) was directly impacted by their response on the stage of engagement for this particular behavior. That is, most people who indicated “No, and I do not intend to unless I have to” likely did not feel a need to indicate a barrier or motivator. Nevertheless, as one can expect, the prevailing barrier was that participants did not feel they needed to use an assistive device at the time (n= 11). Their OA pain severity had not reached a level that necessitated additional support, or as one participant pointed out, pride prevented use even when pain was severe. One older AA woman stated that she delayed using a cane because “she was trying to be cute.” A clear statement of pride, the qualitative analyses earlier also highlighted this. A couple of

participants noted that orthotic devices were irritating and bulky to wear. On the flip side, *“hav[ing] a cane just in case”* indicated that select participants were prepared to use an assistive device when needed (n= 7), such as during pain flares. For those who were using canes and walkers, it was having the added stability that motivated use (n= 7). This was necessary to support balance and posture and prevent falling. Also, the other motivator was, of course, having pain or to ease the pain (n= 4).

As shown, a specific set of barriers and facilitators emerged for each recommended behavior. Not surprisingly however, either having pain or seeking pain relief was both a leading barrier and motivator to engagement in most of the recommended behaviors, except the use of assistive devices. It is clear that participants responded to behaviors in which they felt more confident. While having a provider or physical therapist recommend a behavior was not the leading motivator, it can be noted that providers play a necessary role in engagement. In addition, the level of involvement required for each behavior also influenced engagement. Knowing these barriers and motivators are pivotal for future intervention studies tailored for older AAs.

Aim 4: Discover older AAs’ preferences for culturally tailoring interventions to promote engagement in OA and CJ pain behaviors.

Cultural Preferences

The qualitative and quantitative analyses illuminated clear cultural preferences. This section discusses preference and treatment interests for self-management behaviors (quantitative survey data), perceptions of culturally tailored education (qualitative

interview data) and perceptions of self-management programs (quantitative survey and qualitative interview data).

Self-Management Behaviors

All 110 participants were surveyed on a preference for a treatment; this data was captured on the APSI. Twenty-three participants either didn't answer the question related to personal preference for treatment or had no preference for a specific treatment. Eighty-seven noted a preference; most common responses are given. Top responses: medications (n= 20), exercise (n= 15), and creams/rubs (n= 14). Nine participants favored were warm/cool therapies, and prayer and joint injections were equally preferred by five participants.

In terms of treatment interests (i.e., things interested in using), 49 people did not provide a response, and 61 provided a treatment. Most common treatments: exercise (n= 10), natural remedies (n= 9); medications, TENS, and creams (n= 6 each); and arthroscopic procedures (n= 5). Two specifically mentioned wanting to use a pain management clinic.

Self-Management Education and Programs

Perceptions of culturally-tailored education. Culturally-tailored self-management programs for AAs and Hispanic older adults are gaining attention, thus, it was our goal to understand older AAs' perceptions of culturally-tailored self-management education and programs. During qualitative interviews, participants were asked, "Imagine you are reading a brochure similar to the ones in front of you. What would you think of an educational pain resource that is developed specifically for African

Americans or Black people?” One man replied, *“Very necessary. I mean anything that make a person aware of what they’re dealin’ with, it’s always just a plus. It’s a plus. It’s like a lot of times I’m in pain, and it’s somethin’ out there could help me, like a rub or just—rather than havin’ to go to the doctor every time”* (UI108). Most believed it was a good idea to have a brochure where AAs could find useful information.

When the PI provided two examples of brochures about arthritis in AAs, one man specifically wanted to know who conducted the research for those brochures: *“Well, if this research is done by an African American, I think it’s great ‘cause we know what we do. A lot of the time we pick up brochures and it say for African Americans, but it’s written by another ethnic group. If it’s written by an African American I think these brochures would be great. See it say understand arthritis on the title—who wrote this research? Who did this research? ‘46 million Americans have arthritis or arthritis-related condition. Probably 4.6 million non-Hispanic Blacks report doctor diagnosed arthritis.’ [reading brochure] See what I’m saying? Who did this study? That’s what I feel about the brochure”* (UI057). Having educational material written for AAs by AAs and with AAs is necessary to increase appeal and use. They felt the information could be trusted, particularly when it was developed by another AA. *“Well if I was reading these articles, I believe—I would believe in them. The articles they write about arthritis, I go along with it. I believe the statement or whatever”* (UI097). In addition, several participants noted a need for the AA community to become more involved in research opportunities; however, this is hindered by a lack of research on issues prevalent in the Black community as well as community awareness of research.

On the other hand, there were a few participants who believed that it didn't need to be culturally-tailored. Then there was a small group who suggested developing both a tailored and general brochure; *"Just I know if it's good for African Americans, it's good for everybody, so—"* (UI061).

A couple of AAs preferred more content and fewer pictures. Participants identified multiple topics that should be discussed in the brochure. These primarily focused on self-assessment and self-management: how to recognize and treat different types of pain and other co-occurring chronic conditions, signs and symptoms of OA, safety, treatment options including spirituality, resources (e.g., insurance coverage of treatments, community-based resources), and a Q&A section. Also, a culturally-tailored brochure should (1) correct misconceptions, such as the need to know how to swim to do water-based exercise, and (2) point out AAs' perceptions of helpfulness of recommended behaviors in an attempt to empower them to use these behaviors. To stimulate greater personal engagement in active strategies to manage OA and CJ pain, one man brought to my attention, *"...if they [other AAs with arthritis] come up with a method that helps them that I never tried, I won't be afraid to try their method. I would try their method, right, to see if it would work for me. If they say it worked for them, now I trust them to try their method and see how would it work for me, right"* (UI097).

Perceptions of a self-management program. Based on the quantitative analyses from the PSMEQ, 70% responded they were interested in taking an arthritis or chronic pain self-management program at some point. Whether it was a formal self-management program or as simple as a community-based seminar, there was a great desire for education. As woman puts it, *"They have the meetings for if you're dealin' with heart*

disease or knee replacements. Even if it's to go to pay \$10.00 or whatever it is. They'll give you a little lunch or whatever. You go to it. We need more of that in the community as a whole. It would be nice to have them at the things that we do already have. We don't have anything about healthcare for anything. Cuz it's a lot of people dealin' with stuff nowadays, young and old" (UI007).

Preferable locations were churches, community agencies such as council on aging, local wellness clinics, recreation centers, and public library. Churches were ideal because ease of access and its responsibility in healing and helping the mind-body-spirit. Community-based sessions were most preferred, *"unless there would be some kind of workshops available or some kind of community sponsored sessions or something that would deal with that type thing"* (UI009). Only two participants spoke about home-based services such as pain palliative homecare (UI094) or having *"...somebody come by and just talk about arthritis"* (UI081). The topics for a brochure and a self-management program were the same, with an emphasis on learning how to do various exercises. Older AAs wanted someone to demonstrate how to do these, and wanted to try various products such as creams and TENS during a self-management program. In any self-management program, the facilitator would be expected to have certain qualities like caring/genuine concern, patience, and a strong rapport.

The theme of "dealin' with it" carried over into their discussion about various cultural preferences. The point in summary is that AAs need help "dealin' with pain" and other health issues. Understanding and mitigating factors that prevent personal management, as well as enhancing those factors that increase access and motivation are paramount to improving pain control in older AAs. Couple this with providing culturally-

tailored education further increases chances to improve pain self-management. The extent to which ensuring their particular preferences are incorporated into self-management interventions will be key to the success of symptom science.

CHAPTER 5: DISCUSSION

In this chapter an integrated discussion of the most salient results, limitations, and implications for research, practice, education, and policy are featured. The study of OA pain self-management can fall in one of two epistemological paradigms- empirical approach and interpretive approach (Shin, 2014). The HOPE Study is unique in that it used both approaches to examine and gain a comprehensive understanding of engagement in self-management for OA and CJ pain as a proximal outcome in an older AA sample. The goal is to use this research to address more distal outcomes, such as pain control, quality of life, and function.

Between years 2002-2014, severe arthritis pain for adults increased 37%, mainly for ethnic minorities, women, and those with existing physical disabilities (Barbour et al., 2016). This new evidence from the CDC shows non-Hispanic Blacks disproportionately suffer from higher rates of severe joint pain (Barbour, et al., 2016). In this study, the majority of AAs' pain was intermittent and perceived as moderate having an average pain intensity of 5.47/10. Pain intensity was lower when compared to other studies with older AAs. For example, Park and others (2015b) reported AAs' pain as 7.5/10; however, their sample was significantly smaller (N=32) likely with less variation in pain intensity and greater variation in chronic pain types. In addition, our sample overall was highly educated and insured, which may support greater engagement and access to pain-relieving treatments. Nonetheless, as a result of joint pain, sufferers may experience limited ability to engage in basic activities of daily living, resulting in compromised quality of life.

We found the overall pain interference score to be relatively low (3.53/10) compared to the amount of pain reported. When items were analyzed separately, older AAs had higher mean interference scores for walking (4.53), doing normal work (4.71), and sleep (4.25). There was a moderately-high standard deviation, likely due to extreme ratings of zero on some individual items, such as mood and relations with others. Consistent with the literature, sleep disturbances, either difficulty sleeping or being awakened, due to arthritis pain have been reported in older AAs (Baker & Whitfield, 2015). Some interviewees did report pain interfering with performing activities of daily living and household chores, but in general they didn't let pain stop them from doing general activities which may have influenced lower ratings. At higher levels of pain intensity, pain interference decreases with age, a likely function of enhanced coping skills (Boggero, Geiger, Segerstrom, & Carlson, 2015). Other studies indicate a marginally higher pain interference score (4.8/10) in a majority sample of AA older adults (Smith, Becker, Roberts, Walker, & Szanton, 2016). It has been postulated that AAs have developed stronger spiritual coping mechanisms in response to chronic pain (Booker, 2015; Jordan et al., 1998); thus, race and age in our sample may mediate the relationship between pain intensity and interference.

Patterns of OA and CJ Pain Self-Management: Qualitative Results

Self-management is increasingly emphasized as a key component in OA and chronic pain. It was evident in our findings that self-management of OA and CJ pain was a fluid, non-linear process strongly influenced by temporal contextual and cognitive factors. The experience of older AAs can be summarized by the substantive theme, “dealin’ with pain” which included the minor themes of “bearing the pain”,

“understanding OA pain”, and “experiencing pain.” Loeb’s focus group study with older AAs with chronic conditions, focus groups revealed nine categories of coping, one of which was “dealing with it”. “Dealing with it” was a prevalent theme and represented an attitudinal and emotion-focused form of coping “to persevere despite the adversities faced in relation to chronic illness” (Loeb, 2006, p. 142). Compared to the HOPE study’s comprehensive representation of AAs’ experience with pain management, Loeb’s definition of “dealing with it” was more narrowly focused on coping. Our study aligns with earlier work such as Loeb’s study, but also extends beyond this work and identifies the intrapersonal, interpersonal, and transpersonal experience of AAs with OA and CJ pain.

From an intrapersonal perspective, participants viewed OA and CJ pain as a deeply personal experience, often hiding pain from others. While they noted people may have similar experiences, OA affects everyone differently. Some, particularly women, found it acceptable to share what they were experiencing with others who cared about them; this interpersonal exchange also extended to providers when they felt providers cared about them as a person and was committed to helping them control the pain. One of Loeb’s participants also mentioned a sub-theme expressed in our study, ‘living with it’; she quotes, “...I guess I’m going to have hypertension for the rest of my life, or arthritis, or glaucoma, or something else that I picked up ...I am just going to have to live with it” (2006, p. 142). Similarly, AAs in our study knew OA was a condition they would have to live with, but were able to be thankful and recognized that they were blessed. This transpersonal view helped older AAs realize the broader picture of continually being blessed despite their condition, and that a positive attitude was needed to cope and live

with pain on a daily basis. In this sense, they were able to adapt and normalize the changes that arthritis brings.

It was clear that management of pain is complex and that contextual and cultural factors add to this complexity. Viewing the experience of “dealin’ with pain” out of context does not allow for understanding how self-management strategies are used within the daily lives of older AAs. Self-management is currently viewed as what people do on their own to manage a chronic condition; however, we were able to gain a more comprehensive view of self-management and better understand how AAs are dealing with providers; navigating their social network and dealing other people’s perceptions; using, adhering, and adapting medication regimens; coping; and seeking information. A major deficit was their need for information from providers to help manage OA, but providers rarely had conversations with older AAs about a comprehensive pain management plan nor were educational materials available in providers’ clinics.

Each sub-theme was interconnected in some way and no sub-theme occurred in isolation. Therefore, it is important to acknowledge the interconnections among minor themes and how they influence self-management.

Interconnections among Themes and Sub-categories

Interactions within themes and/or categories and sub-categories are referred to as paradoxes. Paradoxes can be defined as inconsistencies, ironies, or oxymora. When it came to sharing pain with close friends and others’ perceptions of their pain, participants were generally stoic and did not discuss pain, but believed it was okay if others knew they were in pain. Not discussing pain, however, may cause others to discount their pain,

and in somewhat contradictory views, older AAs simultaneously acknowledged a need for greater social support and understanding and compassion from family and friends. They desired for others to care about them without judgment or pity.

In general, older AAs don't talk about pain, and this was actually a way of bearing the pain as well as coping with pain. AAs shared childhood experiences of older relatives with OA who've since passed on. This older generation was rooted in hiding pain in order to continue to care for their family. While maladaptive, from a post-colonial perspective, keeping pain to oneself was a survival mechanism. However, this is detrimental to current generations of older AAs, who prefer to keep pain to themselves. Without sharing pain, especially with providers, they limit opportunities for pain control. Participants' powerful statements shed light on the effect of history on generational health and point to the relevance of epigenetics and the social determinants of genetics. While the genetic component was a troubling issue, most understood that things could be done to try and control the pain.

The second ironic pattern was that of praying for life's problems and health conditions, except OA and CJ pain. It was quite surprising to find that only 42% of AAs used prayer for pain. Upon further probing, it was revealed that while they usually pray on a daily basis or use other spiritual strategies, they had never used prayer for pain management. Many told me, "I do all these things [spiritual strategies], but not necessarily for my pain." Most had never prayed for the pain to go away or for help in managing pain. In fact, some did not understand how prayer or other spiritual strategies could overtly be used in pain management. When the PI explained these as coping mechanisms or distraction techniques, they were quite enlightened. These results provide

some contrast to the current literature. Specifically, the PI has even published an article detailing how older AAs use spiritual mechanisms, such as prayer, hymnals, and scripture, for pain management (Booker, 2015). Others have also found prayer and spirituality as relevant and important strategies for the management of OA and cancer pain in AAs (Buck & Meghani, 2012; Ibrahim et al., 2004). Prayer was a powerful method that helped distract them from pain and spirituality gave meaning to the pain (Buck & Meghani, 2012), while reading the Bible and gospel songs were sources of comfort and guidance for older AAs with experiencing stressful life events, such as arthritis and other chronic illnesses, work-related stress, and death of a loved one (Hamilton, Moore, Johnson, & Koenig, 2013; Hamilton, Sandelowski, Moore, Agarwal, & Koenig, 2013). In the HOPE study, the importance of the Bible in providing guidance for health issues was noted; 23 participants reported reading the Bible or other religious materials. Through it all, AA older adults trusted that God was a healer (Ibrahim et al., 2004; Park, 2013a).

The third paradox is that of being blessed in spite of having OA and CJ pain. AAs were quick to highlight that they were blessed despite having OA and physical limitations. Buck and Meghani (2012) defined this as the ‘living paradox’ in that individuals could simultaneously experience blessings even amid pain. In their study, only AAs expressed this theme. In the scheme of things, for AAs, pain was a small price to pay if their experience could help someone else or show gratitude and appreciation for Jesus’ sacrifice. Feeling blessed and relying on God to heal and alleviate arthritis pain was also noted by Loeb (2006). Many in our study identified blessing, (1) to be alive, (2) arthritis is not as bad as it could be, (3) gives me days without pain, and (4) a select few

had good providers. As one participant relayed, *“Through God I know all things are possible. That’s what I believe, baby. I wouldn’t be walkin’. They [providers] don’t understand to this day how blessed I am... So I’m trusting God. I think if they had not been for him, darlin’, I would be dead. I know I would”* (UI007). To have providers acknowledge these blessings as well as the need to care for the whole man- body, mind, and spirit- may encourage AAs not only to seek professional care but to use treatments as prescribed. This leads to another paradox concerning professional treatment and personal self-management.

A fourth paradox, and quite disturbing, that older AAs seek providers’ help only to be told to “deal with it”. Thus, when recommendations are made, older AAs did not always adhere to the recommendations from providers often adapting them to how they want to use treatments. For example, prescribed oral pain medications were used as needed, primarily when the pain became severe, rather than on a routine basis. From AA elders’ narratives, we identified behaviors that were or weren’t in line with what was recommended. For example, use of assistive devices are recommended to help protect joints from added pressure and injury. However, older AAs made decisions to use assistive devices as functional impairment worsened.

Resting and limiting physical activity was nearly as important as exercise and physical activity for managing pain; this was the second paradox discovered. When the pain was severe, rest was necessary, but exercise was also used to ‘head off’ severe pain. AAs understood that exercise was important in managing pain, but on days when pain was bad, they tended to rest. Sometimes this backfired as one participant noted, *“Sometimes sitting too long, if the pain is there and I sit too long, the pain will get*

worse” (UI075). Resting was a double-edged sword on the one hand it helped to relieve acute flare-ups but long-term rest also increased stiffness and pain. Silverman et al. (2008) noted that limiting activity or using rest was more common among CAs (~40%) and less for AAs (~25%) and provided qualitative examples of specific rest methods used by AAs and CAs (p. 328). We found similar examples were common among AAs in our study. Comparisons are as follows:

Silverman et al.: *“Just get off of it.”*

HOPE Study: *“I have to take some time off whenever they— my knees flare up”* (UI098).

Silverman et al.: *“Prop legs up in my chair.”*

HOPE Study: *“If I’m at home, I just go prop ’em [legs] up and lay and let it pass”* (UI008).

Silverman et al.: *“Rest and elevate it.”*

HOPE Study: *“I know one thing good for leg pain, elevation and massage”* (UI094).

Silverman et al.: *“Stay off of it and rest until the pain goes away.”*

HOPE Study: *“I’m in a flare-up, I’m gonna rest baby. ...cuz if you don’t, it’s just gonna tear you down even more”* (UI007).

While our findings support earlier work, we advance this area of research by investigating helpfulness, reason, and predictors for use of various self-management

strategies, how older AAs engage providers in their self-management and implement their recommendations into their daily regimens, and cultural preferences. With regard to cultural preferences, some early testing of cultural adaptation to programs has been conducted (Parker et al., 2012; Goeppinger et al., 2007) along with exploration of arthritis educational needs (Mingo et al., 2013). Our study adds data specific to cultural-tailoring of educational material and programs and brings attention to misconceptions and areas within the self-management process that warrant greater education.

In addition, our study clearly identifies a shared decision-making process, barriers to this process, and what older AAs want from providers; that is to give their expert opinion on how to manage pain in order to make an informed decision. It was providers' lack of care, time to educate patients, and apathetic management approach that limited older AAs from effectively linking self-management and professional management.

Patterns, Predictors, and Barriers/Facilitators of Self-Management: Mixed Results

The intricate relationship of confounding barriers, facilitators, and preferences has contributed to compartmentalized engagement in self-management behaviors. Long-standing cultural barriers, spiritual beliefs and practices, and healthcare disparities in access to treatment have stood in the way of older AAs capacity to successfully understand and manage OA and CJ pain. As a result, AA older adults have developed a set of culturally-preferred self-management behaviors, some of which are congruent with recommended behaviors.

The top 10 complementary self-management behaviors used by AA older adults were: OTC creams and rubs (57%, 52% respectively), warm baths/showers (56%),

exercise (52%), OTC NSAIDs (48%), Warm/cool compress (43%), prayer (42%), OTC Tylenol® (35%), prescribed NSAIDs (33%), and orthotic devices (33%). Use of thermal modalities and assistive and/or orthotic devices were similar to our results, but OTC and prescribed medications were used by higher proportion in Silverman’s 1999 study (see Table 21). Current reductions in medication use may be influenced by national campaigns in recent years to reduce prescribed opioid use and to reduce inappropriate medication use in older adults. Exercise was used by both groups at generally high rates, over 50%. Despite advances in dissemination of knowledge (online, media outlets), all behaviors had lower rates in the HOPE study compared to AAs from 1999. Perhaps greater emphasis on other chronic conditions plaguing the Black community, such as diabetes, hypertension, heart disease, has taken precedence over chronic pain, something that is expected among older AAs.

Table 21- Comparison Rates for Complementary Behaviors

Behavior/Strategy	Silverman et al. (1999) N= 55	HOPE Study N= 110
OTC medications	70%	48% (NSAIDs) 35% (Tylenol®)
Prescribed medications	58%	33% (NSAIDs)
Exercise	67%	52%
Thermal modalities	58%	43%
Orthotic/Assistive Devices	38%	33%
Self-education	1.8%	< 1%
Creams and rubs	-----	57%, 52% respectively

Because four of the complementary behaviors used by AAs are also recommended behaviors- exercise, analgesic medications, thermal modalities, and assistive and/or orthotic device use- this section will focus only on discussing the patterns, predictors, and barriers/facilitators for the eight behaviors (i.e., seven recommended and one complementary) included in predictive modeling. One strength of the study is its exploration not only of use complementary behaviors but also patterns of engagement in recommended behaviors shown to be effective in reducing pain and improving function.

Land-based Exercise

Land-based exercise is one of the five core OA treatments (McAlindon et al., 2014), and is recommended in 12 of 15 OA guidelines (Nelson et al., 2014). Over half of participants (61%) in this study reported engaging in some type of exercise (i.e., Action stage), but one-third also reported not being engaged (i.e., Preparation stage). Park et al. (2014) reported a slightly higher percentage of 71% of older adult AAs using non-aquatic exercise. Compared to those in the action stage, pain interference predicted non-participation in land-based exercise. That is, those with higher pain interference were more likely to be in the pre-contemplation stage. Pain intensity that interferes with activities such as walking ability is likely to lead to avoidance of any type of impact-related exercises that exacerbate their pain. Participants confirmed this by reporting pain as one of the major barriers to land-based exercise. On the other hand, those in the Action stage reported pain relief as a motivator for engagement. If pain prevents exercising, it may be necessary to introduce low-impact aerobic exercise, such as chair exercises, walking, and dancing.

Park et al. (2014) shed light on ethnically diverse older adults' awareness of non-pharmacological pain treatments. Older adults were highly aware of land-based exercise (labeled non-aquatic exercise in Park's study) and water-based exercise recommendations, yet primary care providers' recommendations of these were extremely low (Park et al., 2014). Our sample of older AAs was also well-aware of land-based exercise for OA and CJ pain, yet barriers, such as pain, mobility and safety, and lack of time and motivation, prevented them from exercising. Similar barriers to physical activity (i.e., structured exercise and physical leisure activities) for AA and CA older adults were identified as pain, falls, injuries, and health issues (Kosma & Cardinal, 2016; see Table 22). Samples in both studies were from southern states, which lends greater credibility and generalizability of our results to other older AAs in the South. Our study adds data on barriers and facilitators to specific types of exercises to help explain stage of engagement. It is likely that more active individuals report fewer barriers and more facilitators as compared to those less active. In retrospect, our land-based exercise variable likely captured both exercise and physical activity, and some participants in their interview reported the importance of "staying active", not necessarily exercising.

Table 22- *Comparison of Sample Quotes on Barriers and Facilitators to Physical Activity*

Category	Advantages & Facilitators (Kosma & Cardinal, 2016)	Facilitators (HOPE Study)
Pain & injury	-----	Sometimes just doing exercise helps minimize pain in joints
Time & accessibility	-----	Have time now since retiring
Mobility & safety	Keeps you moving, Walk better	To keep moving, The exercise helps me to walk and help with my balance
Strengthening	Strengthens muscles	It strengthens my bones and the surrounding muscles and keeps my joints strong

Table 22- continued

Overall health & chronic conditions	Health, Physical health being well, Controls high blood pressure	To keep body in good shape, for health, To help control diabetes, Exercise for blood pressure
Social support	Family, Friends, Peers	Working out with church group and just like it and being with people, Like working out with a partner
	Disadvantages & Barriers (Kosma & Cardinal, 2016)	Barriers (HOPE Study)
Pain	Knee and leg pain, Injury	Knee pain keeps from walking
Time & accessibility	Accessibility, Equipment, Transportation	No time b/c work and family
Mobility & safety	Injuries, Risk of falling	Mobility issues, fear of falling
Overall health	Illness	Health problems, Get out of breath quickly due to enlarged heart
Social support	-----	If could find someone to go with- cousin says it's great

Water-based Exercise

The literature provides little evidence on the use and effectiveness of water exercise for AA older adults. We were able to identify engagement level in and perceived helpfulness of water-based exercise. Although the majority of AAs reported being aware of water-based exercise for OA, approximately 92% of older AAs were not engaged in water-based forms of exercise, and only 8 reported use. Similar results were found by Park and colleagues, wherein most older adults reported knowledge of aquatic exercise, but only 12 of 70 older AAs participated. Only a few participants reported their primary care provider recommending water exercise as a treatment therapy, and none of the family physicians in Park et al.'s study recommended this therapy. However, the high

rates of awareness point to the strong influence of family and friends and media in attaining knowledge and affecting behaviors.

When the barriers and facilitators were analyzed, it became apparent that inability to swim (i.e., fear) and access to a pool were the primary factors limiting engagement. Even while some acknowledged the benefit of aquatic exercise in relieving pain, these barriers were overwhelming constraints. A study by Fisker and colleagues (2016) revealed that pain relief was perceived as a benefit and motivator for use of water-based exercise by New Zealander older adults. Perhaps if older AAs had access and resources to overcome the fear and attitude towards water-based exercise, they would be better equipped to understand the benefit of this type of therapy. A future intervention study may do well to include a swimming class or partner with local facilities with pools (i.e., YMCA) to offer a free or reduced price swimming class. One study of middle-aged and older adults with OA reported reductions in joint pain and stiffness and improvement in muscle strength and function after a three month swimming and cycling intervention (Alkatan et al., 2016). Research shows the benefit of water-based exercise resulted in relieving pain intensity and improving function in those with knee and hip OA (Zhang et al., 2009), with the knee as the most common site for older AAs. Due to the high number of people not involved in water exercise, none of the independent variables were significantly correlated with engagement. It is highly probable that access, fear beliefs, and inability to swim are the factors most salient to this variable.

Strength Training

Engagement in strength training was related to having knowledge about this strategy, motivation, and confidence. Those who were not knowledgeable about strength training were likely to be in the pre-contemplation and preparation phases. Very few studies have examined strength training in older AAs for chronic pain, but one study did find that strength training increased after participating in an arthritis self-management program (Parker et al., 2011). It is quite plausible that awareness and knowledge are key factors for certain groups of AAs' engagement. Strengthening exercises, in combination with land- and water-based exercises, are important because they are associated with reduction in OA pain (knee: 0.32, 95% CI 0.23, 0.42; hip: ES 0.38, 95% CI 0.08, 0.68) (Zhang et al., 2009).

Self-Management Education

Data reveal that nearly all older AAs had not participated in an arthritis or chronic pain self-management program, but are interested in attending such a program at some point. Currently, there is no chapter of the Arthritis Foundation based in Louisiana; the nearest is located in Little Rock, Arkansas. In addition, a quick online search for health and wellness seminars offered in the cities where our participants resided yielded little success. At one of the local health systems, a free Joint Replacement Camp, was offered, but nothing on self-management or preventative interventions were found.

In our sample less than 1% engaged in a self-management program or self-directed education, and in Silverman's study it was less than 2%. We know from previous studies that accessibility to self-management programs is low for AAs, and the lack of tailoring to AAs' needs and culture negatively impact interest, participation, and

outcomes (McIlvane et al., 2008; Shengelia et al., 2013). Water-based exercise and self-management exercise had the least engagement, perhaps due to major challenges in access. Knowledge of self-management education was the only significant predictor, wherein not being aware of this recommendation was predictive of being in the pre-contemplation and preparation stages.

Accessibility, availability, and cost of this modality may therefore factor into the discrepancy between awareness (knowledge) and low level of engagement but high interest. As one older gentleman commented in regards to the need for a tailored educational brochure for AAs with OA, *“Very necessary. I mean anything that make a person aware of what they’re dealin’ with, it’s always just a plus. It’s a plus. It’s like a lot of times I’m in pain, and it’s somethin’ out there could help me, like a rub or just—rather than havin’ to go to the doctor every time”* (UI108). There appears to be some discrepancy in what older AAs need, want, and can access. Older AAs needed more education and easy-to-access resources. Yet, providers were not providing adequate health resource materials in office or making recommendations or interdisciplinary referrals to physical therapy, pain management clinic, or orthopedic specialists. Thus some AAs became disillusioned with providers’ care and felt a need to seek second opinions. Older AAs gave the impression that some providers were defensive when patients discussed seeking a second opinion. So older AAs left to “deal with it” on their own.

Analgesic Medication

Taking analgesic medication, whether prescribed or OTC, was one of the most commonly used behaviors by 93%. Forty-eight percent used OTC NSAIDs, 34% used OTC Tylenol, 33% prescribed NSAIDs, and 30% prescribed opioids. Older AAs in this study used OTC and prescribed medications at lower rates, 48.2% and 33% compared to 70% and 58% respectively (Silverman et al., 1999). A more recent study with 400 AA older adults documents that 47% are taking pain medications for chronic pain, and NSAIDs had the highest rate of 77% (Yazdanshenas et al., 2016). While our NSAID rate was lower than Yazdanshenas, this was the drug class with the highest usage rate for both OTC and prescribed.

Most AAs reported using OTC and prescribed NSAIDs medications as needed. This is common in older AAs; take the response from an older AA man in Loeb's study, "I take medicine for it [arthritis]. And when I take it, it clears up" (2006, p. 144). Despite not having a consistent medication regimen, they had taken OTC and prescribed NSAIDs over an extended period of time. This has serious implications for medication safety. Long-term use of NSAIDs in older adults is not recommended, and many prescribed NSAIDs and some muscle relaxers are found on the Beers criteria as potentially inappropriate medications (PIMs) (American Geriatrics Society, 2015). The Beers criteria is a list of PIMs whose risks and adverse effects outweigh the benefits, and these medications are classified as "Avoid" or "Use conditionally or cautiously". Adverse effects related to gastrointestinal bleeding and increased risk for cardiovascular events are the major risks limiting NSAID use. Findings from a meta-analysis provide evidence of significant increases in risk for or occurrence of major vascular, coronary, and gastrointestinal effects. In particular, "-coxibs," diclofenac, and ibuprofen increased risk

for coronary events such as myocardial infarction; ibuprofen use doubled heart failure occurrence and all NSAIDs significantly contributed to upper gastrointestinal problems (Coxib and Traditional NSAID Trialists' (CNT) Collaboration, 2013). NSAIDs use is a significant risk factor for acute kidney injury in older adults (Kane-Gill et al., 2015), specifically "-oxicams" (e.g., meloxicam) place patients at twice the risk for chronic kidney disease (Ingrasciotta et al., 2015). Among those who reported the name of medication in our study, the most common prescribed NSAID was meloxicam (Mobic®) and OTC NSAIDs were naproxen (Aleve®) and ibuprofen. Fewer than 10 participants reported using diclofenac. Despite the risks and Beers criteria, older AAs have high rates of NSAID use (Bazargan, Yazdanshenas, Han, & Orum, 2016b; Yazdanshenas et al., 2016).

In terms of skeletal muscle relaxants, cyclobenzaprine (Flexeril®) was most common among HOPE participants, which is listed on the Beer's criteria. Although not an explicit question, no one reported any adverse effects of muscle relaxers; in fact, most rated these as moderately or very helpful. Controversy surrounds effectiveness of muscle relaxers for reducing pain, but if older AAs believe these to be effective, it is worthwhile exploring how these can be safely implemented into care given their high neurological risk for increased incidence of falls. In Bazargan's et al. (2016b) PIM study, only 13% AAs were taking some type of muscle relaxer.

When Bazargan and colleagues (2016b) reviewed the types of medications, 278 (N= 400) AA older adults with chronic pain were using at least one PIM. Specifically, 63% had arthritis and were using an average of 0.85 (\pm 1.04) PIM pain medications. Most of these were in the NSAID category, with aspirin having the highest users (N= 170,

42%). The authors noted that high use of aspirin may be related to its treatment of cardiovascular and cerebrovascular conditions, but they did not provide any information on the dosage for aspirin or any other NSAID medications (Bazargan et al., 2016b). Therefore, the indication for aspirin is unclear. The use of PIMs was significantly associated with drug-drug interactions, medication duplication, and having multiple chronic conditions and multiple providers.

Compared to the 12% (N= 48/400) using opioids in Yazdenshenas et al.'s study (2016), greater than 30% were prescribed opioids in our sample. However, older AAs mainly used opioids on a prn basis, only using when pain was severe. Using Pound et al.'s Model of Medicine-Taking, Paterson and colleagues qualitatively examined opioid use decision-making for chronic pain. They found that patients "used a variety of strategies to evaluate, avoid, reduce, self-regulate, and replace opioids" (2016, p. 716), and these decisions were related to being prescribed opioids and patient–doctor communication, lay evaluation of concerns related to risks, benefits, and acceptability, concerns related to stigma and identity, outcomes of use as defined by self-regulation and self-care patterns (Paterson et al., 2016). This same model can be applied to our sample.

Greater prn use of opioids was related to concerns about the negative effects medications have on the body, such as kidney and heart function. One woman particularly did not take opioids because she didn't want to "*kill her heart*" (UI007). Older AAs' evaluations of what opioids would do to their body and health was a strong determinant in its use. These concerns were fueled by the stigma of taking opioids, and not wanting to be someone dependent on strong pain medications to function. Lastly, older AAs developed their own regimen for taking opioids with regards to frequency and

medication substitution. Paterson et al. defined this as self-regulation, in which patients adjust the dose, either increasing or decreasing the dose and replacing or supplementing with other medications or treatments (2016). It was a pattern for older AAs to substitute non-opioid medications such as Aleve®, Tylenol®, or ibuprofen for opioids or use opioids as needed rather than routinely. Anecdotal data reveal that despite a high use of medication, many older AAs prefer not to use medications as first-line treatment, resorting to creams and rubs and thermal therapies instead.

Assistive and/or Orthotic Device

Participants either fell into the pre-contemplation or action stage with regard to assistive and/or orthotic device use, 46% and 49% respectively. This was higher than the proportion reported in Silverman and others' study with 32% (1999). Those in the pre-contemplation stage cited there was no need at this time. On the other hand, people using these devices were significantly less likely to be employed or have social support, have greater pain interference, and moderate-severe OA. Because no validated tool to measure actual support was used and measured as a yes/no variable, our social support variable is more indicative of perceived social support. It was surprising that most responded they did not receive help from informal and formal caregivers, whether family, friends, or health professionals. This contradicts the traditional close kinship nature of the AA family and community. This begs the question whether social dynamics and values of the AA community are changing in a rapidly growing technological and self-preoccupied society. Even though the logistic regression models are touted as "predictive models", only relationships or factors associated with dependent variables are shown. Findings are spurious in terms of causation or prediction for engagement. Factors considered

predictors aren't antecedents for engagement but are consequences of functional decline. For example, employment and social support are not really needed for AAs to use assistive devices. Rather, as function declines, AAs are more likely to be unemployed and less social. Thus these are consequences of use versus predictors of use; function and/or pain interference are confounding factors.

The main barriers were no need and finding the equipment bulky or irritating. The decision-making process to use assistive devices lies in adjustment and acceptance of their condition as well as perceptions of need. An older study examined this process in nine older African Americans, and identified four themes: interpreting cues for need, accepting use, integrating use in daily life, and anticipating future use and/or discontinuation (Copolillo, 2001). A couple of women in our study commented that pride delayed their eventual use of a cane, and others wanted to maintain their independence and not depend on an assistive device. The stigmatizing perception that use of mobility aids equates to aging, having difficulty walking and losing your independence, and wanting to remain fashionable are relevant concerns for AAs (Resnik, Allen, Isenstadt, Wasserman, & Iezzoni, 2009). When discussing her inconsistent use of assistive devices, one woman explains, *"You're not ready for everybody to see that. You done got here. You still wanna be who you was. And you haven't accept the fact that you're not"* (UI018). Identity and social perception may deter utilization, and providers may need to provide more aggressive recommendations for use.

Although some did not use devices on a consistent basis, they were prepared to use them especially during a pain flare. Environmental specific use was identified when participants mentioned keeping these devices in their car, as they anticipated its use

because they never knew when the pain would start. They felt more inclined to use such mobility aids in public to enhance safety. Devices included canes, walkers, wheelchair/motorized wheelchair, crutches, knee braces, and joint sleeves. Facilitators for use included improved balance and stability to prevent falling and relief of joint pressure and subsequent pain. Interestingly, AAs are 1.2 times more likely to use assistive devices as CAs, and being middle-aged to younger-old cohorts increased likelihood by 40% (Resnik & Allen, 2006).

Rubs-OTC

Older AAs often selected use of creams and rubs to manage pain, 52% and 57% respectively. From participant narratives, it was clear that use of creams and rubs as an acceptable treatment was not only passed down through generations but a strong cultural strategy. In fact participant comments, such as “*I’d rather rub something on it*” (UI081), explain why previous studies show that AAs (43%) used topical modalities for OA at three times the rate of CAs (14%) (Silverman et al., 2008). AAs are likely to perceive OTC creams and rubs as safer and helpful, both motivators for use. OTC creams were referred to as ointments, liniments, salves, and rubs. However, rubs were usually thin liquids such as rubbing alcohol and Watkins liniment. These rubs were massaged directly on the painful area or poured into their bath water for soaking. Sometimes, Epsom salt was also put in bath water. A recent study by Quandt and colleagues also reported that older AAs use rubbing alcohol and Epsom salts for joint aches (2015). A few in our study used Vick’s salve (Vick’s vapor rub) for soreness with the belief the mentholatum would alleviate some aches. However, none in their study used Vicks vapor rub for this purpose; it was mainly used for colds and respiratory illnesses (Quandt et al., 2015). The overall

model with both pain interference and OA pain severity was significant, but only the pain interference was significant for use of rubs. Greater pain interference increases use of creams of rubs.

Our findings present clear evidence on cultural preferences for current and future care. The behaviors with greater engagement have similar characteristics: relatively inexpensive, accessible, easy to use, and perceived as safe and helpful. It is possible that strategies and behaviors such as use creams and rubs, warm baths and showers, and OTC medications are more accessible, tangibly and mentally, than other effective complementary modalities, such as TENS, physical therapy, or cognitive behavioral therapy.

In summary, there are notable contextual and process factors influencing older AAs engagement in recommended behaviors. Each behavior is associated with its own set of factors that limit or facilitate engagement. Engagement levels in various behaviors point towards cultural preferences which have important implications for patient education and provider cultural competence.

Triangulation of Findings

A central tenet of MMR is intentional triangulation, that is, meaningful integration of quantitative and qualitative results when gathered to address different questions or aims. The purpose of triangulation refers to several activities (1) collection of quantitative and qualitative data, (2) using each data source to explain divergent findings or support convergent findings, and (3) understanding the whole of a phenomenon through connecting, merging, and embedding data. The triangulation

process for this study took on a reflexive (or constant comparison) approach, going back and forth between the results of each strand to understand the comprehensive process of pain self-management. The outcome of triangulation often leads to future research questions and/or current implications for practice, research, education, and policy.

So what does all of this data mean? Overall, this study explored engagement in pain self-management, and two aspects clearly emerged: self-management is both a personal experience and cultural experience, each of which are influenced by an individual's contextual environment. Research findings provide compelling evidence related to major concepts of self-management engagement, bio-behavioral interventions, spirituality, shared decision-making, and pain interference and disability in AA older adults.

Both the qualitative and quantitative data show that AAs engage in a variety of physical, mental, emotional, and spiritual self-management and coping behaviors. Engagement in some of these are based on AAs' knowledge of their effectiveness, whereas others are based on cultural norms and tradition. Moreover, the various factors (or predictors) either alone or in combination work to diminish or enhance the process and outcomes of OA and CJ pain self-management. According to the Motivational Model for Pain Self-Management, motivation is key to how individuals learn to manage, cope, adapt and maintain pain management (Jensen et al., 2003a). However, motivation was not a predictor for engagement in behaviors in this sample, but may conceivably be a mediating factor (or an intrinsic or less conscience factor) along with knowledge, pain interference, and confidence.

Mixed modeling is beneficial for understanding an under-studied issue, but deconstructing and re-constructing older AAs' patterns of self-management is complex. For example, we now have a more comprehensive picture of exercise behaviors. Most older AAs engaged in some form of land-based exercise and found it to be helpful in controlling the pain, despite pain being both a barrier and facilitator. Exercise also meant staying active through physical activities. Despite high levels of exercise engagement, qualitative interviews further revealed a continuing need for education on how to do various types of exercises based on individual arthritis severity. Subsequently, this study demonstrates that reducing pain disparities through consistent and effective engagement in evidence-based behaviors requires attention to multiple intrinsic and extrinsic factors.

Limitations

Generalizability and Transferability

Findings are limited to community-dwelling, non-institutionalized older AAs residing in a discrete geographic location (north-central/northwestern LA), and therefore cannot be generalized or transferred to other populations of older African Americans. However, participants were generally either from a rural or urban area, and findings on stage of engagement were not significantly different between those in rural and urban settings which strengthens external validity. Our sample had a fairly high education level- only 12 (11%) did not complete high school and 31 (28%) with only a high school diploma or GED, and 23% had a college degree. This may help explain greater engagement in select recommended behaviors such as land-based exercise or use of medications and a stronger appeal for shared treatment decision-making. Because our

sample was highly educated, insured, and had a primary care provider, findings are not generalizable to other communities of older AAs with lower education levels and access to care. Our findings compare to national data where 23% of AAs have a bachelor's degree, but the number with college degrees decreases as age increases (United States Census Bureau, 2016).

Inferences and Power

The cross-sectional nature of the study only demonstrates associations between the dependent and independent variables; therefore, causal inferences cannot be drawn. In addition, because this was a descriptive exploratory study, the traditional rule of thumb for determining sample size was used: number of predictors * 10. Because we expected some variables to be eliminated at the correlational stage, a sample size of 110 was considered sufficient. Despite this, the distribution of categorical variables on some levels (or stages of engagement) of the dependent variable resulted in what appeared to be “missing cell values” or cells with zero frequencies. Because there were no missing data points, we attempted to resolve this issue by collapsing the five stages of engagement into three stages without losing the theoretical significance and empirical predictive value of the stages. The number of cells with zero frequency was reduced, but this issue nonetheless reduced power to determine true effect of the factors on predicting engagement in these various behaviors. The overall strength of relationship and model fit were interpreted with caution and transparency. Only one recommended behavior, self-management education, was normally distributed which allowed for a more accurate interpretation.

A few independent variables lacked objectivity and measured “perceptions of” rather than actual representation (i.e., social support, self-efficacy), which limits the inferences that can be made regarding the effect and/or importance for self-management. Also, there was a considerable lack of variability in a number of independent and dependent variables, possibly resulting in extrapolative conclusions about the population of older AAs. The simplistic method of questioning and measurement could arguably have contributed to the homogeneity of responses. On the other hand, homogeneity of responses can be meaningful in understanding a population as a cultural group.

Biases

Data for this study were obtained from a convenience sample and through self-report measures which introduces several sources of bias. For the first 50 participants, OA was determined by asking participants a single question, “Do you have osteoarthritis?” However, some participants (1) unsure if they had osteoarthritis or rheumatoid arthritis, referring simply as rheumatism or “it’s not the crippling kind”, (2) some of the symptoms later described by some participants appeared to be related to rheumatoid arthritis or other chronic joint conditions. Because information was based solely on self-report, a misclassification bias of OA may be present. Thus, a decision was made to improve sensitivity of the OA status. The remaining 60 participants were now asked the following questions:

1. Have you ever been told by a doctor that you have osteoarthritis? Yes or No

If **yes**, have you had an x-ray, MRI, or other imaging procedure to determine if you have osteoarthritis? Yes or No

If **no**, do you experience any of the following symptoms of osteoarthritis?

- a. swelling in any joint: Yes or No
- b. stiffness in the morning or after being inactive: Yes or No
- c. pain that gets better with rest but worse with activity: Yes or No
- d. crepitus or grating sound or feel when walking or bending: Yes or No

If at least 3 symptoms/signs are not present, **EXCLUDE** and do not proceed with questionnaire.

The above questions were already included in the Participant Characteristics Questionnaire, but were not used as eligibility screening criteria for the first half of sample. We do not anticipate that the initial criteria yielded any false positives with regard to some having RA versus OA. If so, chronic joint pain was still present, and the behaviors used are not likely to skew results given that those with RA and OA use many of the same pain management strategies. There may be potential differences in types of medications and rates of assistive and/or orthotic device use given a more critical need to protect joints.

Secondly, self-report often produces socially desirable responses, particularly on questions that are perceived to be associated with a societal norm. For example, questions about exercise or healthy diet and weight control may have elicited desirable response. Thirdly, because participants were asked about strategies used within the past month, recall bias is a possibility, but older AAs were typically able to identify the strategies they

have used for pain. Although increasing the period of time for which participants must remember events decreases the accuracy of recall, it “may also make the period more representative” especially when self-reporting symptoms, such as pain, which are highly variable from day-to-day (Fadnes, Taube, & Tylleskär, 2008, no page). Lastly, interviewer bias may have prompted some older AAs to report more or less strategies.

Implications

National OA recommendations emphasize research, quality and equity in OA care, access to evidence-based arthritis interventions, and promotion of self-management (Lubar et al., 2010). The IOM (2011) and National Pain Strategy (2016) provide key recommendations related to education of providers, increasing recruitment of AAs into scientific studies, reducing disparities through promotion of self-management and equitable treatment. Thus, the implications for practice, education, research, and health policy are abundant; this section will attempt to succinctly overview key implications.

Practice

Eighty-four percent of AA older adults reported that managing pain was just as important as managing their other health conditions. However, clear gaps in education, provider support, and access to resources limit management. The clinical significance is that older AAs with symptomatic OA and CJ pain are in great need of self-management and clinical interventions that are both effective and preferred. The only way this can be done is through continuous engagement with community-based older AAs in practice and research settings. From a stage-theory perspective, interventions to facilitate change will be most effective if they are tailored to the stage an individual has reached within this

process (Eccles et al., 2012). For AAs, this means taking into account critical contextual factors such as pain interference levels, social support, and increasing knowledge. When geriatric and community-health nurses consider cultural norms and values, pain interventions for ethnically diverse older adults can be optimized. This means providers being open to working within older AAs' patterns of medication use, understanding their preference for creams and rubs and less invasive strategies, and use of spirituality to cope with pain. There are clear indications for assessment, treatment, and monitoring.

Assessment. Given that pain interference was such a strong predictor of engagement in OA behaviors, providers should always assess how pain impacts various elements of physical and mental health but also use of various recommended behaviors. If pain interferes with behaviors such as land-based exercise, it would be wise that providers make referrals to physical therapy or exercise physiology who can demonstrate to older AAs low-impact exercises to help with pain.

Treatment. While there are efforts to promote OA self-management, providers must be instrumental in ensuring their patients have access to the resources that motivate engagement in self-management. This includes simple solutions, such as having educational material in clinic offices or distributing to local churches, offering free health seminars at churches and community centers, or having a patient education nurse where patients could take time to discuss a pain management plan. Understanding and mitigating factors that prevent personal management, having provider support, and increasing motivation are paramount to improving pain control in older AAs. Providers must become clear on the contextual factors, such as lifestyle habits, environmental stressors, and access to resources that impact treatment and management. Without

knowing and understanding this information, care was fragmented, non-individualized, and not holistic.

Engagement in transparent conversations with older AAs can facilitate shared decision-making. From this study, we learned that AAs desire to have providers collaborate and communicate on the best treatment plan. Discussions about safety, efficacy, effectiveness, and costs of medications are very important. It was clear from multiple conversations that older AAs did not believe in taking medications if they were not helpful or were too expensive. Providers can utilize this research by working more collaboratively with patients to understand their current methods for pain management and incorporate these into a long-term pain management plan. For example, providers might ask patients how they using their medication? How often and how much they take it? What other medications or treatments do they substitute with? Also, providers should make recommendations for other complementary strategies they might work more effectively, including physical therapy and TENS. Most importantly, coordination of resources in addition to identification of resources can improve older AAs' ability to self-manage pain. Utilization of community resources (e.g., recreation centers for swimming and physical activity, public transportation) are also helpful for older adults' self-management of OA pain (Martin et al., 2012). In the same manner, patients should feel comfortable to discuss with providers other complementary therapies and home remedies they use to control pain.

Education

Provider education. The IOM (2011) emphasized a need for greater pain education of providers across the healthcare spectrum, and incorporating the core

competencies for interprofessional pain into professional education is one start. These competencies focus on contextualized pain assessment and treatment in special populations across settings of care (Fishman et al., 2013). Nursing education should expand focus from medical treatments to complementary and alternative therapies for specific populations with chronic pain. Park et al. (2014) suggests that cultural diversity of chronic pain be included as part of cultural competence in nursing curriculum. One strategy is to invite older AAs into the classroom to provide first-hand narratives on how they manage chronic pain. This exposes students to racially and culturally diverse patients but also contextualizes the realistic nuances of care that disadvantaged populations face on a daily basis.

Patient education. Patient teaching and activation are needed for self-management, but a lack of patient education was a significant finding in this study. Many older AAs relied upon their provider or family/friends for information. Few engaged in self-directed education through online resources or community-based resources. One particular participant suggested I begin a monthly online newsletter that provides information about OA and pain. We know that to adequately self-manage OA and CJ pain, older AAs must have access to resources and education. Mingo et al. (2013) was instrumental in showcasing over 20 arthritis needs and skills that AAs and CAs needed. Aging AAs, more than CAs, reported a need for internet sources, healthcare options other than a provider, problem-solving skills for arthritis, and ways to reduce pain (Mingo et al., 2013). However, Schofield and partners (2014) reported that online resources for pain self-management for older adults are scarce to non-existent. The apps available for chronic pain management have exploded in recent years. Young and middle-aged persons

would consider using apps for chronic self-management (Reynolds et al., 2014); however, smartphone application use for older adults also has a place in management of pain but the current evidence use and quality of apps is limited (Docking, 2016).

Informational support is severely lacking, and innovative ways to increase access to quality education needs to be explored in the near future. Specifically, two men spoke about home-based programs- a home-based self-management education program and home-based palliative care. Community-based lay workers could provide personnel support for both programs. Information learned about a culturally-tailored brochure and preference for education attainment can guide development of educational materials to be delivered a variety of ways. It would be worthwhile for national organizations advocating for self-management to develop culturally-responsive educational resources for targeted populations.

Research

Because older AAs have traditionally been under-represented in pain studies, there are numerous opportunities for research advancement. To this point, research on older AAs has been to clearly demonstrate that disparities exist in this population. Carmen Green, MD has trail-blazed this scientific discovery in her leadership of the seminal paper on pain and disparities (Green et al., 2003) and ongoing research and advocacy efforts. Another aspect of emerging research is the intersection of race and ethnicity with age-related differences in pain sensitivity. Roger Fillingim, PhD, the leading authority on ethnic differences specifically between AAs, CAs, and Hispanic Americans, has published seminal papers on this topic (Campbell, Edwards, & Fillingim,

2005; Rahim-Williams et al., 2007). The HOPE study builds on these foundations by exploring self-management in a population with treatment disparities and ethnic differences in pain tolerance and threshold.

Utilizing current research. The current research can inform self-management program development that incorporates the essential topics wanted by AAs. Studies by Cary Reid and others are foundational and can provide additional guidance for culturally-tailoring a self-management program.

Developing a research infrastructure. Several participants discussed the need and importance of the Black community in participating in research. The National Pain Strategy (2016) and also our study call attention to increasing older AAs' participation in research. Recruiting from a community not privy to research necessitated a grass-roots recruitment effort. Our experience was that interest needed to be generated among large groups of AAs through multiple outlets: media, community-based, and word-of-mouth. Ensuring privacy and confidentiality of data on an individual-level was very important. One way to support greater research participation is to develop AA-led community-based advisory councils to work with local researchers to determine need factors of the AA community. Thus, research-practice partnerships can help healthcare professionals to determine which self-management needs and interventions are most effective in community-based older AAs and community-based settings.

Culturally-tailored interventions. Our research can be used to provide an update to the continuing disparities in access and need for a common support structure in disseminating evidence-based self-management interventions. The findings will be used to begin development and preliminary testing of a brochure tailored to AAs as a

culturally-innovative intervention (Tripp-Reimer, Choi, Kelley, & Enslein, 2001) and a culturally-responsive decision-making tool to enhance self-efficacy and motivation to engage in pain self-management. Preliminary topics will include those identified by participants, supported by other research on arthritis information needs (Mingo et al., 2013).

Refining current research. The Individual Self-Management Model in Older African Americans proposed that contextual factors directly influence process factors which together all impact stage of engagement. While this study did not perform a path analysis, we were able to determine associations between contextual and process factors and self-management by using correlations. Recruiting a larger sample in order to perform advanced statistical tests such path analysis for each behavior and factor analysis for 5 stages of engagement is a future project. Refining the current research entails determining best instrumentation, measurement, and study variables to develop the best model that represents the process of pain self-management in older AA.

Instrumentation. Instruments sensitive to the cultural nuances of older AAs with chronic pain are needed. For example, a 5-structure engagement tool may not be valid or reliable in older AAs; this lends itself to exploratory factor analytic methods. In this study, based on participant responses, we were able to combine stages two and three, and four and five. This resulted in three stages of engagement: Pre-contemplation, Preparation, and Action. These stages of based on the stage of change. In 1997, Robert Kerns developed the pain stages of change questionnaire (PSOCQ) to assess four stages of change, excluding preparation. The PSOCQ can predict engagement in pain self-management treatments (Biller, Arnstein, Caudill, Federman, & Guberman, 2000; Kerns

& Rosenberg, 2000). Future should examine the reliability and sensitivity of the three-stage structure in comparison to Kerns' four stages.

Future research also offers opportunities itself to understanding how pain and self-management, individually and jointly, impact other outcomes such as quality of life, sleep, function, and global health. Though the HOPE study did not evaluate quality of life, we can make judgments about this through the results of the BPI-SF. While newer tools, such as the PEG (pain intensity, interference with enjoyment of life, and interference with general activity), are recommended for pain assessment by the new CDC's guidelines on management of chronic pain (Dowell, Haegerich, & Chou, 2016), interference with enjoyment of life (3.63) and general activity were rather low on the BPI-SF in our sample. Like previous studies, a recent study determined that AA older adults rate health-related quality of life for physical health low (\bar{x} = 34.7/100) but higher for mental health (\bar{x} = 57.4/100) when compared to Afro-Caribbean-, Caucasian-, and Hispanic-Americans (Park et al., 2015b). Shorter tools may facilitate greater utilization in practice, but as noted have several rather obvious conceptual limitations for disparities research. This does not refute the need to evaluate psychological impact, but does underscore a need to test whether tools are culturally-relevant in older AAs, and if a different tool is needed for development.

Measurement. Most measures of pain used in OA studies do not adequately capture the multidimensional nature and experience of pain, and including more than one measure of pain or function will improve validity. This same conclusion was posed by de Luca et al. noting "There is a fraught complexity in the multidimensionality of the experience of pain in osteoarthritis, and studies exploring osteoarthritis pain in older

people should attempt to capture this multidimensionality by employing multiple valid and reliable outcome measures that capture specific dimensions of the pain experience” (2015, p. 1461). This requires different ways of measuring pain and engagement in various behaviors and treatments. For example, pain intensity is measured using four separate questions on the BPI-SF, but rarely do tools ask questions such as “What is your pain intensity when you do not use various treatments?”. Perhaps we should also examine expectations for benefit as opposed to simply helpfulness.

Study variables. A common set of data elements to advance the scientific comparison and understanding across self-management studies have been proposed by leading nurse researchers and include activation, self-regulation, and self-efficacy. The HOPE study measured two of these: self-regulation and self-efficacy. Because symptom self-efficacy was important for engagement in OA self-management behaviors, future study should explore various cognitive processes further. Moreover, improving confidence was not a concept many participants had ever considered. The unconscious lack of confidence may play a key role in their ability to engage consistently and effectively in pain management control. Self-regulation as measured by motivation levels is also recommended. Particularly in this study, motivation trended toward significance in correlations with several recommended OA behaviors, and qualitative results were able to illuminate that a lack of motivation impacts any engagement in self-management. Some hypothesize that unmeasured psychological characteristics/variables may explain some of these racial disparities in pain (Shavers et al., 2010). A few potential unmeasured variables may include empowerment, optimism, resilience, and patient activation. Because AA in general were highly motivated to manage pain, this did not always

translate into use of effective strategies. It may be that older AAs feel less empowered to have control over their pain. AAs typically hold fatalistic beliefs toward health, and this was shown in older AAs' narratives about disbelief and expecting pain. Perhaps having a low level of optimism may prevent older AAs from considering ways that they gain control of pain.

An emerging concept, patient activation may be a more relevant and tangible concept to explore as opposed to motivation. Patient activation measures a patient's willingness and actual and perceived capability to independently perform a set of self-management activities (Hibbard & Greene, 2013; Moore et al., 2016). Individuals vary in their ability, confidence, and willingness to take on a role in management of their chronic disease (Schulman-Green et al., 2012). Consequently, activation of self and self-management "resources [will] vary in intensity and complexity depending on the illness and the role that the individual can assume in managing the illness" (Schulman-Green et al., 2012, p. 141). Fittingly, patient activation allows individuals to determine realistic self-management behaviors that meet their current level of need and ability. For example those unable to engage in various types of exercise due to mobility difficulty (i.e., those in the pre-contemplation and preparation stages) can identify realistic ways to adapt physical activity that considers their functional ability but also meets exercise standards.

Advancing current research. If more is known about ethnic variations in response to and the mediators of the relationship specifically between pain interference, pain intensity, and self-management behaviors, we will be better able to inform treatment support and improve their efficacy and effectiveness. In addition to barriers and facilitators, identifying mediators and moderators using advanced statistical methods and

better understanding the role of providers in older AAs' self-management process would add understanding of these complex relationships.

Next steps also include (1) evaluating acceptability of mobile health technology for self-management ([SM]; real-time assessment, online pain diaries), (2) exploring expectations for provider management, and (3) developing and validate a culturally-tailored educational brochure on arthritis pain management in older AAs. Information learned about a culturally-tailored brochure and preference for education attainment can guide development of educational materials to be delivered a variety of ways. One particular participant suggested I begin a monthly online newsletter that provides information about OA and pain. We know that to adequately self-manage OA and CJ pain older AAs must have access to resources and education. Mingo et al. (2013) was instrumental in showcasing over 20 arthritis needs and skills that AAs and CAs needed. Aging AAs, more than CAs, reported a need for internet sources, healthcare options other than a provider, problem-solving skills for arthritis, and ways to reduce pain (Mingo et al., 2013). However, Schofield and partners (2014) reported that online resources for pain self-management for older adults are scarce to non-existent. The apps available for chronic pain management have exploded in recent years. Young and middle-aged persons would consider using apps for chronic self-management (Reynolds et al., 2014); however, smartphone application use for older adults also has a place in management of pain, but the current evidence for use and quality of apps is limited (Docking, 2016). Informational support is severely lacking, and innovative ways to increase access to quality education will be explored in the near future. Utilization of community resources (e.g., recreation

centers for swimming and physical activity, public transportation) are also helpful for older adults' self-management of OA pain (Martin et al., 2012).

Another issue to address in advancing research is that of male recruitment. Women were overrepresented in this sample; only twenty males were successfully enrolled. Although women are overrepresented in OA and chronic pain studies (Albert et al., 2008a), and the female-male ratio in our study was consistent with research, this finding is reflective of the demographics of older adults and thus those experiencing OA and CJ pain. Based on this, the HOPE study achieved similar representation based on general population studies. However, this study was interested in achieving a higher percentage of men in order to describe this particular population more comprehensively. We were able to accomplish this in the stratified recruitment of equal samples of male and female participants in the qualitative portion of the study. Though the body of work on chronic pain and older AAs is expanding, there are still areas that have not been fully explored with regard to older AA men.

It was difficult to recruit men to participate in a 45-minute quantitative interview. Much of this may be related to their views towards talking about chronic pain, and lack of understanding on the “potential benefit” versus “direct benefit” of research. Most who enrolled were gained through snowball sampling, in which their family members (typically wives) or male friends highly encouraged them to participate. Flyers were posted at barbershops and given to a male minister to handout. The PI learned that to engage AA men establishing trust and emphasizing the long-term importance of the research is key. Also being flexible in scheduling was essential.

Lastly, there was considerable prescribing of NSAIDs and opioids in older AAs. Because each are associated with serious adverse effects in older adults, drug development using different mechanisms and pathways are needed to ensure safe health outcomes. Not only that, but the IOM and the CDC guidelines support non-pharmacological strategies as first-line; consequently, more randomized controlled trials are warranted to test the effectiveness of complementary and alternative strategies in all older adults, but especially ethnic minority older adults.

Health Policy

As the structure of the American healthcare system changes, health policy will be an important driver in improving the overall care of older AAs with OA and CJ pain. In particular, there needs to be an open dialogue highlighting how national recommendations for the management of chronic pain (e.g., CDC guideline) will perpetuate disparities in already disadvantaged populations like older AAs. Because research clearly shows that older AAs are already under-prescribed opioids (Green & Prabhu, 2013), providers who implement a strict interpretation of the CDC guidelines as the standard of care may further restrict access to opioids older AAs, thereby causing additional disparities in treatment and potentially worsening pain management. Current shifts to limit opioid prescribing resulted in the release of the highly controversial CDC guidelines (Dowell, Haegerich, & Chou, 2016), which are expert-based and not evidence-based (Pergolizzi, Raffa, & LeQuang, 2016). Furthermore, the experts involved in drafting the guidelines have clear conflicts of interest with anti-opioid advocacy groups. Consequently, first-line treatment recommendations emphasize non-pharmacological therapies. While these guidelines are meant to “guide” providers in treatment decision-

making and improve quality of pain management for patients with chronic pain, it creates a double entendre for AAs. Thus, the focus on the opioid crisis displaces needed attention to the management of chronic pain in older AAs.

Our data specifically calls for greater promotion and dissemination of self-management education and development of a community infrastructure, and additional research on behavior change and testing behavioral interventions. Lubar and colleagues (2010) developed recommendations for a national public health agenda for OA and examples of approaches to actualize select recommendations proposed by the PI are provided:

1. Self-management education should be expanded as a community-based intervention for people with symptomatic OA (p. 323).
 - a. Incentives for providers and agencies to provide evidence-based and culturally-tailored self-management programs are starting solutions. Centers for Medicare and Medicaid should expand health promotion and self-management activities that are covered.
 - b. Communication campaigns targeted to AA communities to show that chronic pain is not something you have to live with and pain relief is available. “Improve the perception of people with osteoarthritis and chronic pain by facilitating a positive environment surrounding the management of osteoarthritis and chronic pain” (American Pharmacist Association, 2016, p. 6).

2. Low impact, moderate intensity aerobic physical activity and muscle strengthening exercise should be promoted widely as a public health intervention for adults with OA of the hip and/ or knee (p. 324).
 - a. Some insurances, such as Humana, are offering fitness-based programs such as the Silver Sneakers. Partnership between agencies or researchers who implement a self-management program and the Silver Sneakers program can provide the self-management education and hands-on practice related to learning types of exercises needed and desired by older AAs.
 - b. Develop media campaigns to encourage AA elders to remain active and engage in low impact physical activity.
 - c. Develop group exercise teams in community-based agencies and churches that support and/or represent the local council on aging.
3. Existing policies and interventions that have been shown to reduce OA-related joint injuries should be promoted, implemented and enforced (p. 324).
 - a. Safety programs, as well as self-management programs, should be implemented at facilities where older AAs currently work. This could reduce injury and increase worker productivity and longevity.
4. Weight management should be promoted for the prevention and treatment of OA... (p. 324).
 - a. Food deserts must be minimized and made available at low-costs for AA older adults through expansion of federal food assistance programs for allowable purchases of fresh fruits and vegetables with

known anti-inflammatory properties, fish oil, and glucosamine and chondroitin.

5. Research and evaluation should be pursued to enhance surveillance, better understand risk factors, refine recommended intervention strategies, evaluate workplace interventions, and examine emerging evidence on additional promising interventions (p. 326).
 - a. Develop community advisory panels, a research registry with names and contact information for AAs who are willing to participate in research studies.
 - b. Implement the short-term, medium-term, and long-term strategies and goals proposed by the National Pain Strategy to improve surveillance and data collection methods of racial minorities (Interagency Pain Research Coordinating Committee, 2016).
 - c. A part of refining recommended strategies lends itself to testing the efficacy, effectiveness, and sustainability of existing and novel and behavioral interventions and measuring outcomes such as behavior change, improvement in pain, pain interference, and function.

While these recommendations in theory are great, the need for translation into practice and in the community is even greater. For older AAs to engage in recommendations 1, 2, and 4, external and internal barriers must be reduced, motivators enhanced, and partnerships with community organizations and churches developed. Only when older AAs understand the options available and the benefits they provide can greater engagement in recommended behaviors occur.

Conclusion

The design of the HOPE study emphasized the construction of an emic understanding of the context, processes, and outcomes of OA and CJ pain self-management in older AAs. We identified unique patterns, preferences, and predictors for engagement in OA and CJ pain self-management in AA older adults. The patterns illuminated pathways for greater understanding of the contextually- and culturally-laden cognitive and behavioral processes that occur on a daily basis to control pain. Aging AAs used multiple ways to “deal with pain”, which included a clear preference for topical agents, and strong interests in treatments such as different types of exercise, massage, and TENS. Nevertheless, it was predictors, such as symptom self-efficacy, pain interference, knowledge of the specific recommendation, which provided additional awareness to the complexity of engagement in self-management OA behaviors. These results provide fascinating knowledge for future behavioral interventions.

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APPENDIX A: COMMUNITY RECRUITMENT FLYER



DO YOU HAVE ARTHRITIS OR CHRONIC JOINT PAIN?

If so, come talk to me!



My name is Star Booker, and I am a nurse (RN) conducting the Help for Osteoarthritis Pain in African American Elders (HOPE) study. This study explores how you manage arthritis pain. If you live in/near the Shreveport, Ruston, or Monroe areas, I would like to talk with you. Compensation for completing the interview is provided. Call at 318-533-2024 any day between 9am-8pm. *Thank you!*

To complete an interview:

- Must be at least 50 years of age or older
- Have arthritis (*osteoarthritis*) or chronic joint pain for at least 3 months
- Identify as African American/Black (men and women)

APPENDIX B: FACILITY RECRUITMENT FLYER



DO YOU HAVE ARTHRITIS OR CHRONIC JOINT PAIN?

If so, come talk to me!



My name is Star Booker, and I am a nurse (RN) conducting the Help for Osteoarthritis Pain in African American Elders (HOPE) study. This study will explore how you manage arthritis pain. If you live in/near the Shreveport, Ruston, or Monroe areas, I would like to talk with you. Compensation for completing the interview is provided. Thank you!

I will be at the () on () from (). Please stop by.

To complete an interview:

- Must be at least 50 years of age or older
- Have arthritis (*osteoarthritis*) or chronic joint pain for at least 3 months
- Identify as African American/Black (men and women)



Recruiting Black Seniors with Arthritis and Joint Pain

You are invited to participate in a study exploring Black seniors' management of osteoarthritis and joint pain.

You may be eligible to participate if:

- Are 50 years of age or older
- Have osteoarthritis (not rheumatoid arthritis) and joint pain
- Identify as Black or African American

What is required to participate? About an hour of your time for a face-to-face interview to share your experience on how you control arthritis pain and to complete questionnaires.

Are there any benefits of participation?

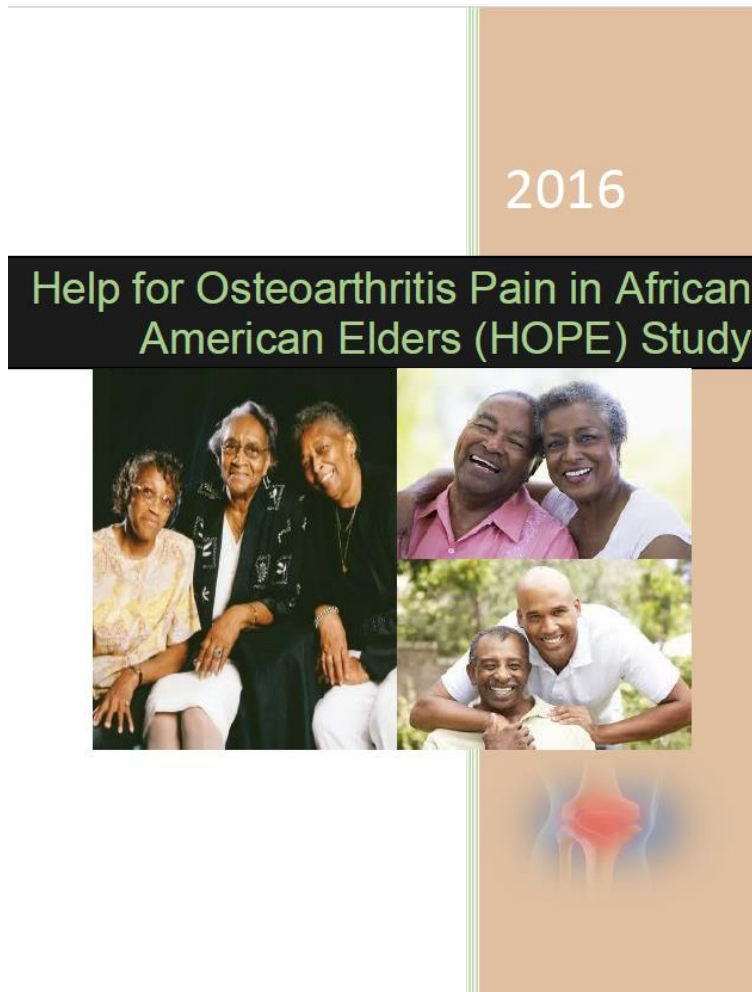
- This study does not provide any medication or treatments.
- The information you share will help nurses and other healthcare professionals understand what you do to manage pain.
- All participants are compensated for completion of questionnaires with a \$15 gift card and an educational brochure on managing osteoarthritis.

If you would like to participate, contact:
Star Booker, MS, RN, PhD(c)
318-533-2024



APPENDIX D: RECRUITMENT BROCHURE

Cover page



APPENDIX D: CONTINUED

Page 1

Purpose: The purpose of the HOPE study is to understand how African American/Black adults manage arthritis and chronic joint pain.

To participate in this study, you must be:

- 50 years of age or older
- Identify as African American/Black
- Have osteoarthritis or chronic joint pain
- Live in/near the Shreveport, Ruston, and Monroe (Louisiana) areas.



Enrollment period: March 1 – September 1, 2016.

All interested individuals will be screened using a questionnaire to ensure you are indeed eligible to participate.

APPENDIX D: CONTINUED

Page 2

Frequently Asked Questions and Answers

1. What is the purpose of this project?
This project seeks to understand how African Americans/Blacks manage arthritis and chronic joint pain. This includes gathering information about what you do to control pain on a daily basis.
2. Who can participate?
Anyone who identifies themselves as African American or Black, is at least 50 years of age, and have osteoarthritis pain for at least 3 months can participate. I will ask you a few questions to ensure you are eligible to participate. You do not need to have a diagnosis from a doctor and you do not need permission from your doctor to participate. However you are free to discuss with your doctor or family about participation. It is solely your decision and choice to participate.
3. What will I be asked to do?
If you decide to participate, you will complete a questionnaire and some people will also be asked to also participate in a 45 minute interview. The interview will ask more about how you manage arthritis pain. There are no physical exam or other medical tests.
4. Will I have to pay for anything concerning the project?
There is no cost to participate in this study. Also, participation does not affect your Medicare/Medicaid, Retirement, or Social Security benefits.
5. Will I receive payment for participating?
You will receive a \$15 gift card when you complete the questionnaires. If selected to participate in the 45 minute interview, additional compensation is unfortunately not provided.
6. Will I receive any type of treatment if I participate?
This study does not provide any treatment for arthritis. However, as a "thank you" for participation in this project, you will be given a brochure

APPENDIX D: CONTINUED

Page 3

that discusses ways to manage your pain. You are encouraged to talk with a doctor or nurse about treatment options.

7. Will someone in my neighborhood or church know about my participation in this project?
Your participation is confidential. I can't discuss your participation in this project with anyone. However, you may share my contact information for this project to your family, friends, and neighbors.
8. How will this project help me, my family, or my community?
Your participation will provide important information on ways to best help African Americans/Blacks manage their arthritis pain. I will use the information you provide to me to inform health professionals what they need to do to help us with arthritis.
9. Will any information about my responses on the questionnaire be shared with anyone?
The information you provide on questionnaires is anonymous. This means no one will know any personal information about you or be able to link your responses to you. I will publish the results of the HOPE study in nursing and healthcare journals and present these at various conferences. Again, I will not share any personal information about you.

If you are interested in participating or learning more about this study, please contact me:

Staja "Star" Booker, RN, MS, PhD(c)

Phone:

Hours: **Monday-Saturday – 9am-8pm**
Sunday – 2pm-8pm

Email: staja-booker@uiowa.edu



FACTS ABOUT ARTHRITIS IN AFRICAN AMERICANS

- Approximately 5 million African Americans/Blacks have arthritis in the United States.
 - Nearly 80% of chronic pain in African American seniors is due to arthritis.
- Recent studies show that arthritis pain in African Americans/Blacks is often more severe and physically disabling.
- Arthritis pain often limits walking and ability to perform daily chores and activities.
- Many African Americans/Blacks manage their arthritis pain on their own, often using multiple strategies, such as medications, creams, rest, warm wraps and prayer, to control pain. Sometimes, however, these strategies do not significantly reduce pain.



This is where the HOPE study comes in. I am trying to learn more about what African American/Black adults do to manage their arthritis and chronic joint pain and find ways to assist in self-management of pain.



APPENDIX D: CONTINUED

Back page

My name is Staja "Star" Booker, and I am a nurse currently completing my PhD in Nursing at the University of Iowa, College of Nursing. I am conducting the "Help for Osteoarthritis Pain in African American Elders (HOPE): Patterns, Preferences, and Predictors of Osteoarthritis and Chronic Joint Pain Self-Management Study." The HOPE study seeks to understand how Black seniors (50 years and older) manage arthritis and joint pain. Therefore, my goal is to talk with you about how you control your arthritis or chronic joint pain.

Research shows that the impact of arthritis and joint pain are disproportionately worse in African Americans, but currently we do not fully understand how African Americans control their pain. We also know that 25% or more of African Americans in Louisiana have arthritis. As a Louisiana native and nurse, I am aware of the health issues that impact African Americans and Black communities. This is why I want to understand your needs regarding management of arthritis pain, and to identify approaches to manage pain effectively.

Thank you for your time and interest, and I hope you will consider participating in this study. Feel free to make copies of this brochure and pass along to family, friends, and colleagues. Do not hesitate to contact me using the information provided earlier if you have questions or need additional information.

"Be joyful in hope, patient in affliction, faithful in prayer." Romans 12:12

Indebted to Serve,

Staja "Star" Booker, RN, MS, BSN (GSU '10), PhD(c)



Support Ribbon for Osteoarthritis

APPENDIX E: EMAIL ADVERTISEMENT

FOR IRB USE ONLY APPROVED BY: IRB-02 IRB ID #: 201601784 APPROVAL DATE: 03/02/16 EXPIRATION DATE: N/A

Email and Newsletter Advertisement

Re: Invitation to Participate in Osteoarthritis and Chronic Joint Pain Study

We invite you to participate in a brief study about arthritis pain self-management. If you have osteoarthritis and chronic joint pain, are 50 years of age or older, and identify as African American/Black, you may be eligible to participate in the Help for Osteoarthritis in African American Elders (HOPE) Study. The HOPE study is being conducted by Staja “Star” Booker, a nurse and doctoral student from the University of Iowa. The purpose of this study is explore how African American/Black adults manage their arthritis and chronic joint. Participants will be compensated a \$15 gift card for completion of survey and interview. A flyer and brochure are attached to this email. For more information, please contact Ms. Booker by phone at . or by email at staja-booker@uiowa.edu.

APPENDIX F: ENROLLMENT SCRIPT

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Help for Osteoarthritis Pain in African American Elders (HOPE) Study
The University of Iowa, College of Nursing
Project Lead: Staja "Star" Booker, MS, RN

Enrollment Script

Thank you for contacting me to find out more about the osteoarthritis study [or I calling you to provide you with more information about the osteoarthritis study. My name is Star, and I am working on my PhD in nursing from the University of Iowa, but I was born and raised in Jonesboro. As you may know, I am looking to talk to Black adults with arthritis to understand how you manage your arthritis pain. I am asking people to complete a questionnaire and interview to discuss the things that you do to control your pain. There is no cost to participate and the decision to participate is completely up to you and you do not need to make a decision today. If you would like more information, I can send you some materials in the mail. Do you have any questions or concerns so far? Do you think you are interested in participating? [If yes], I will need to determine if you are eligible. I have 12 brief questions to ask, this will only take 5-10 minutes. [If no], Thank you for taking time to talk with me, and please share this information with family, friends, and co-workers.

[Administer Eligibility Questionnaire].

[If meet criteria], Based on your responses, you are eligible to participate.

[If by phone], So now I would like to schedule a day and place to meet with you to complete the questionnaires and interview.

[If in person], Would you like to complete the questionnaires and interview now or schedule for another day?

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[If do not meet criteria], Unfortunately you do not meet criteria to participate because [reason]. I do have a few more questions about how you heard about this study. [Administer Part A only of Participants Characteristics Questionnaire].

Thank you for taking these few minutes to talk to me, and please share this information about this study to your family, friends, and co-workers. If you have any further questions, please contact me at this number [phone #] and feel free to give this number to others.

APPENDIX G: INFORMATION LETTER FOR PARTICIPANTS

FOR IRB USE ONLY
APPROVED BY: IRB-02
IRB ID #: 201601784
APPROVAL DATE: 05/12/16
EXPIRATION DATE: N/A

We invite you to participate in the Help for Osteoarthritis Pain in African American Elders (HOPE) Study being conducted by Staja “Star” Booker at the University of Iowa. The purpose of the study is to understand what Black seniors do to manage osteoarthritis and chronic joint pain.

If you are eligible and agree to participate in the study, you will complete several questionnaires asking you about the things you do to control your chronic joint pain. You will need to complete the questionnaires with me in-person so that I can provide any assistance should you need it. You are free to skip any questions that you prefer not to answer. It will take approximately 45 minutes to complete the questionnaires. You may also be asked to complete a 45-minute interview to further discuss and illustrate how you care for your osteoarthritis and chronic joint pain on a daily basis and to understand the barriers and facilitators in the daily management of your pain. This interview will be recorded, but you can choose not to have it recorded. No one other than myself will listen to the recorded interviews. Your participation in the interview is voluntary and you can decline the invitation. If you are asked and agree to complete the interview, you do not have to complete the interview and questionnaires on the same day. We can schedule a second day to complete the interview. Questionnaires and interview can be completed at a location that is most comfortable for you, whether this is your home, church, or other quiet public location. If you complete the 45-minute interview, you may be asked to be re-contacted for a follow-up interview to review and verify the study’s results. Again, your participation is voluntary and it is your decision to decline or accept.

There are no costs to participate. For completing the surveys, two brochures on osteoarthritis management and a \$15 gift card will be paid to you. You will need to provide your name and address so that a gift card can be issued to you. We have taken care to ensure all gift cards are properly loaded with money. In case the gift card is lost, stolen, or does not work, we cannot issue a replacement gift card or re-load gift cards.

We will not collect your name or any identifying information about you on the questionnaires. We will use an ID number on your questionnaires to keep track of your data, but this ID number cannot be traced to your name in any way. It will not be possible to link you to your responses on the survey. We will keep all information you provide confidential.

Taking part in this research study is completely voluntary. If you decide not to be in this study, or if you stop participating at any time, alert or call () the PI to express this.

If you have questions about the rights of research subjects, please contact the Human Subjects Office, 105 Hardin Library for the Health Sciences, 600 Newton Rd, The University of Iowa, Iowa City, IA 52242-1098, (319) 335-5564, or e-mail irb@uiowa.edu.

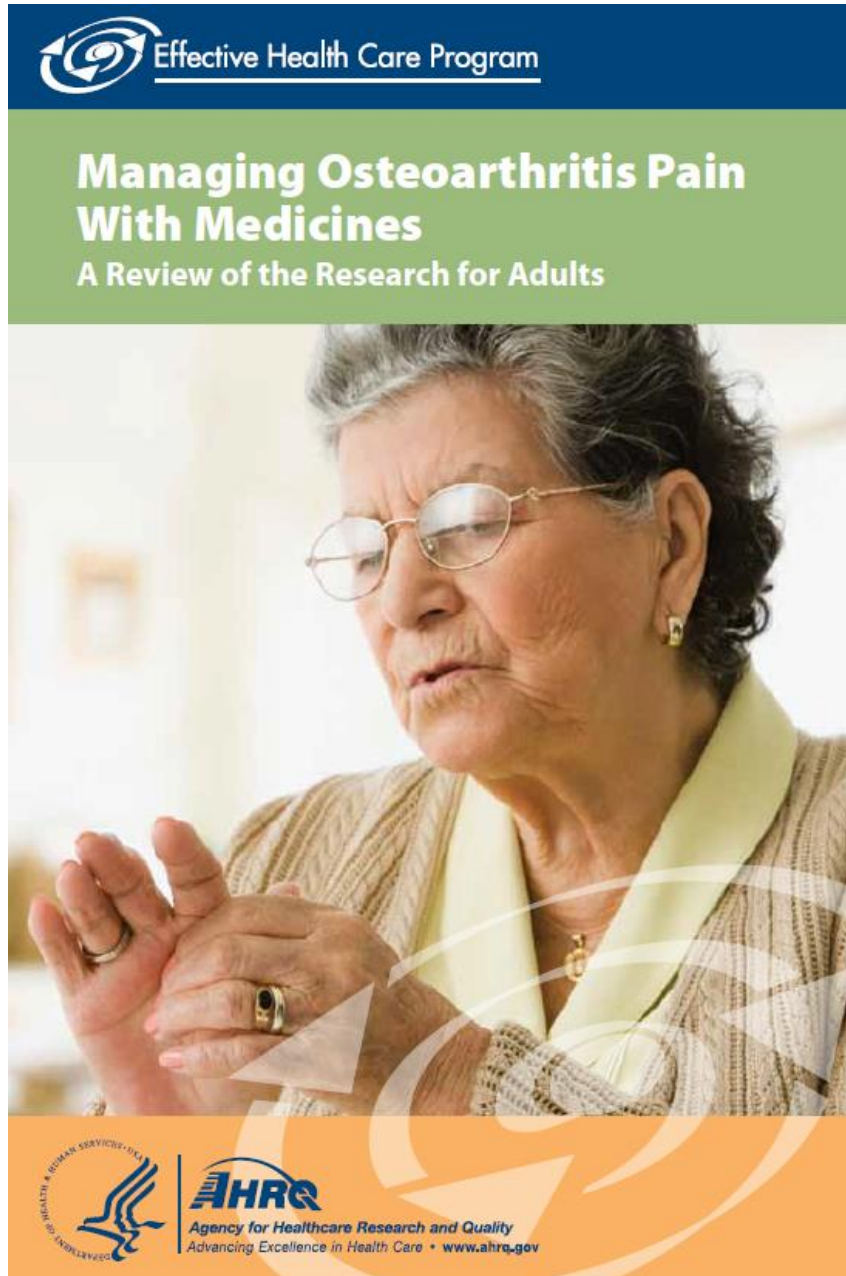
Your participation is sincerely appreciated,

Staja “Star” Booker

Staja “Star” Booker, RN, MS, PhD(c)
Principal Investigator (PI) – HOPE Study
The University of Iowa
College of Nursing
50 Newton Road
Iowa City, IA 52240

APPENDIX H: OSTEOARTHRITIS PAIN BROCHURE

Cover page only [snapshot provided]



APPENDIX I: LIST OF ONLINE RESOURCES

Helping Osteoarthritis Pain in African American Elders (HOPE) Study

The University of Iowa, College of Nursing
Project Lead: Staja "Star" Booker, MS, RN

List of Resources for Arthritis

Arthritis Foundation <http://www.arthritis.org/>

Centers for Disease Control and Prevention
<http://www.cdc.gov/arthritis/basics.htm>

National Institute of Arthritis and Musculoskeletal and Skin Disease
http://www.niams.nih.gov/health_info/arthritis/

Johns Hopkins Arthritis Center
<http://www.hopkinsarthritis.org/patient-corner/>

Cleveland Clinic
http://my.clevelandclinic.org/health/diseases_conditions/hic_Arthritis/hic_Arthritis_Resources

Stanford's Arthritis Self-Management Program
<http://patienteducation.stanford.edu/programs/asmp.html>

Stanford's Chronic Pain Self-Management Program
<http://patienteducation.stanford.edu/programs/cpsmp.html>

American Chronic Pain Association
www.theacpa.org

APPENDIX J: ELIGIBILITY SCREENING QUESTIONNAIRE

Help for Osteoarthritis Pain in African American Elders (HOPE) Study

The University of Iowa, College of Nursing

Eligibility Screening Questionnaire

ID: UI Day: _____ Date: _____ Time: _____ am/pm

1. Are you of Hispanic or Latina background? Yes or No
If yes, EXCLUDE and do not proceed with questionnaire.
2. Do you identify as African American or Black? Yes or No
If no, EXCLUDE and do not proceed with questionnaire.
3. Are you 50 years of age or older? Yes or No
If no, EXCLUDE and do not proceed with questionnaire. ~~Exact~~ age _____ y/o
4. Do you live in an assisted living or a nursing home? Yes or No
If yes, EXCLUDE and do not proceed with questionnaire.
5. Have you ever been told by a doctor that you have osteoarthritis? Yes or No
If **yes**, have you had an x-ray, MRI, or other imaging procedure to determine if you have osteoarthritis? Yes or No

If **no**, do you experience any of the following symptoms of osteoarthritis?
 - a. swelling in any joint: Yes or No
 - b. stiffness in the morning or after being inactive: Yes or No
 - c. pain that gets better with rest but worse with activity: Yes or No
 - d. crepitus or grating sound or feel when walking or bending: Yes or NoIf at least 3 symptoms/signs are not present, EXCLUDE and do not proceed with questionnaire.
6. Have you had pain in your joints for at least three months or longer? Yes or No
If no, EXCLUDE and do not proceed with questionnaire. ~~Exact~~ duration _____
7. Do you live within 100 miles of any of the following cities: Shreveport, Ruston, or Monroe? Yes or No
If no, EXCLUDE and do not proceed with questionnaire.
8. Do you have any of the following health conditions? If yes to any, EXCLUDE and do not proceed with questionnaire.
 - a. Rheumatoid or psoriatic arthritis? Yes or No
 - b. Lupus? Yes or No
 - c. Sickle cell disease? Yes or No
 - d. Parkinson's disease? Yes or No
 - e. Ever had a stroke? Yes or No
9. This next question will check your memory. Perform 1-minute cognitive screen: Name as many animals as you can in one minute.
If name <15 animals, screen is positive for cognitive impairment, so EXCLUDE.

Result: _____
(E= Eligible, NE= Not Eligible)

Version 2

IRB Approved 5/12/2016

APPENDIX K: PAIN SELF-MANAGEMENT ENGAGEMENT QUESTIONNAIRE (PSMEQ)

Pages 1-2

Pain Self-Management Engagement Questionnaire (PSMEQ)

ID: UJ _____ Day: _____ Date: _____ Time: _____ am/pm

Directions: Please check the box that best answers the question. There is no right or wrong answer.

Self-Efficacy Scale

1. Do you develop intentional goals for your pain control? For example, "Today my goal is to keep my pain from becoming severe."
☐ No
☐ Yes
☐ Don't know how to do this
2. Do you know how to make a pain management plan or do you have a daily pain management plan?
☐ No
☐ Yes
☐ Don't know how to do this
3. Do you use a pain diary or log to track how bad your pain is from day to day?
☐ No
☐ Yes
☐ Don't know how to do this

4. Are you able to use a computer or smart tablet (such as an iPad) to find online resources on controlling pain?

☐ No
☐ Yes
☐ Don't know how to do this

5. Are you able to recognize things that make your pain worse?

☐ No
☐ Yes
☐ Don't know how to do this

6. Osteoarthritis pain is due to a breakdown in cartilage in between the bones, which causes the bones to rub together and muscles to be weakened.

☐ False
☐ True
☐ Don't know

7. Osteoarthritis and rheumatoid arthritis are the same thing.

☐ False
☐ True
☐ Don't know

APPENDIX K: CONTINUED

Pages 3-4

8. Taking a corticosteroid, including a joint injection, can cause someone with diabetes to have high blood sugars.

- ☐ False
☐ True
☐ Don't know

9. It is safe for someone with heart failure to take a non-steroidal medication (NSAID) such as aspirin, naproxen, or Aleve.

- ☐ False
☐ True
☐ Don't know

10. People with chronic kidney disease or kidney failure should not take opioid medications.

- ☐ False
☐ True
☐ Don't know

11. I am confident I can use various strategies that I've learned to control my pain.

- ☐ No
☐ Yes

12. I am confident that I can develop new strategies to help control my pain.

- ☐ No
☐ Yes

Please turn over. More questions are on the back side.

3

13. I am confident that I can take actions that will help prevent or minimize pain.

- ☐ No
☐ Yes

Motivation Scale

14. On a scale of 0-10, how motivated are you to effectively manage your pain?

0= being not motivated and 10= being highly motivated. Circle the number that best describes your motivation level.



15. Managing my pain is just as important as managing my other health conditions.

- ☐ No
☐ Yes

16. Keeping my pain level under control takes first priority whenever I am doing something.

- ☐ No
☐ Yes

Please turn over. More questions are on the back side.

4

APPENDIX K: CONTINUED

Pages 5-6

Normative Practice Scale

17. When you have mild pain, do you do anything for pain relief?

- ☐ Never
- ☐ Sometimes
- ☐ Always

18. When you have moderate pain, do you do anything for pain relief?

- ☐ Never
- ☐ Sometimes
- ☐ Always

19. When you have severe pain, do you do anything for pain relief?

- ☐ Never
- ☐ Sometimes
- ☐ Always

20. Think about your responses to the previous three questions. On a scale of 0-10, choose a number that best describes how engaged or involved you are in managing your pain. 0 = not doing anything, 5 = somewhat engaged and doing some things, 10 = extremely engaged and doing everything I know to do



21. Based on the things you do to manage your pain, do you believe they are helpful in controlling your pain?

- ☐ No
- ☐ Yes

Please turn over. More questions are on the back side.

5

Directions: For questions 23-29, please check the box on **Side A** and **Side B** that best applies to you. There is no right or wrong answer.

22. Do you engage in exercise, such as walking or aerobics, at least 3-4 times per week for 20 minutes to help with pain?

SIDE A

- ☐ I did not know this was recommended for pain.
- ☐ I did know this was recommended for pain.

SIDE B

- ☐ No, and I do not intend to.
- ☐ No, and I do not intend to within the next 6 months, but at some point.
- ☐ No, but I intend to within the next 6 months.
- ☐ Yes, I have been but for less than 6 months.
- ☐ Yes, I have been for more than 6 months.

If you selected **no**, what things prevent you from being able to exercise?

If you selected **yes**, what things help/motivate you to exercise?

Please turn over. More questions are on the back side.

6

APPENDIX K: CONTINUED

Page 7-8

23. Do you engage in water exercise at least 3-4 times per week for 20 minutes to help with pain?

SIDE A

- ☐ I did not know this was recommended for pain.
- ☐ I did know this was recommended for pain.

SIDE B

- ☐ No, and I do not intend to.
- ☐ No, and I do not intend to within the next 6 months, but at some point.
- ☐ No, but I intend to within the next 6 months.
- ☐ Yes, I have been but for less than 6 months.
- ☐ Yes, I have been for more than 6 months.

*If you selected **no**, what things prevent you from being able to do water exercise?*

*If you selected **yes**, what things help/motivate you to do water exercise?*

Please turn over. More questions are on the back side.

7

24. Do you do any strengthening exercises or stretching to help with pain?

SIDE A

- ☐ I did not know this was recommended for pain.
- ☐ I did know this was recommended for pain.

SIDE B

- ☐ No, and I do not intend to.
- ☐ No, and I do not intend to within the next 6 months, but at some point.
- ☐ No, but I intend to within the next 6 months.
- ☐ Yes, I have been but for less than 6 months.
- ☐ Yes, I have been for more than 6 months.

*If you selected **no**, what things prevent you from doing strengthening exercises or stretching?*

*If you selected **yes**, what things help/motivate you to do strengthening exercises or stretching?*

Please turn over. More questions are on the back side.

8

APPENDIX K: CONTINUED

Pages 9-10

25. Do you take any medications (prescribed or over the counter) for your pain?

SIDE A

- ☐ I did not know this was recommended for pain.
- ☐ I did know this was recommended for pain.

SIDE B

- ☐ No, and I do not intend to.
- ☐ No, and I do not intend to within the next 6 months, but at some point.
- ☐ No, but I intend to within the next 6 months.
- ☐ Yes, I have been but for less than 6 months.
- ☐ Yes, I have been for more than 6 months.

*If you selected **no**, what things prevent you from taking pain medications?*

*If you selected **yes**, what things help/motivate you to take pain medications?*

Please turn over. More questions are on the back side.

9

26. Do you use warm or cool compresses for your pain?

SIDE A

- ☐ I did not know this was recommended for pain.
- ☐ I did know this was recommended for pain.

SIDE B

- ☐ No, and I do not intend to.
- ☐ No, and I do not intend to within the next 6 months, but at some point.
- ☐ No, but I intend to within the next 6 months.
- ☐ Yes, I have been but for less than 6 months.
- ☐ Yes, I have been for more than 6 months.

*If you selected **no**, what things prevent you from using warm or cool compresses?*

*If you selected **yes**, what things help/motivate you to use warm or cool compresses?*

Please turn over. More questions are on the back side.

10

APPENDIX K: CONTINUED

Page 11-12

27. Do you use any assistive devices, such as canes or braces, to help with pain?

SIDE A

- ☐ I did not know this was recommended for pain.
- ☐ I did know this was recommended for pain.

SIDE B

- ☐ No, and I do not intend to unless I have to.
- ☐ No, and I do not intend to within the next 6 months, but at some point.
- ☐ No, but I intend to within the next 6 months.
- ☐ Yes, I have been but for less than 6 months.
- ☐ Yes, I have been for more than 6 months.

*If you selected **no**, what things prevent you from using assistive devices?*

*If you selected **yes**, what things help/motivate you to use assistive devices?*

Please turn over. More questions are on the back side.

11

28. Have you participated in an educational program or workshop on osteoarthritis self-management or chronic pain self-management?

SIDE A

- ☐ I did not know this was recommended for pain management.
- ☐ I did know this was recommended for pain management.

SIDE B

- ☐ No, and I do not intend to.
- ☐ No, and I do not intend to within the next 6 months, but at some point.
- ☐ No, but I intend to within the next 6 months.
- ☐ Yes, I have been but for less than 6 months.
- ☐ Yes, I have been for more than 6 months.

*If you selected **no**, what things prevent you from participating in an educational program on osteoarthritis or pain?*

*If you selected **yes**, what things help/motivate you to participate in an educational program on osteoarthritis or pain?*

Please turn over. More questions are on the back side.

12

APPENDIX L: ARTHRITIS PAIN SELF-MANAGEMENT INVENTORY (APSI)

[Snap shot provided]

MEDICATIONS	FREQUENCY	HELPFULNESS	REASON FOR USE
1. Prescribed oral pain medications <input type="checkbox"/> Opioid/narcotic medications (such as hydrocodone, tramadol, Dilaudid, fentanyl...)	<input type="checkbox"/> Never <input type="checkbox"/> Everyday <input type="checkbox"/> Several days a week <input type="checkbox"/> Once a week <input type="checkbox"/> Monthly	<input type="checkbox"/> Not helpful <input type="checkbox"/> A little helpful <input type="checkbox"/> Moderately helpful <input type="checkbox"/> Very helpful	<input type="checkbox"/> Helps with pain <input type="checkbox"/> Just trying it too see if it helps <input type="checkbox"/> Prescribed by doctor <input type="checkbox"/> Recommended by a family/friend
<input type="checkbox"/> NSAIDs (such as diclofenac, naproxen, ketoprofen...)	<input type="checkbox"/> Never <input type="checkbox"/> Everyday <input type="checkbox"/> Several days a week <input type="checkbox"/> Once a week <input type="checkbox"/> Monthly	<input type="checkbox"/> Not helpful <input type="checkbox"/> A little helpful <input type="checkbox"/> Moderately helpful <input type="checkbox"/> Very helpful	<input type="checkbox"/> Helps with pain <input type="checkbox"/> Just trying it too see if it helps <input type="checkbox"/> Prescribed by doctor <input type="checkbox"/> Recommended by a family/friend
<input type="checkbox"/> Muscle relaxers (flexeril, robaxin, soma, baclofen)	<input type="checkbox"/> Never <input type="checkbox"/> Everyday <input type="checkbox"/> Several days a week <input type="checkbox"/> Once a week <input type="checkbox"/> Monthly	<input type="checkbox"/> Not helpful <input type="checkbox"/> A little helpful <input type="checkbox"/> Moderately helpful <input type="checkbox"/> Very helpful	<input type="checkbox"/> Helps with pain <input type="checkbox"/> Just trying it too see if it helps <input type="checkbox"/> Prescribed by doctor <input type="checkbox"/> Recommended by a family/friend
<input type="checkbox"/> Mood stabilizers/ antidepressants (such as duloxetine, Tofranil, Elavil...)	<input type="checkbox"/> Never <input type="checkbox"/> Everyday	<input type="checkbox"/> Not helpful <input type="checkbox"/> A little helpful	<input type="checkbox"/> Helps with pain <input type="checkbox"/> Just trying it too see if it helps

APPENDIX M: PARTICIPANT CHARACTERISTICS QUESTIONNAIRE (PCQ)

Help for Osteoarthritis Pain in African American Elders (HOPE) Study

Participant Characteristics Questionnaire

ID: UI Day: _____ Date: _____ Time: _____ am/pm

Directions: For each question, please check or circle the appropriate response.

Part A: Study Response Inventory

1. How did you hear about the study?
 - ☐ Flyer
 - ☐ Church
 - ☐ Email
 - ☐ Friend or family
 - ☐ Other _____
2. How were you contacted?
 - ☐ I contacted Star by phone or email
 - ☐ Star contacted me by phone or email
3. What is your city of residence?
 - ☐ Shreveport/Bossier City
 - ☐ Monroe
 - ☐ Ruston/Grambling
 - ☐ Other _____
4. If applicable, please provide a reason why you decided to participate in this study?
5. If applicable, please provide a reason for deciding not to participate in this study?
6. May I contact you at a later date to review the study's results?
 - ☐ Yes
 - ☐ No

Please turn over. More questions are on the back side.

1

APPENDIX M: CONTINUED

Part B: Participant Characteristics

7. What is your gender?
 1. Female
 2. Male
 3. Transgender
8. What is your marital status?
 1. Married
 2. Single, Widowed, or Separated/Divorced
 3. Partnered but not legally married
9. What is your highest level of education?
 1. Didn't complete high school
 2. Completed high school only or received GED
 3. Completed high school and some college
 4. Completed high school and graduated from college
 5. Graduate degree
10. Are you currently employed (including owning your own business)?
 1. Yes Occupation _____
 2. No Retired _____
 3. No Disabled
 4. No Other, please provide reason _____
11. Are you the primary guardian or caregiver for children, grandchild(ren), spouse, or dependent adult(s)?
 1. Yes
 2. No
12. Would you say your monthly income is...?
 1. Not enough to pay bills and buy necessities
 2. Just enough to pay bills and buy necessities
 3. More than enough to pay bills and buy necessities
13. Do you currently have health insurance?
 1. Yes
 2. No

APPENDIX M: CONTINUED

14. When visiting a doctor or purchasing medications, are you responsible for a co-payment?
1. Yes
If **yes**, do you find that amount difficult to pay? _____
 2. No
15. Does financial difficulty hinder you from managing your arthritis pain?
1. Yes
 2. No
16. Does financial difficulty hinder you from seeing a doctor about your arthritis pain?
1. Yes
 2. No
17. How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?
1. Never
 2. Rarely
 3. Sometimes
 4. Often
 5. Always
18. Do you have problems with getting to and from doctor's appointments, such as having reliable transportation or having to travel long distances?
1. Yes
 2. No
Travel distance _____; Travel mode (e.g., car, bus) _____
19. Do you have any of the following health conditions? Circle all that apply.
1. Diabetes
 2. Hypertension (high blood pressure)
 3. High cholesterol
 4. Heart disease
 5. Asthma
 6. Chronic bronchitis or emphysema (COPD)
 7. Chronic kidney disease
 8. Peripheral vascular disease
 9. Acid reflux
 10. Fibromyalgia
 11. Other _____; Total # _____

APPENDIX M: CONTINUED

20. Do you have a regular doctor?

1. Yes
2. No

21. Are you a VA patient?

1. Yes
2. No

Part C: Osteoarthritis and Chronic Joint Pain

22. Would you describe your osteoarthritis or chronic joint pain as constant (all the time or almost all the time) or intermittent (come and go)?

1. Constant
2. Intermittent

23. On average, would you describe the severity of your arthritis pain as mild, moderate, or severe?

1. Mild
2. Moderate
3. Severe

24. Do you believe you have controlled your pain well?

1. Yes
2. No
3. Don't know

25. Do you believe that treatment from a doctor would be/is helpful in controlling your pain?

1. Yes
2. No

26. Do you receive help with daily activities/duties from family, friends, or other caregiver (e.g. paid unlicensed)?

1. Yes
2. No

APPENDIX N: REALM-SF

Menopause	<input type="checkbox"/>
Antibiotics	<input type="checkbox"/>
Exercise	<input type="checkbox"/>
Jaundice	<input type="checkbox"/>
Rectal	<input type="checkbox"/>
Anemia	<input type="checkbox"/>
Behavior	<input type="checkbox"/>

APPENDIX O: BRIEF PAIN INVENTORY – SHORT FORM (BPI-SF)

STUDY ID# UI HOSPITAL #

DO NOT WRITE ABOVE THIS LINE

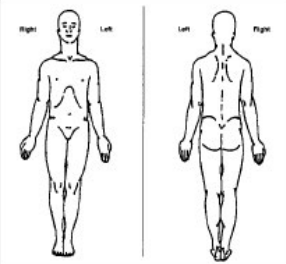
Brief Pain Inventory (Short Form)

Date: / / Time:

Name: Last First Middle Initial

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


- Please rate your pain by circling the one number that best describes your pain at its worst in the last 24 hours.

0	1	2	3	4	5	6	7	8	9	10
No										Pain as bad as
Pain										you can imagine
- Please rate your pain by circling the one number that best describes your pain at its least in the last 24 hours.

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

APPENDIX O: CONTINUED

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

8. In the last 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 Complete
Relief 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 Completely
Interfere Interferes

B. Mood

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

C. Walking Ability

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

E. Relations with other people

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

F. Sleep

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


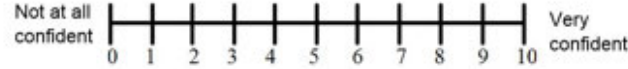


G. Enjoyment of life

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

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APPENDIX P: CHRONIC DISEASE SELF-EFFICACY SCALES (CDSES)

Manage Symptoms Scale

1. How confident are you that you can reduce your pain?

2. How confident are you that you can keep the pain of arthritis from interfering with the things you want to do?

3. How confident are you that you can keep other symptoms of arthritis, such as stiffness and swelling, from interfering with the things you want to do?

4. How confident are you that you can keep the fatigue caused by your chronic pain from interfering with the things you want to do?


APPENDIX Q: INTERVIEW GUIDE

Perceptions	<ul style="list-style-type: none"> • Meaning: What is your understanding about <u>arthritis</u>? When you hear the word <u>pain</u>, what is the first word that comes to mind? • Etiology: What causes arthritis? Pain? • Seriousness: How serious is your arthritis to you, in terms of life priorities? • Susceptibility: What things place African Americans at risk for arthritis pain?
Symptom Experience	<ul style="list-style-type: none"> • Describe what your pain is like on a daily basis? • Can you please describe how your arthritis pain has progressed over time? • Some people try to hide their pain from others like friends, family, and doctors, while others don't mind sharing that they are in pain. Where do you fit? Probe: What or how would you feel if you shared your pain?
Daily Self-Management	<ul style="list-style-type: none"> • Tell me about how you care for your arthritis pain on a "typical day?" "Good day?" "Bad day?" • What do you do to keep arthritis pain from getting worse? • What things keep you from being able to manage your pain? • What things help you control your pain? • How do your family or friends help you manage your arthritis pain?
Cultural Self-Management	<ul style="list-style-type: none"> • What are some things that Black people do to manage their arthritis pain? • How do you see spirituality, religion, and faith being related to pain or its management? • What would a doctor or nurse need to know about African American culture to better help you manage your pain? • Imagine you are reading a brochure similar to the ones in front of you. What would you think of an educational pain resource that is developed specifically for African Americans or Black people? • What do you think keeps aging AAs from managing their pain better? Probe: system issues, insurance, access, how they would be treated • What could we do to motivate our people manage their pain better?
Self-Management Programs	<ul style="list-style-type: none"> • What programs would you like to see in your community to help you manage your arthritis? • To educate yourself on OA pain, how you prefer to obtain such information? • What would help you increase your confidence to manage your OA pain? • Are there particular skills you think would help you better manage and cope with OA pain?