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Chivon A. Mingo
University of South Florida

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Identifying and Addressing Health Disparities in Black Older Adults with Osteoarthritis

by

Chivon A. Mingo

A dissertation submitted in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy
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College of Behavioral and Community Sciences
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Co-Major Professor: Jessica M. McIlvane, Ph.D.
Co-Major Professor: William E. Haley, Ph.D.
Victor Molinari, Ph.D.
Brent J. Small, Ph.D.
Tamara A. Baker, Ph.D.

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Dedication

I dedicate this doctoral dissertation to the following:

To my grandfather, Samuel Terry, a 91 year old that still works every day. You provided me with a clear example of perseverance, strength and tenacity. You taught me the importance of working hard and staying committed to the things that were important to me. Thank you for providing me with the lessons that fueled my energy to complete this dissertation.

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Abstract

Osteoarthritis (OA), the most common form of arthritis in older adults, often results in pain, disability and poor psychological well-being. Compared to White adults, Black adults consistently report more pain, more activity limitations, and have different perceptions about OA. Racial disparities also exist in treatments, and prevalence of arthritis. It is imperative to have effective interventions and treatment options for older Blacks. Yet, few arthritis interventions have included Black participants in their samples, and nearly all of those have failed to report separate analyses indicating the effectiveness for Black adults, thus leaving a gap in the literature. The purpose of this study is to begin to identify factors needed to design arthritis interventions that will reduce barriers and increase appeal to Blacks.

The present dissertation consists of one study with two related parts. The first part consists of a needs assessment that examined intervention preferences, barriers to healthcare, knowledge about interventions and care, utilization, and health beliefs among Black and White adults with self-reported physician-diagnosed OA. The second part evaluated materials used in an existing arthritis intervention for acceptability. The study was based on the Arthritis Self Management Program (ASMP). Frequencies were examined to determine needs related to arthritis healthcare of Blacks and Whites recruited from the community. Independent samples t-tests and Pearson's Chi-square analyses were examined to determine group differences between Blacks and Whites.

Blacks were more likely to report cost, lack of trust, fear of being the only person of their race, lack of recommendation from their doctor, and lack of recommendation of a family or friends as barriers to participating in arthritis interventions. In addition, Blacks were more likely to prefer the intervention content, structure and delivery, and arthritis resources presented in the needs assessment in comparison to Whites. As for the evaluation of the intervention materials, Blacks and Whites were similar on most sections.

Based on our findings we suggest that practical adaptations (e.g., cost) be made to existing arthritis interventions to increase cultural sensitivity. Such adaptations have the potential to minimize barriers and offer a program that would be appealing to Blacks with OA.

Chapter One: Background

Overview

The research conducted for this dissertation has been organized as one study with two parts. The overarching theme of the research study was to get a better understanding of arthritis health disparities and identify ways to address such health disparities. Health disparities are a growing public health concern. The study focused broadly on arthritis health disparities in symptoms and service utilization between Black and White adults, while identifying effective ways to begin to overcome the intergroup disparities that are often seen. Chapter one will begin with an overview that will briefly state the problem and address the specific phenomena of interest. Following the overview will be the literature review which will include research on health disparities in general, arthritis health disparities, and arthritis interventions. The review is then followed by the research questions and hypotheses.

The dissertation research is timely in that arthritis is the leading cause of disability in the United States (Centers for Disease Control and Prevention [CDC], 2008a). Arthritis or rheumatic conditions affect almost 70 million Americans (CDC, 2003) with about 46 million being physician-diagnosed cases (CDC, 2008a). It is important to note that the estimation of the population prevalence of arthritis (i.e., 70 million Americans) is based on data using the self-reported physician-diagnosed case definition from the Behavioral Risk Factor Surveillance System (BRFSS) and the National Health Interview

Survey (NHIS). Such definitions are generally used in public health research and are generally broader than clinical definitions (CDC, 2009a). While the case definitions used by BFRSS and NHIS are less stringent than clinical case definitions, self-reports of arthritis have been shown to be valid (Sacks et al., 2005).

Arthritis is oftentimes thought of as one single illness. However, arthritis is an umbrella term for over 100 rheumatic conditions that affects the joints, and surrounding tissue (CDC, 2007a). The physical damage from arthritis can contribute to activity or functional limitations, including activities that are considered basic (i.e., using the computer, climbing up and down the stairs, eating or cutting food, brushing teeth or hair, and walking). In addition, arthritis may result in pain, and disability such as visible deformities, joint swelling and weakness, and instability (Arthritis Foundation, 2007a; CDC, 2007a). Arthritis can also be associated with negative psychological responses such as an increase in anxiety, depression, and feelings of helplessness (Keefe, Abernathy, & Campbell, 2005; National Institute of Arthritis and Musculoskelatal and Skin Diseases [NIAMS], 2002). Being one of the most prevalent chronic illnesses, arthritis not only has an individual impact but also a societal impact. Including both direct and indirect costs, in 2003 arthritis cost the United States over 120 billion dollars, and this amount is only expected to increase (CDC, 2008a; Hootman & Helmick, 2006).

Arthritis is not a condition that should be taken lightly as the prevalence rates are expected to rise astronomically with the aging of our population (CDC, 2008a; Hootman & Helmick, 2006). The prevalence of physician diagnosed cases of arthritis or rheumatic conditions is expected to increase by over 25% by the year 2030 resulting in 67 million people diagnosed with arthritis. Activity limitations associated with the condition are projected to increase by approximately 10% (Hootman & Helmick, 2006). Moreover, certain groups are at a greater risk for having arthritis. Arthritis is more prevalent among women (e.g., osteoarthritis (OA), fibromyalgia, rheumatoid, lupus), older adults (e.g., OA), and people with less education (e.g., overall arthritis; CDC, 2006; Helmick et al., 2008; Lawrence et al., 2008). While research on arthritis prevalence rates vary, it has been reported that arthritis is more prevalent among minorities (Dominick & Baker, 2004; Dunlop, Manheim, Song, & Chang, 2001; Kington & Smith, 1997; Odutola & Ward, 2005). These findings reflect prevalence rates of both overall arthritis or rheumatic conditions (Dunlop et al., 2001; Kington & Smith, 1997; Odutola & Ward, 2005) and specifically OA (Dominick & Baker, 2004). It is also important to note that as the overall arthritis prevalence rates increase, over half of those cases will be in older adults (Hootman & Helmick, 2006). In addition, work limitations associated with arthritis, currently affecting one in every twenty working age adults, are also on the rise (CDC, 2007b). Interestingly, the projected prevalence rates, which are based on self-reports, do not include those who may have arthritis but have not received a diagnosis. However, it is evident that the number of undiagnosed cases will also increase at a rapid rate. It is critical that attention be brought to the expected increase in undiagnosed cases of arthritis, and to consider that minorities may be represented in that category at a disproportionate rate.

The focus of the current study is on OA. OA which is also known as degenerative joint disease, is the most common form of arthritis, and results in the deterioration of the cartilage that protects the joints (CDC, 2008b; NIAMS, 2002). The most common sites for such deterioration are the weight bearing joints (e.g., knees, hips, spine), but it also affects hands, feet, small joints of the fingers, the big toe, and the base of the thumb. OA can result in pain and physical limitations (CDC, 2008b; NIAMS, 2002). Although arthritis is the leading cause of disability in the United States (CDC, 2003, 2008b) with OA being the most common (NIAMS, 2002), it is oftentimes incorrectly thought of as a normal part of aging resulting in a condition that is not often viewed as a serious health concern. The onset of the disease usually begins around middle age and most commonly affects middle aged and older adults (Arthritis Foundation, 2010; CDC, 2010a). Knowing the impact of arthritis in general and specifically the impact of OA, it is imperative that effective arthritis interventions are designed and utilized as a way to minimize the negative impact associated with the condition.

According to the literature, minorities are consistently at a disadvantage in the impact of arthritis, reporting differences in symptoms and arthritis treatment (CDC, 2005a; Dominick & Baker, 2004; Jordan, et al., 2002; Odutola & Ward, 2005). Specifically, in comparison to Whites, a higher proportion of Blacks report arthritis related activity limitations, and severe arthritis related pain (CDC, 2005a; Dominick & Baker, 2004). Racial differences are also found in utilization of treatments for arthritis, although it is unclear how much of these differences are due to differences in patient preferences, versus choices by health care providers. In terms of arthritis medications, Blacks are less likely than Whites to be prescribed narcotics and more likely to be prescribed non-steroidal anti-inflammatory drugs (NSAIDs; Odutola & Ward, 2005). Moreover, there are disparities between Blacks and Whites specific to total joint replacement. Blacks report being less willing to consider total joint replacement as an arthritis treatment option, and less likely to receive joint replacements as a treatment option in comparison to Whites (Ang, Ibrahim, Burant, Siminoff, Kwoh, 2002; Jordan, et al., 2002; Odutola & Ward, 2005). Such differences and disparities are seen between Blacks and Whites not only with arthritis or rheumatic diseases in general, but also specifically between Blacks and Whites who have been diagnosed with OA (Dominick & Baker, 2004; Jordan, et al., 2002; Odutola & Ward, 2005). As reviewed in detail below, Blacks are also greatly underrepresented in research on behavioral interventions for arthritis (McIlvane, Baker, Mingo, & Haley, 2008), and most likely in their attendance at behavioral interventions offered by groups such as the Arthritis Foundation which has reached less than 1% of those with arthritis in the US (Brady, Kruger, Helmick, Callahan, Boutaugh, 2003).

Based on what is known about health disparities in general and health disparities in arthritis, it should be expected that as the prevalence rates increase so will the disproportionate negative impact in minority populations. OA is a serious illness that warrants attention from both researchers and clinicians to minimize the negative impact and improve the quality of life of those affected by the condition. Public health efforts will need to focus on promoting and disseminating interventions that have been shown to be effective (e.g., exercise, self-management, and coping skills interventions; Brady et al., 2003; Hughes et al., 2006; Keefe et al., 2005) as well as to develop interventions that are innovative and meet the needs of minority populations. There is so much to be learned about arthritis in diverse groups. In spite of the fact that there are arthritis interventions that have been shown to be effective (Brady et al., 2003; Keefe et al., 2005), it is unknown if this is true across diverse racial/ethnic groups (McIlvane et al., 2008). It is also unclear if the underrepresentation of Blacks in arthritis interventions and health care services are a result of barriers (e.g., cost of health care services and programs; lack of trust in the health care system in general), preferences (e.g., services and programs are unappealing), or lack of knowledge (e.g., unaware of various health care options and services). Not only is it important to determine the effectiveness of arthritis interventions in minorities (i.e., Blacks), but it is also important to understand why there has been little participation from Blacks in the research studies and the programs offered by the Arthritis Foundation.

The present doctoral dissertation is organized as one study with two parts that will broadly focus on addressing arthritis health disparities between Blacks and Whites, and improving the impact of osteoarthritis in Blacks. The research will address whether modifications might be made in arthritis intervention programs that would make them more appealing to Black participants, remove barriers to participation, and provide practical guidelines for researchers and clinicians who want to reach Black individuals with OA. Specifically, the first part will consist of a needs assessment. The goal of the needs assessment is to identify the needs of both Blacks and Whites in reference to arthritis care, and begin to understand how to offer culturally sensitive arthritis interventions based on those needs that will eliminate barriers to participation in arthritis interventions by Blacks. The second part evaluates the material of an existing arthritis intervention. Both the needs assessment and the evaluation of materials are based on the existing Arthritis Self-Management Program (ASMP) also referred to as the Arthritis Self Help Course (ASHC; CDC, 2010b; Lorig & Holman, 1992; Lorig Ritter, & Plant, 2005). This program has been widely offered through the Arthritis Foundation, but there has been relatively low inclusion of minorities in research studies focused on the ASMP

(Brady et al., 2003; McIlvane et al., 2008) and no indication that the program has been utilized by a substantial amount of Blacks. Lastly, according to the information learned in part one and part two, recommendations will be made for assuring that arthritis interventions are culturally sensitive and how barriers to participation might be decreased, as a way of mitigating the negative impact of osteoarthritis in Blacks.

Literature Review

Health disparities. In spite of the efforts being made to address health disparities in the U.S., with few exceptions, ethnic minorities fare worse than Whites on most conditions (e.g., cancer, AIDS, diabetes, stroke; CDC, 2005b; Frist, 2005; Institute of Medicine of the National Academies [IOM], 2003). According to the CDC (2005b), health disparities plague racial and ethnic minority groups across the life course, and have become a major public health concern. Moreover, due to the rapid increase of those 65 and older in the U.S. population and the dramatic increase in the proportion of racial and ethnic minority groups, health disparities will pose even more of a problem among older adults (CDC & Merck Company Foundation, 2007). The reasons for such disparities are unclear, yet in order to successfully address the concerns of health disparities continued research is imperative. Initiatives such as Healthy People 2010 have been put into place to mitigate and hopefully even eliminate health disparities (CDC, 2005b). While the goals of Healthy People 2010 are laudable, in order to successfully complete such a task (i.e., eliminate health disparities) efforts must be made to identify the progress of such initiatives and evaluate our current state. In addition, we must go beyond merely documenting disparities. It is essential to understand the causes of health inequalities, which in turn will allow them to be addressed in a proper manner.

As previously stated, ethnic minority groups experience a disproportionate burden of many diseases. While it is important to evaluate various health disparities in different racial and ethnic minority groups, this review will focus on the disparities between Blacks and Whites. Despite the fact that public health efforts have focused on health disparities, and research has consistently been conducted addressing health disparities, the reasons behind health disparities are varied. Many factors have been identified as possible contributors to health disparities such as race, SES, culturally related preferences, lack of access to healthcare, utilization, and quality of healthcare (Frist, 2005; IOM, 2003; Mayberry, Milli, & Ofili, 2002; Rathore & Krumholz, 2004). In addition, minorities are under-represented in health research (Curry & Jackson, 2003; Tilley, Wisdom, Sadler, & Bradford, 2003). As a part of the literature review, access, utilization, quality of healthcare and recruitment and retention and the correlation of those factors to current health disparities will be discussed in further detail. Within each section race and socioeconomic status are discussed as integral contributors for each of the aforementioned factors. It is impossible to discuss health disparities without considering the impact of both race and socioeconomic status which are complexly intertwined with almost every possible health disparity contributor.

Understanding the causes and consequences of health disparities in a broad sense is an integral part of understanding health disparities within a specific illness or condition. Therefore, this review will address health disparities in a broad sense and then specifically discuss the same factors in the context of arthritis. Moreover, it is important to focus on the broader issues when trying to understand arthritis health disparities because little work on health disparities has focused specifically on arthritis.

Access. According to the literature, minorities are represented at a disproportionate rate when it comes to lack of access (i.e., the right and opportunity) to adequate healthcare (IOM, 2003). Barriers to access include socioeconomic status, the number of healthcare choices available, and obtaining quality health insurance or obtaining health insurance at all. According to the Institute of Medicine (2003), Blacks are represented disproportionately in each of the aforementioned categories. In addition, Blacks are less likely than Whites to see a primary care physician, and more likely to seek care at a hospital emergency room (Mayberry et al., 2002).

Regardless of how SES is measured it still remains a persistent and pervasive indicator of health status (Kirby, Taliaferro, & Zuvekas, 2006; Mayberry et al., 2002; Weinick, Zuvekas, & Cohen, 2000; Williams & Jackson, 2005). There are marked race differences in socioeconomic status between Blacks and Whites. Blacks are more likely to have a lower level of education, lower income, and more likely to be exposed to occupational hazards than their White counterparts (Rooks & Whitfield, 2004; Williams, 2004). The differences in income and occupation remain present even when comparing Blacks and Whites with similar education levels (Williams, 2004). Reasons as to why these differences persist vary. While socioeconomic status seems to be one of the unmistakable indicators for the lack of access to healthcare for minorities and continued health disparities, it is important to note that in certain studies when controlling for poverty and SES in general, measured race disparities still exist (Kirby et al., 2006; Mayberry et al., 2002; Weinick et al., 2000). Such findings suggest that factors other than SES may explain health disparities (e.g., cultural values). The disparities pertaining to access are well documented in the literature (Anderson & Armstead, 1995; Edwards, Fillingim, & Keefe, 2001; Farmer & Ferraro, 2005; Frist, 2005; IOM, 2003; Mayberry et al., 2002; Rooks & Whitfield, 2004; Weinick et al., 2000 Williams & Jackson, 2005).

The ability to obtain health insurance, particularly adequate health insurance is oftentimes a result of socioeconomic status. Blacks are less likely to have health insurance, and if they are able to obtain health insurance frequently it is restricted to suboptimal services (IOM, 2003; Rooks & Whitfield, 2004). Such race differences persist into old age, even when SES differences are thought to decline (Rooks & Whitfield, 2004). It may seem that Medicare would eradicate access disparities in older adults; however, Blacks with Medicare receive fewer services, lower cost procedures, and have lower rates of physician visits and surgeries than Whites (Dunlop, Manheim, Song, & Chang, 2002; Rooks & Whitfield, 2004). The continued access disparities for older adults with Medicare may be a result of less access to optimal supplemental health insurance, or the lack of wealth accumulation over a lifetime to aid in funding healthcare expenses that are not covered by Medicare. As with all health insurance plans no two are the same, and the best plans are usually the most expensive. Therefore, the inability to purchase the best health insurance plans restricts access to healthcare. Patients with lower tier insurance plans have limited access to quality products and services (IOM, 2003). It is evident that SES and race have a negative impact on access to adequate healthcare. Designing culturally sensitive programs or interventions is a way to address this issue and possibly mitigate the negative impact.

To add to the complexity of understanding the impact of access to healthcare on health disparities, it is important to understand the effects of institutionalized racism or racial segregation. Institutional racism and victimization includes both political and social forces that confine a certain racial/ethnic group to impoverished neighborhoods, and racially isolated schools and places of employment (particularly positions) and even certain hospitals or healthcare settings (Poussaint, 1990; Williams, 2004). While segregation is no longer enforced legally, Blacks still suffer the consequences (Williams, 2004; Williams & Jackson, 2005). Institutional racism and victimization has forced Blacks into positions of hard labor with low benefits, unemployment, and limited access to health and social services (Poussaint, 1990; Williams, 2004). Understanding the impact of access is complicated and multi-faceted. However, based on the literature it appears that minorities, specifically Blacks do not have the same access to healthcare options as the White population. This suggests that this population may be information poor when it comes to healthcare options as a result of the restricted access. The health disparities literature is replete with information on access, yet it seems very little has been done differently to rid the problem. Programs and interventions that take into account some of the access issues that plague our minority communities may actually be beneficial and result in meeting the laudable goals set forth by Healthy People 2010 and more recently Healthy People 2020.

Utilization. In addition to having poor access, minorities also tend to have different healthcare utilization patterns, patterns to which individuals put to use healthcare options, and services, in comparison to Whites (Mayberry et al., 2002). While it is true that some utilization patterns may be strongly correlated or a result of access, when controlling for access indicators disparities in utilization patterns remain (IOM, 2003). Minority patients are more likely to refuse recommended and needed services, adhere poorly to treatment regimens, and delay seeking care (IOM, 2003; Pincus, 2004).

These patterns are similar to those found in osteoarthritis care (Figaro, Russo, & Allegrante, 2004), and could contribute to the disparities that we see in disability. Such utilization differences seem to not be solely based on limited access to healthcare, but may be rooted in the patient's perception of the healthcare system, religious beliefs, and personal belief systems (Pincus, 2004). Varying utilization patterns between Whites and Blacks may also be a result of the different time points in which disease related symptoms are recognized as disease related (LaVeist, 2004). There has been a significant amount of research that has documented the differences in awareness of disease risk factors and disease related symptoms between minorities and their White counterparts. Specifically, Blacks are less likely to be aware of disease risk factors and disease symptoms in comparison to Whites (LaVeist, 2004). This suggests that there is a need for healthcare providers and public health efforts to make stronger efforts to educate minorities on a variety of disease related symptoms and risk factors which may in turn affect healthcare utilization patterns. Another aspect of utilization patterns to consider when discussing health disparities is the fact that minorities tend to report a lack of a stable relationship with a primary care physician. Regardless of whether Blacks are insured at the same level as Whites, Blacks are more likely to receive care in emergency rooms than to visit a primary care physician (IOM, 2003). In addition, Blacks are likely to see a physician less often than Whites which holds true even after controlling for health and income (Mayberry et al., 2002). Specific reasons for such disparities are subject to future research.

When addressing health disparities between Blacks and Whites, it is necessary to find out why varying utilization patterns exist and to determine if these are merely differences or indeed contributors to disparities. A few potential factors that may influence healthcare utilization include beliefs about one’s health condition, beliefs about the healthcare system, cultural values, affordability, family/work responsibilities, and transportation difficulties. It is important to note that simply because one group is different from the other does not indicate one group is inferior to the other. Differences in health care utilization between Blacks and Whites may be deeply rooted in each group’s preferences for health care options and services. Moreover, utilization differences may be a result of public health efforts and health care providers failing to see the importance of addressing preferences when designing programs and offering health care services. As greater insights are gained into the causes of the differences that we see in the healthcare utilization patterns between Blacks and Whites, we can begin to develop programs that will counteract the negative impact of those differences by addressing modifiable causes.

Quality of healthcare. Consistent with other aspects of health and healthcare, minorities are disadvantaged in the quality of healthcare received in comparison to Whites. Quality of healthcare can be defined as healthcare options that increase the likelihood of positive health outcomes, and are concordant with existing and up to date medical knowledge (IOM, 2003). The quality of the interaction between the healthcare provider and the patient has a bearing on one’s healthcare decisions. After controlling for access to healthcare, researchers report that Blacks continue to experience a lower quality of health services than Whites which means that Blacks are more likely to receive less than excellent health care in comparison to Whites (IOM, 2003). Warranting further research, race has been identified as a determinant for such disparities (Mayberry et al., 2000). Research discovered that Blacks were less likely than Whites to express confidence in their primary healthcare provider, and less likely to consider the relationship with the provider as excellent (Lopez, Burant, Siminoff, Kwoh, & Ibrahim, 2005; Williams, 2004). Moreover, Blacks tend to be less satisfied with their visit with the physician in comparison to Whites (Mayberry et al., 2002). The Institute of Medicine (2003) reports Blacks often experience discrimination (i.e., differences in care as a result of stereotypes, prejudices, and biases) which may result in suboptimal care. Specifically, researchers have shown that even among patients who have insurance, Blacks tend to receive worse care (Kahn et al., 1994).

Even though access emerges in several studies as a strong predictor of the quality of healthcare one may receive (i.e., those with private insurance plans receive better care, and those with public insurance plans or no insurance at all receive worse care), it does not negate the fact that upon controlling for access, race remains as a predictor of the quality of healthcare (Balsa & McGuire, 2003; IOM, 2003). Such findings suggest that the reasons for minorities receiving worse healthcare in comparison to their White counterparts goes beyond that of access and may also be a consequence of stereotyping, discrimination and perceptions (i.e., patient's perceptions of the healthcare provider and provider's perceptions of the patient). Negative perceptions of the healthcare system could lead to disparities that emerge. Perceptions may be shaped by a poor cultural match between minority patients and their providers, medical mistrust, misunderstandings (i.e., the provider's instructions), prior negative interaction with health care systems, or simply from lack of knowledge of how to best use the healthcare services (IOM, 2003). Discrimination and stereotyping, whether intentional or not, undeniably impacts the quality of care the patient is likely to receive. Discrimination in the healthcare system can be traced back to historic patterns of legalized segregation and discrimination (IOM, 2003). Blacks have reported that they perceive discrimination between themselves and their healthcare provider, and some aspects of perceived discrimination are correlated with utilization patterns (Bird & Bogart, 2001). Such reporting underscores the complexity of the problem and suggests that health disparities may partially be the result of a long history of discrimination and mistrust of the healthcare system.

Physicians' perceptions play a role in the quality of care as well. A person's race has been known to influence a physician's recommendation (Schulman et al., 1999). In other words, if physicians or healthcare providers are prejudiced against members of minority groups and treat minority patients with less regard than Whites, this could result in poorer quality of care. In addition to prejudices, physicians or healthcare providers may have preconceived perceptions or stereotypes about the type of healthcare a minority individual may seek. In other words if the research consistently reports that Blacks refuse joint replacement as a form of treatment, physicians may be less likely to offer joint replacement even though this may be the most effective treatment. If physicians have a preconceived idea that a person is less likely to comply because of their racial/ethnic background and therefore the patient is not offered treatment, this would understandably increase the issues surrounding health disparities, particularly in quality of care (Balsa & McGuire, 2003). Barriers of this kind have presented themselves in the arthritis literature where Blacks are less likely to receive a referral to a rheumatologist than their White counterparts. Such findings may be a result of the physician's perception that Blacks are less likely to want to see a specialist for their condition (Katz et al., 1998).

Figaro et al. (2004) suggest that designing and utilizing culturally sensitive programs may be beneficial in overcoming the barriers that minorities face to receiving quality healthcare (e.g., intervention programs that address the negative perceptions of joint replacement as a treatment option within the Black community). This suggestion is also set forth by the Institute of Medicine (2003). Moreover, physicians should strive to be culturally competent, meaning efforts are made to make the healthcare system diverse, remain sensitive to minorities, and guarantee access to quality healthcare (Betancourt, Green, Carrillo, & Ananeh-Firempong, 2003). In other words, while it may seem that certain perceptions are entrenched in the minds of minorities and non-minority healthcare providers, it is still true that programs and services can modify those perceptions. Both healthcare providers, including those who design healthcare interventions, and patients can take part in assuaging the impact of health disparities.

There is so much about health disparities that remains unexplained, but beginning to answer such questions in the area of health disparities is important for future studies. In light of the health disparities between Blacks and Whites, future research should strive to have services, programs and interventions that are culturally sensitive and that appropriately address biological, social, and psychological concerns and issues specific to minorities.

Recruitment and retention. Another challenge that impacts understanding and addressing health disparities is the lack of minorities in health related research. In order to move forward in research on health disparities, more minority participants must be included in health research. Even though it may pose a significant challenge (Curry & Jackson, 2003), researchers must overcome the barriers of recruiting and retaining individuals from racial/ethnic minority groups in research. Research needs to include representative samples of the population of interest.

While it is necessary to find ways to recruit and retain minorities in general in health related research, for the sake of this paper we will focus on Blacks. Due to a long history of discrimination and exploitation there is oftentimes reluctance among Blacks to participate in research, specifically health research (Curry & Jackson, 2003). Despite the fact that safeguards have been put into place to protect research participants from unethical treatment, individuals from minority groups are still reluctant to participate in research (Ryall, Abdulah, Rios, & Hausdorff, 2003). Several barriers affect recruitment and retention of minorities including the researcher's approach (e.g., lack of sensitivity, ineffective communication, lack of knowledge, researcher bias), recruitment methods (e.g., use of conventional methods such as print materials, and media recruiting), access (e.g., transportation, and location) and the perception of the participant (Curry & Jackson, 2003; Reed, Foley, Hatch, & Mutran, 2003; Ryall et al., 2003; Tilley et al., 2003; Warren-Findlow, Prohaska, & Freedman, 2003). Moreover, we know that Blacks are more likely to have lower socioeconomic status than their White counterparts (Williams, 2004; Williams & Jackson, 2005). Complex questionnaires and measurements may serve as barriers to those with low education levels resulting in refusal or withdrawal. It is imperative to use materials that are appropriate to the target audience. Researchers should identify recruitment methods that are best for reaching the target population, and use those methods in future research. Traditional methods may not be beneficial in reaching minority participants (Curry & Jackson, 2003). It is imperative that researchers do not allow their own biases or convenience to dictate their recruitment efforts (Curry & Jackson, 2003).

Lack of successful recruitment efforts of individuals from ethnic minority groups consistently seems to be an issue in health research (Curry & Jackson, 2003). Similar discrepancies are seen specifically in the context of arthritis care and arthritis research (Ang, Monahan, & Cronan, 2008; Lopez et al., 2005; McIlvane et al., 2008). Without the inclusion of hard to reach participants (i.e., minorities) in current research, research questions continue to be unanswered (e.g., reasons for disparities) or inaccurately answered (e.g., estimations of the magnitude of the disparities). The current study has a specific focus on these issues in Blacks and Whites with arthritis.

Arthritis health disparities. Previously, the complexities of health disparities in general were discussed. However, for the sake of the current study it is essential to note that the complexity is no different when studying specific illnesses such as arthritis. Currently research varies on whether there are disparities in the prevalence rates of rheumatic conditions including osteoarthritis. Certain findings suggest that Blacks have a higher prevalence of arthritis than Whites (Dominick & Baker, 2004; Dunlop et al., 2001; Odutola & Ward, 2005), and other findings suggest that Whites and Blacks have similar prevalence rates (CDC, 2005a; Lawrence et al., 1998). Albeit, the findings of the prevalence rates vary, Blacks consistently fare worse from arthritis in general than their White counterparts (CDC, 2005a; Dominick & Baker, 2004; Jordan et al., 2002; Lawrence et al, 1998; Odutola & Ward, 2005). Functional impairment and pain are associated with the progression of arthritis or rheumatic conditions (CDC, 2008a), and

Blacks report more pain, more activity limitations, and are more likely to attribute work limitations to arthritis than their White counterparts (Blake et al., 2002; CDC, 2005a; Dominick & Baker, 2004; Odutola & Ward, 2005). Marked race differences have also been found in other rheumatologic symptoms (e.g., muscle tenderness and morning stiffness) with the worst impact being in Black participants (Odutola & Ward, 2005; Satish, Postigo, Ray, & Goodwin, 2001). Race differences continue to exist without a clear explanation. Further research should be conducted that examines the relationship between well documented contributors of health disparities and the disparities in arthritis symptoms seen between Blacks and Whites.

While oftentimes intertwined, specifically in the area of arthritis, examining the impact of access, utilization, quality of care and perceptions (i.e., patient's and provider's perceptions) is pivotal to begin to address arthritis-related health disparities. In concordance with general health disparities, access poses a problem for minorities with arthritis (Song et al., 2007). In comparison to Whites, minorities with arthritis are less likely to have adequate medical access resources, with access factors explaining 60% of excess risk of developing disability for Blacks (Song et al., 2007). Furthermore, in comparison with Whites with arthritis, Blacks find it problematic to obtain health insurance, are more likely to be uninsured, and more likely to rely on Medicaid (Lopez et al., 2005; Song et al., 2007). It is highly unlikely that access is the exclusive explanation to the disparities seen in arthritis between Blacks and Whites with arthritis; however, it is intricately linked to other factors.

Extant literature on joint replacement as a treatment option has shown consistent disparities between Whites and Blacks, with Blacks being 3 -25 times less likely to undergo the surgery (Ibrahim, 2007; Jordan et al., 2002). Approximately 90% of the patients who undergo joint replacement experience a decrease in pain and disability (Callahan, Drake, Heck, & Dittus, 1994). Despite the benefits of joint replacement surgery, ethnic differences in utilization of this particular treatment option remain (Ibrahim, 2007; Mahomed et al., 2003). This is one example of how the utilization patterns differ between Blacks and Whites even in arthritis care. There are several possible reasons that may lead to the disparities in utilization of joint replacement for arthritis. Lack of knowledge about surgical outcomes may be responsible for low utilization rates among Blacks. Blacks have reported that they do not feel as if the procedure is efficacious, and thought that surgery should only be used as a last resort after all other options have been exhausted (Blake et al., 2002; Figaro et al., 2004).

Perceptions and utilization are closely linked. While the current section will touch on arthritis perceptions, they will be reviewed in greater detail in future sections. The purpose in the current paragraph is to further understand the utilization disparities. While not believing in the biomedical model of arthritis, Blacks reported that there was nothing that surgery could do to help the disease because it was due to old age and the climate (Figaro et al., 2004). Such beliefs ultimately impact healthcare utilization patterns. According to Blake et al. (2002), social network (e.g., people you know personally) and perceptions of the benefit of joint replacement therapy can be associated with utilization. Blacks are less likely than their White counterparts to know someone who had joint replacement therapy, and for the people they did know who had the surgery, Blacks in comparison to Whites were less likely to report that the surgery was beneficial (Figaro et al., 2004; Ibrahim, Siminoff, Burant, & Kwoh, 2002a). Blacks were more likely than their White counterparts to have a fear of dying as a result of joint replacement therapy (Figaro et al., 2004), when the mortality rates are approximately one percent (Mahomed et al., 2003). Blacks have expressed that they feel after a surgery such as joint replacement therapy, they would suffer from post treatment pain, a slow recovery, a longer hospital stay and even disability. Major factors explaining such beliefs have not been determined specifically. However, fear of surgery and information collected from family and friends were associated with the negative beliefs about surgery. On the other hand, age, SES, and disease status were not associated with the negative beliefs concerning joint replacement therapy (Figaro et al., 2004; Ibrahim, Siminoff, Burant, & Kwoh, 2002b).

Figaro et al. (2004) found that urban Blacks expressed that other things outside of the perception of the treatment led them to not assume the risk of surgery for arthritis. Still impacting healthcare utilization, participants expressed a preference for natural or over the counter remedies, a strong belief that God was in control, and preference to continue in their current state (Figaro et al., 2004; Ibrahim, Siminoff, Burant, & Kwoh, 2001; Price, Hillman, Toral, & Newell, 1983). Findings also demonstrate that Blacks used prayer as a form of pain management and believed that prayer would alleviate the condition all together (Ibrahim, Zhang, Mercer, Baughman, & Kwoh, 2004; Ibrahim et al., 2001). The utilization of joint replacement therapy may also rest upon the physician’s perceptions of the patient’s religious beliefs. Blacks seem to prefer that the information they receive is from a physician who respects their faith and does not frown upon one praying before making a healthcare decision (Ibrahim et al., 2004). Most of the research on perceptions of arthritis treatment has focused on the comparison of Blacks and Whites. Results from such research are imperative and does inform better approaches to healthcare. However, a research area that has been under-studied is that of within-group differences. Therefore, being mindful not to over generalize the between-group research findings will also strengthen the development of culturally sensitive interventions. For example, while Blacks report using prayer for pain management it may not suit all Blacks. Therefore, it may be counterintutive to the goal of mitigating health disparities to design a program for Blacks that included a mandatory prayer component.

Distinct differences in the quality of care for arthritis have also been documented. It is imperative to reiterate that many of the possible contributing factors to arthritis health disparities can be closely intertwined. Blacks continue to report being twice as likely to seek care for arthritis in an emergency room, and more likely to see a primary care physician instead of a specialist for arthritis treatment (Blake et al., 2002). While this may be a consequence of lack of access, it may result in poor or less optimal quality healthcare. Proportionately fewer Blacks are referred for specialist care (i.e., orthopedic clinic; Lopez et al., 2005). It is imperative to consider that the information disclosed about arthritis treatment may be different at the clinic and emergency room versus the information one would receive from a primary care physician or particularly a specialist. Lopez and colleagues (2005) showed that Blacks with knee and hip osteoarthritis when compared to their White counterparts were less likely to report being satisfied with their primary physician, and less likely to have confidence in their primary physician.

Lastly, varied perceptions have the potential to result in the current arthritis disparities seen between Blacks and Whites. Common myths and misperceptions associated with rheumatic diseases vary by race. Such myths and misperceptions pertain to both the disease and treatment options for the disease (Arthritis Foundation, 2007b; Price et al., 1983). Although a misconception, research has shown belief in ideas such as arthritis being caused by cold and wet climates, and poor diet (Figaro et al., 2004; Price et al., 1983). The idea that arthritis could be due to wet and cold climates was believed more so by Blacks than their White counterparts (Price et al., 1983). This exemplifies the need to implement interventions that address the physical impact of the disease as well as educate people about the disease in general.

Being unaware of effective treatments is also problematic particularly when people rely on what is referred to as “quack” treatments or unproven remedies (Price et al., 1983). Despite their ineffectiveness, it was still believed that treatments such as bee venom, vitamins, copper bracelets, special diets, dimethylsulfoxide (DMSO), green alcohol, sliced potatoes, liniment, kerosene, and various herbal creams and rubbing lotions would benefit the complications associated with arthritis. Blacks were more likely to rely on natural remedies or unproven remedies for their arthritis complications than to undergo surgery (Figaro et al., 2004; Price et al., 1983). Importantly, the lay public, particularly Blacks, need to be educated about arthritis and arthritis care and management. Misperceptions could lead to mistreatment, which in turn could lead to increased pain, physical limitations, and other negative outcomes associated with arthritis. The aforementioned findings and continued efforts to understand arthritis health disparities are crucial when developing programs and interventions that are culturally sensitive. It is also an indicator that there is no such thing as a one size fits all intervention.

Future researchers' ability to design and provide efficacious interventions to ameliorate the disparities mentioned is based on understanding the influence of culture. Reducing arthritis health disparities may be a matter of providing education to a population that otherwise may be information poor or may weigh information that is provided differently. In other words, it is important to design interventions that will educate persons in a culturally sensitive manner about arthritis itself and the benefits and risks of various care options. Also, it is important to provide education that will allow individuals to self-manage their illness and reduce the negative impact of symptoms. Even something as small as educating Blacks about the benefits of seeing a rheumatologist over a primary care physician, where research has shown that there is a health advantage to having a rheumatologist provide arthritis healthcare (Yelin, Such, Chriswell, & Epstein, 1998), is a way to begin to address arthritis health disparities. Therefore, the proposed set of studies is a vital piece to this burgeoning area of research.

Arthritis interventions. Osteoarthritis can be treated through surgery, and the pain can be managed through medications (CDC, 2007a). However, such treatment options do not seem to be completely eradicating all of the negative symptoms associated with the condition (Keefe et al., 2005). Educational and psychological approaches such as cognitive-behavioral training or self-management training can be used to successfully treat arthritis (Brady et al., 2003; CDC, 2007a; Keefe et al., 2005). In addition, exercise interventions have been shown to be effective (Brady et al., 2003). The above findings are pivotal when considering utilizing interventions as a way to manage arthritis. Arthritis not only affects an individual physically, but also mentally (Keefe et al., 2005). Treatment options should positively impact both physical and mental health.

Many arthritis interventions have been shown through randomized controlled trials to be effective (e.g., coping, self-management, exercise; Brady et al., 2003; McIlvane et al., 2008). Effective interventions include, but are not limited to the Arthritis Foundation Aquatics Program (Suomi & Lindauer, 1997), the Arthritis Self-Management Program, (Lorig, Gonzalez, Laurent, Morgan, & Laris, 1998; Lorig, Mazonson, & Holman, 1993; Lorig, Ritter, & Laurent, 2004) and psychological interventions for symptom management (Dixon, Keefe, Scipio, Perri, & Abernathy, 2007). Arthritis interventions such as the self-management, exercise, and cognitive behavioral interventions, have been shown to decrease pain, depression, medical visits, disability, discomfort, medical expenses, and to increase relaxation, quality of life, self-efficacy, functional ability, self-care behavior, perceived self-efficacy, and knowledge about arthritis (Brady et al., 2003; Dixon et al., 2007). However, the positive effect is only true for the populations that the interventions reach. The majority of arthritis interventions have sampled predominately White populations, meaning that it is unknown if these effects hold true in a Black population (Brady et al., 2003; McIlvane et al., 2008). Research has also shown that Blacks are less likely to even participate in an arthritis self-management program (Bruce, Lorig, & Laurent, 2007). A recent review article reported that arthritis interventions conducted approximately over the past ten years have been conducted mostly without any special attention to minorities (McIlvane et al., 2008). The authors reported that inclusion of minorities was limited. Specifically, only a small portion of the studies (i.e., 2 of the 25) examined and showed effectiveness in a minority sample, and only one study showed special efforts to recruit and retain minorities. In addition, none of the interventions between the years of 1997 – 2008 included in the review made any mention of including components that would meet the needs of a racial/ethnic minority population (McIlvane et al., 2008).

It is important to note that recent research has acknowledged that the lack of inclusion of minorities is problematic and has begun to make an effort to address the gap in the literature by including Blacks in the ASMP trials and by adapting the materials to become more culturally sensitive (Goeppinger, Armstrong, Schwartz, Ensley, & Brady, 2007; Goeppinger et al, 2009). However, the process of modifying the materials and delivery of the program for cultural sensitivity were not described in detail (Goeppinger et al., 2007; Goeppinger et al., 2009). Moreover, Goeppinger et al. (2009) collected data from 156 Black participants, however analyses specific to this group were not presented. To our knowledge only one study to date has examined the acceptability or the effectiveness of the ASMP among Blacks (Goeppinger et al., 2007). Without randomized controlled trials for arthritis interventions including minorities (e.g., Blacks), researchers making efforts to have a diverse sample, or information on diverse samples being clearly reported in the literature, the question will remain as to whether arthritis interventions are acceptable or effective in racial/ethnic minority populations.

The fact that minorities continue to be underrepresented in arthritis intervention research exacerbates the inability to provide adequate healthcare options to the population and may play a role in arthritis health disparities. Therefore, as one way to address such an issue, efforts should be made to design culturally sensitive arthritis interventions or to see if current interventions are effective with minorities as is. In other areas of research, interventions that have been modified to be appropriate for ethnically diverse populations have been shown to be effective (Gallagher-Thompson et al., 2003).

In arthritis research it may not be a matter of tailoring an intervention for a specific minority group to make a positive impact, but it may be that making the interventions culturally sensitive and appealing to minorities would increase participation and aid in reducing current disparities. Such initiatives are in line with the laudable goals of Healthy People 2010 and more recently Healthy People 2020 to eliminate health disparities between those with disabilities and those without (e.g., arthritis-related disability) as well as to prevent illness and disability associated with rheumatic conditions (CDC, 2000; Department of Health and Human Services [DHHS], 2009a).

Future directions. By knowing that arthritis interventions have shown a positive effect in the populations sampled, and that interventions for other conditions modified to benefit ethnically diverse populations have been effective, it is speculated that an arthritis intervention designed to be culturally sensitive for Blacks will be more likely to result in positive outcomes (e.g., decreasing pain and functional impairment) when compared to intervention that does not place an emphasis on cultural sensitivity. This dissertation research seeks to fill the gap in the arthritis intervention research by identifying needs and preferences as well as perceptions of a widely accepted arthritis intervention. The research will inform the design of a culturally sensitive feasibility arthritis intervention that will reduce barriers and appeal to Blacks. It is important to note that by culturally sensitive we do not mean a program that is tailored to a specific group. However, our intentions are to inform the design of an intervention that takes into account the preferences, beliefs, and practices of racial/ethnic minorities.

Research objectives/research questions. The objective of this dissertation is to make an attempt to contribute to the overall goal of eliminating arthritis health disparities by providing recommendations regarding culturally sensitive arthritis interventions specific to the ASMP. In addition, it is hoped that the contributions made through this dissertation research will be a template that can be applied to other arthritis interventions and also be used for fighting health disparities in other conditions or diseases as well. We must be cognizant of the fact that good healthcare is tied to quality of life. Therefore, the ultimate goal of the dissertation research is to go beyond simply stating that disparities should be addressed and actively address health disparities. Specifically, the purpose of the first part of the research is to conduct an arthritis intervention needs assessment for Blacks and Whites with OA. Presently there is no uniform definition as to how to define a needs assessment (Baldwin, 1998). For the sake of this study a needs assessment is an assessment used to gather valid and reliable information, which will aid in developing better services (Soriano, 1995). Past research has examined the needs of patients with arthritis, however samples included predominately White participants, and analyses did not examine race differences (Buckley, Vacek, & Cooper, 1990; Hirano, Laurent, & Lorig, 1994).

While limited work using needs assessments have been conducted in the area of arthritis and arthritis disparities, utilizing needs assessments to evaluate the care needs of a target population is not a novel concept (Corona, Gonzalez, Cohen, Edwards, & Edmonds, 2009; Jenkins, Lapelle, Zapka, & Kurent, 2005). Researchers have used needs assessment to gather information on health service needs in various areas (e.g., health service needs for Latino youth (Corona et al., 2009) and end of life care needs for African Americans; Jenkins et al., 2005). Recommendations have been made for service providers to adopt a more culturally sensitive approach to healthcare. It is imperative that we use such research as a model to gain information on developing a culturally sensitive arthritis intervention.

Therefore the needs assessment will address the following research questions:

1. Are there race differences in intervention preferences, barriers to healthcare, knowledge about arthritis interventions and care, utilization, and health beliefs between Blacks and Whites with OA?

2. What are the most common intervention preferences, barriers to healthcare, utilization preferences among Blacks and Whites with OA?

   Based on previous literature it is hypothesized that there will be significant race differences in barriers to participation in healthcare (i.e., arthritis interventions). Black participants will be more likely to report that lack of trust in the healthcare system, family responsibilities, cost, and transportation are barriers to participating in the intervention. Due to the lack of an extensive previous literature on issues of preferences for arthritis interventions, racial differences in the other issues will be explored without hypotheses.

The purpose of the second part of the study is to conduct an evaluation of a portion of the materials used in the ASMP toolkit. As mentioned previously there are many arthritis interventions that have failed to include significant numbers of minorities (i.e., Blacks). Therefore, addressing this concern in any existing arthritis intervention would be beneficial. However, for the sake of this research the focus will be on the ASMP which is the most accessible arthritis intervention to the public. Such accessibility is the result of the endorsement of the ASMP by the CDC, Arthritis Foundation, and

American College of Rheumatology. The ASMP is a 6-week community-based course (weekly 2 hour sessions) for people with arthritis. The focus of the program is to teach skills to self-manage arthritis and build confidence to carry out the skills learned (Lorig, Ritter, Laurent, & Fries, 2004; Lorig et al., 2005; CDC, 2009a). The mailed version of the ASMP is referred to as the ASMP toolkit. The objectives of the toolkit are synonymous to that of the ASMP community-based program (Goeppinger et al, 2009).

Previous research found it difficult to get Blacks to participate in the ASMP toolkit intervention, and thought a possible explanation may be that Blacks found the materials and structure of the intervention to be unappealing (Goeppinger et al., 2009). Therefore, the purpose of this study is to determine if the ASMP toolkit materials would be utilized and evaluated favorably by Blacks and Whites with OA and if those findings differ by race. Knowledge about the acceptability of the existing interventions such as the ASMP toolkit could lead to the development of better designed interventions that would effectively address the needs of minorities. Therefore the evaluation of a selected portion of the ASMP toolkit materials will provide answers to the following research question:

1. Are there race differences in the acceptability of the different components of the ASMP toolkit between Blacks and Whites with OA?

   Due the exploratory nature of this research no hypothesis can be drawn specific to the research question.

Chapter Two: Research Methods

Needs Assessment

Participants. The research protocol was approved by the University of South Florida's Institutional review board. Participants were recruited from multi-purpose senior centers, church groups, and senior housing communities in the Tampa, Florida area. In addition, participants were recruited from an existing USF Arthritis participant registry. The arthritis participant registry was created in the School of Aging Studies at the University of South Florida. The names included participants with osteoarthritis from previous studies who have agreed to participate in future studies. The participant registry was the first source of recruitment. In addition, flyers, presentations, and the snowball method was used to recruit and inform participants about the study. Those interested in the study were provided with additional information about the study, and administered a prescreening tool to determine eligibility. The onset of OA begins around middle age (Arthritis Foundation, 2010; CDC, 2010) and the impact seems to worsen around age 50. Research has documented specific outcomes that take place at age 50 and above. Specifically, OA is one of the leading causes for work disability for men age 50 and above, and women tend to be affected more frequently than men beginning at age 50 (Lawrence et al., 2008; Lawrence et al., 1998). Therefore, eligible participants included individuals age 50 and older self-reporting a doctor-diagnosis of osteoarthritis, with no other complicating musculoskeletal diseases, if possible. The self-reporting method used to identify individuals with osteoarthritis is similar to the method used by the Centers for Disease Control and Prevention to examine arthritis prevalence rates in the population (CDC, 2001). Moreover, this method has been shown to be a valid method among older adults (Sacks et al., 2005). All participants provided written informed consent prior to enrollment.

The final sample for the project consisted of 115 volunteers with an average age of 72 years (SD=10.2). The sample size is sufficient for a needs assessment with the intent of reporting descriptive analyses (Berkowitz, 1996).

Procedure. This study was conducted using a survey research design to collect information from community dwelling adults with osteoarthritis. Once the volunteers were screened for eligibility, the researcher scheduled a time and place convenient to the participant to meet to fill out the survey (i.e., needs assessment questionnaire). Based on what was convenient for the participants, surveys were self-administered in either a group setting or individual appointments. On average it took the participants 30 minutes to complete the questionnaire. Participants were provided a five dollar Target gift card as a token of appreciation for their participation. While recruitment efforts and data analyses did focus on recruiting Black and White adults with OA, volunteers from other race groups were not excluded from participating if they showed an interest in the study.

Measures. The instrument used in this study was designed as a semi-structured questionnaire (including a combination of structured questions and open-ended questions; Appendix A). The study gave participants an opportunity to comment on open-ended questions as a supplement to the quantitative findings (e.g., Do you see the need for an arthritis self-help program for people who have been diagnosed with arthritis, Yes or

No?; Please explain why or why not). Specifically, the instrument included structured questions that are designed to assess demographics, socioeconomic status, health status, knowledge, barriers, preferences and utilization. The measures included in the questionnaire are listed below and explained in further detail.

Demographics. Race was assessed by asking participants to "please tell me your race or ethnicity" with the choices being 1) White/ Caucasian, 2) Black/African American, 3) Latino/Hispanic, 4) Asian/Pacific Islander, 5) Native American, or 6) Other. Age was based on date of birth and measured as a continuous variable. Participants were also asked to report their marital status and gender.

Socioeconomic status. Socioeconomic status was assessed based on income and education level. Participants were asked to identify their total annual family income (i.e., wages, pensions, dividends, and any additional household income) by selecting an income starting at $5,000 dollars and increasing incrementally with the final choice being more than $100,000. Education was assessed with a 1-item question that asks "What is the highest grade of school or year of college you have completed?" Choices ranged from 0 to 17+.

Health status. Overall health status, disability, and pain of the participant were assessed using single item questions from the Behavioral Risk Factor Surveillance System (BRFSS) Questionnaire (CDC, 2009b). Participants were asked to rate their health in general with choices ranging from excellent = 4 to poor = 0. Disability was assessed by asking participants to respond yes =1 or no = 0 to the question, "Are you limited in any way in any activities because of physical, mental, or emotional problems?" Pain was measured by asking participants to rate their average joint pain over the past 30 days using an 11-point Likert scale (0=no pain, 10= extreme pain; Centers for Disease Cnntrol and Prevention (CDC), 2009b). Participants were also asked to report the number of years they have had arthritis related symptoms, and the number of years that they had been diagnosed with osteoarthritis by a doctor.

Knowledge and beliefs. To determine what participants know and believe about arthritis, three questions were asked about arthritis in general and arthritis treatment using and 11-point Likert scale (i.e., Do you consider arthritis to be a normal part of getting older, 0=not at all, 10=normal aging; Do you think anything can be done about arthritis once you have it, 0=don't believe at all, 10=definitely believe; Do you think once you get arthritis it can only get worse not better, 0=don't believe at all, 10=definitely believe). The questions were adapted from a questionnaire used to evaluate the public's perception of arthritis (Price et al.,1983). The questions used in the research by Price et al. (1983) were similar in nature asking participants to respond yes or no to questions assessing if the participant believed arthritis could be prevented, arthritis could be helped by treatment, and arthritis could be cured once a person gets it.

Potential barriers. Barriers were assessed by presenting the participants with two vignettes describing existing arthritis interventions. Participants were asked to read the first vignette and answer the questions that follow. Participants were then asked to read the second vignette and answer the questions that follow. The purpose of having the participants read each vignette was to assess barriers to participation (e.g., mistrust, cost, transportation) in both an existing mailed arthritis intervention and an existing community-based arthritis intervention.

The first vignette stated, “Imagine that you have been diagnosed with arthritis and have been asked to participate in an arthritis group education course. The course will be offered at the local community center and will be taught by a person who has arthritis and has been trained to offer this course. The course will cost you $30. You will be asked to come to the center once a week from 10:00am – 12:00 noon for six weeks. In addition, to the weekly meetings you will receive *The Arthritis Helpbook* (a textbook for the course), Arthritis Foundation brochures, and a year’s subscription to the *Arthritis Today* magazine. During the six weeks you will develop an exercise program just for you, discuss arthritis medications, learn how to manage your pain, learn how to solve arthritis-related problems, and learn how to communicate with your health care providers. You will be responsible for getting yourself to and from the community center.”

The second vignette stated, “You have been diagnosed with arthritis and have been informed that you can participate in an at home arthritis management program. The information will be mailed to you. The cost of the information is $30. You will be able to go through the information at your own pace. The mailed package will include *The Arthritis Helpbook* (a textbook for the course), information sheets describing arthritis problems and solutions, a self-test, and a relaxation and exercise CD. The self- test will help you determine the areas that you will need to focus on to develop a personalized arthritis health care plan. You will be responsible for scoring the test yourself. The information sheets and textbook will include information on pain, physical limitations, fatigue, health concerns, exercise, medications, healthy eating, finding community resources, dealing with your emotions, and how to work with your doctor and the health care system.” Following each vignette was a list of potential barriers to participation (e.g., I believe my lack of trust in the health care system would prevent me from participating; I believe it would be difficult to afford the cost of the program; I believe it would be difficult to find time to participate in the arthritis program; I believe it would be difficult to find transportation to the local community center). Participants were asked to determine how much they believed each statement using an 11-point Likert scale (0=don't believe at all, 10=definitely believe).

Arthritis intervention preferences. Intervention preferences were assessed by asking about components of an existing arthritis intervention and about components that could be included in potential arthritis interventions. The questionnaire was modeled after a questionnaire developed to assess preferences in bereavement service utilization (Bergman & Haley, 2009). The questionnaire assessed preferences for the content (e.g., information about medications, nutrition, reducing pain, coping with negative emotions; 0=not helpful at all, 10=extremely helpful), structure (e.g., individual, group, family), and delivery (e.g., preference for in-home program, mailed program; 0=not at all, 10=extremely) of arthritis interventions by having the participant rate the value of intervention components on an 11-point Likert scale.

Utilization patterns. Utilization patterns were assessed by asking questions about the utilization of the Arthritis Foundation resources in general (How familiar are you with the Arthritis Foundation, 0=not at all, 10=extremely; How often have you used the Arthritis Foundation resources, 0=not at all, 10= quite a bit) Participants were also asked to determine their utilization of existing arthritis interventions available through the Arthritis Foundation (e.g., ASMP, People with Arthritis can Exercise, Aquatic Program, Tai-Chi). Specifically, participants were presented with a list of interventions from the

Arthritis Foundation and were asked to determine if they had ever heard of the interventions by responding yes or no. In addition, participants were asked whether or not they had ever participated in the interventions by responding yes or no.

Participants were also asked to determine potential resources one would utilize for arthritis information. Questions were adapted from a previous research questionnaire used to examine the knowledge and beliefs that individuals have about arthritis (Price, Hillman, Toral, & Newell, 1983). In the work conducted by Price et al. (1983), by responding yes or no participants were asked to determine from what people or media have they received information about arthritis (i.e., friends, relatives, television, radio, newspaper, magazines, books, physician, and Arthritis Foundation). In the current study, utilization of resources for arthritis information was assessed by providing participants with a list of places or people one may go to find information about arthritis (i.e., internet, friend, health care provider, physician, someone with arthritis, television, radio, relatives, books, religious leader, and Arthritis Foundation). Participants were asked to determine the likelihood of seeking arthritis information from each source using an 11-point Likert scale (0 = not likely at all, 10 = extremely likely).

Data analysis. Using SPSS, descriptive analyses were conducted as they are the most common and appropriate analyses for a needs assessment (Soriano, 1995). First, exploratory data analysis was used to identify outliers and missing data. While missing data was minimal in this particular study, missing values were replaced with the mean of the non-missing values for most variables. Mean imputation is a sound way to address the missing data in that the mean of the variable being studied would not be changed.

Demographic and nominal variables were not included in the mean imputation calculations.

Frequencies were examined to assess the knowledge and beliefs, barriers, intervention preferences (i.e., content, structure and delivery), and arthritis resources and intervention utilization of the sample. Inferential statistics were conducted to determine the differences between Blacks with OA and Whites with OA. To address research question one, independent samples t-tests and chi-square analyses were used to examine between group differences in demographics, arthritis knowledge and beliefs, arthritis intervention content preferences, arthritis intervention structure and delivery preferences, utilization of select arthritis interventions, where one seeks arthritis information, and barriers to participating in arthritis interventions. While several questions were listed under specific categories (e.g., barriers), each question within the category was treated as an individual dependent variable. All tests were examined at the significance level of .05. Chi-square analyses require a relatively even distribution of subjects to ensure that the expected frequencies for most of the cells are above five (Morgan, Leech, Gloeckner, & Barrett, 2004). When greater than 20% of the cells had expected count less than five, a Fisher's exact test for 2X2 crosstabs was conducted.

In addition to the independent samples t-tests that were conducted to determine statistical significant differences between Blacks and Whites, practical significance was examined by calculating the effect size for each statistically significant outcome. The effect sizes were examined to determine the magnitude of the difference between Black and White participants on the dependent variables. Effect sizes were calculated by hand using the equation $d = M_A - M_B/SD_{pooled.}$ As for Chi-square analyses Phi was examined to determine the effect size. To address research question two, scores were ranked from a high mean to a low mean for items among each racial group. No statistical tests were conducted to determine the significance of the rank order.

ASMP Toolkit Evaluation

Participants. Participants were recruited in the same manner as the participants from the needs assessment. Individuals who participated in the needs assessment were given the opportunity to participate in the ASMP Toolkit Evaluation. The study was approved by the Institutional Review Board of the University of South Florida. All participants provided written informed consent prior to enrollment. The sample consisted of 61 participants (M age = 74 years, SD = 9.13).

Procedure. This study was conducted using a quantitative survey research design. The questionnaire (Appendix B) was designed to evaluate the acceptability of the ASMP toolkit (i.e., evaluating how likely one is to use the toolkit, and if the toolkit materials would be rated favorably). The eligibility requirement for this portion of the dissertation research was the same as the requirements for the needs assessment (i.e., self-reported doctor diagnosed OA and age 50+). Based on what was convenient for the participants, surveys were self-administered in either a group setting or at individual appointments. Participants were provided a five dollar Target gift card as a small token of appreciation. On average participants completed the questionnaire in one hour. It is important to be reminded that this study was conducted in two parts and participants in the needs assessment may have but did not necessarily participate in ASMP materials evaluation.

Measures.

Demographics. Survey questionnaires were used to gather information on participants' demographic characteristics (i.e., race, age, marital status, and gender). For race, participants were asked to "please tell me your race or ethnicity" with the choices being 1) White/ Caucasian, 2) Black/African American, 3) Latino/Hispanic, 4) Asian/Pacific Islander, 5) Native American, or 6) Other. Age was based on self-reported date of birth and measured as a continuous variable. Participants were also asked to report their marital status and gender.

Socioeconomic status. Socioeconomic status was assessed based on income and education level. Participants were asked to identify their total annual family income (i.e., wages, pensions, dividends, and any additional household income) by selecting an income starting at $5,000 dollars and increasing incrementally with the final choice being more than $100,000. Education was assessed with a 1-item question that asks "What is the highest grade of school or year of college you have completed?" Choices ranged from 0 to 17+.

ASMP toolkit. The ASMP toolkit is a mailed version of the Arthritis Self-Help Management Program (Goeppinger et al., 2009). The development of the toolkit was the result of collaboration between Stanford University School of Medicine Patient Education Research Center, the University of North Carolina School of Nursing, and the University of North Carolina Center for Health Promotion and Disease Prevention. In addition, the development of the toolkit was supported by the Arthritis Section of the CDC. The complete packaged toolkit includes a self-test that allows individuals to determine how they are impacted by arthritis and how to develop an individualized self-management program based on that impact, the Arthritis Self-Help book (Lorig & Fries, 2006), information sheets that address problems common to those with arthritis (e.g., pain management, healthy eating, working with your doctor, problem solving), action plan information sheets, a relaxation CD, two exercise CDs, and an illustrated guide to accompany the exercise CDs.

Evaluation of materials (Appendix B)**.** Participants were asked to read or listen to select components of the arthritis toolkit and evaluate the components for acceptability. Select components included the 1) action plan information sheet, 2) problem solving information sheet, 3) healthy eating information sheet, and 4) the finding community resources information sheet. Participants were asked to rate the acceptability of the materials on an 11-point Likert scale. The questions varied based on the select component (See Appendix B). However, examples of some of the questions are as follows; 1) based on what I read about the action plan: I am likely to create an action plan? (0 = not at all likely, 10 – extremely likely), 2) based on what I read about problem solving: It seems the problem solving steps were designed with people like me in mind? (0 = not at all, 10 = definitely), 3) Based on what I read about healthy eating: I feel the healthy eating section fits my needs? (0 = not at all, 10 = extremely), 4) Based on what I read about community resources: I am likely to use detective tools to find the answers to questions I may have about arthritis? (0 = not at all likely, 10 = extremely likely).

Participants were also asked to evaluate the acceptability of a portion of the illustrated exercise guide that is included in the tool kit by answering questions similar to those listed above. In addition, to the written components of the program, each questionnaire consisted of questions that asked participants to listen to four minutes of a

CD. There are three questions of this nature (i.e., listening to four minutes of a relaxation CD, listening to four minutes of a guided imagery CD titled “A Walk in the Country”, and four minutes of an exercise CD). The relaxation CD is a recording of instructions on how to turn off the outside world in order to let your body relax. The instructions provide both mental and physical relaxation tips. The speaker presents the instructions in a soft tone accompanied by soft background music. The guided imagery CD is used to teach you to transport yourself to a pleasant time or place in order to take your mind off of any unpleasant feelings. The scripts for both the relaxation CD and the guided imagery CD are included in the appendix (See Appendices C and D). The exercise CD is a recording of instructions for exercises that can be done at home. An instructor talks you through each exercise. Materials included were selected to be representative of the kind of content included in the toolkit.

Data analysis. To assess the data for errors, missing data, and outliers, an exploratory data analysis was conducted. Basic descriptive analyses were used to assess the demographic characteristics of the sample. Missing data was imputed with the means of the sample on each item. Demographic variables were not included in the mean imputation calculations. Comparisons of acceptability of the ASMP toolkit between Blacks with OA and Whites with OA were performed using independent samples t-tests. Effect sizes were calculated to assess practical significance. Effect sizes were computed by taking the difference of the group means and dividing it by the standard deviation pooled.

Chapter Three: Results

Needs Assessment

Sample characteristics. Descriptive statistics for the sample are displayed in Table 3.1. Analyses were conducted including only Black and White participants. Participants included 55 White and 60 Black adults who self-reported doctor diagnosed osteoarthritis. Black and White participants in this sample were similar with respect to education. Less than 30% of the participants in each group reported being married. This may be a result of the average age of the participants. Older women are more likely to live longer than older men and become widows. Blacks in this sample were more likely to be younger, and more likely to have a lower annual household income than Whites. Blacks reported significantly worse health in general and more arthritis related pain than Whites. However, there was no significant difference in the level of disability between Black and White participants. Blacks reported having arthritis symptoms and being diagnosed with OA for a less amount time than their counterparts.

Arthritis knowledge and beliefs. Table 3.2 shows that there were no statistically significant differences reported between Blacks and Whites concerning arthritis perceptions and arthritis knowledge. Both Blacks and Whites seem to have similar perceptions on whether or not arthritis is a normal part of aging, whether or not anything can be done about arthritis, and whether or not arthritis will only get better or worse.

Table 3.1 Needs Assessment Sample Characteristics

Variable	Black Participants (N=60)	White Participants (N=55)	
	M (SD)	M (SD)	t(x^2)
Age (M in years)	67.21 (9.61)	77.25 (8.25)	5.90***
Education (M in years)	13.27 (2.26)	13.81 (2.45)	1.21
High school or less (%)	47.5	32.1	(2.75)
More than High School (%)	52.5	67.9	
Marital Status (%)			
Never Married	11.9	1.8	(13.11)*
Separated	8.5	0	
Divorced	25.4	20	
Widowed	33.9	47.3	
Living with Partner	0	3.6	
Married	20.3	27.3	
Gender (% female)	93.2	78.2	(5.34)*
Income	4.29 (2.88)	5.57 (2.48)	2.31*
< $5,000 – 9,999	32.7	10.9	(9.81)*
$10,000 – 19, 999	28.6	28.3	
$20,000 – 39,999	20.4	21.7	
$40,000 – 59,999	8.2	26.1	
≥ $60,000	10.2	13.0	
Health Status	1.76 (.90)	2.26 (.96)	2.85**
Pain	6.81 (2.37)	5.45 (2.42)	-3.03**
Disability (% Yes)	63.2	71.7	(.91)
Symptoms (M in years)	11.67 (9.79)	18.57 (15.22)	2.85**
Arthritis Diagnosis (M in years)	10.35 (7.89)	15.99 (14.43)	2.55*

*p < .05; **p < .01; ***p < .001

Table 3.2 Arthritis Knowledge and Beliefs

Variable	Black Participants (N = 60)		Whites Participants (N=55)			
	M	SD	M	SD	df	t
Normal Aging	6.14	3.64	6.13	3.21	113	-.02
Something can be done about arthritis	5.70	3.62	6.42	3.25	113	1.11
Arthritis can only get worse	6.18	3.46	5.56	3.46	113	-.95

Potential barriers. Participants' perceptions of need or lack thereof for an arthritis self-help program could serve as a barrier to participation. A Fisher's exact test was used to compare the participants' perceived need for an arthritis self-help program between Blacks and Whites. Of those participants who identified themselves as Black, 90% reported there was a need for an arthritis self-help program. In addition, of those who identified themselves as White, 100% also reported there was a need for an arthritis self-help program. There was no statistically significant difference between Black and White participants. Participants were also asked to explain the reason for their response. The following quotes reflect several of the participants' explanations.

> "A class would be a blessing to help us who are suffering from arthritis. Please get a class as soon as possible." (Black, Female, Age -70)
>
> "All alternatives should be made known to the patient." (Black, Female, Age - 61)
>
> "Anything that can help people." (Black, Male, Age - 50)
>
> "Because I need help with my aching and pain." (Black, Female, Age - 68)
>
> "Because it's a lot of things I try to do and not able to do so any advice that anyone could give would be helpful." (Black, Female, Age - 59)
>
> "Because patients need to know it is like a baby starting over again. You have to walk in different shoes! Sleep, sit, and walk how to do these things all over again. Also, you have to limit what you pick up, how long you sit, and how far you can walk." (Black, Female, Age - 52)

> "Because when I go to the doctors and tell him I'm hurting he just gives me medication for pain." (Black, Female, Age - 71)
>
> "Educating yourself about how to manage the condition can have a positive impact. Sometimes not knowing what to do can cause more pain." (Black, Female, Age - 56)
>
> "Getting medical help from professional with proper knowledge is expensive and frustrating. One needs to handle the problems from arthritis on their own as much as possible." (White, Male, Age - 85)
>
> "I believe it is something I have to live with and self-help instructions could make it easier." (Black, Female, Age - 77)
>
> "I believe that there are very few people who are diagnosed and given any more than medication. No education how they "got it" and/or what they can do about it other than meds." (White, Female, Age - 67)
>
> "It helps deal with the challenge. It can keep you realistic on how you deal with this challenge in your life." (White, Female, Age - 68)
>
> "Too much conflicting information out there, not sure what is fact and what is fallacy." (White, Female, Age - 67)
>
> "People want to be active without pain." (White, Female, Age - 74)
>
> "We all need all the help we can get." (White, Female, Age - 82)
>
> "Especially for younger people if the service can provide some exercising, meditation, training which might detour the progression of arthritis." (White, Female, Age - 81)
>
> "It would help with pain and movement." (White, Female, Age - 79)
>
> "There are ways to help people cope with arthritis, but many people don't have access to them." (Black, Female, Age, - 71)

Table 3.3 reports race differences in barriers to participating in the community-based ASMP. While there were no significant differences between Blacks and Whites on the perceptions of need for an arthritis self-help program, there were significant group differences on other variables assessing potential barriers to participation in the ASMP. First, results will be reported for the barriers for the community-based intervention. Then results will be reported for barriers of the ASMP toolkit, the at home version of the ASMP. Specific to the community-based self-management program, differences were found on five variables. Blacks were more likely to report that their lack of trust in the healthcare system, fear of being the only person of their race in the program, and the cost of the program would be a barrier to participating in comparison to Whites. Blacks were also more likely to report that they would only participate in the program if family and friends thought it was a good idea, and only if recommended by a doctor. Effect sizes for statistically significant findings ranged from .37 to .67. According to guidelines suggested by Cohen, .20 is considered a small effect size, .50 is considered a medium effect size, and .80 is considered a large effect size (Morgan et al., 2004; Newton & Rudestam, 1999). The medium effect sizes found in these analyses suggest that not only are the group differences concerning fear of being the only person of their race and cost statistically significant, but also practically significant. There were no statistically significant race differences in believing the program would be helpful, finding the drive or determination to participate in the program, the difficulty to find time to participate, conflict with family responsibilities, lack of neighborhood safety, other health concerns, or being physically unable serving as potential barriers to participation in a community-based ASMP. Contrary to expectations, there were no group differences in transportation or family responsibilities as potential barriers to participation in the traditional arthritis self-management course. No statistical tests were conducted to determine the significance of the rank order of the barriers to participating in the community-based ASMP, however Blacks and Whites were similar reporting cost, difficult to find time, and hard to find the drive and determination as the top three barriers. Cost was the largest barrier for Blacks whereas difficult to find time was the largest barrier for Whites.

Table 3.3 Barriers to Participation in ASMP (community-based intervention)

Variable	B	W	Black Participants (N = 60)		White Participants (N=55)				
	Rank	Rank	M	SD	M	SD	df	t	d
Cost	1	3	5.95	4.19	3.71	3.80	113	-2.99**	.54
Difficult to find time	2	1	5.23	3.77	4.65	3.73	113	-.83	.15
Hard to find the drive or determination	3	2	4.98	3.70	4.49	3.77	113	-.71	.13
Only if recommended by my doctor	4	6	4.57	4.15	3.06	3.75	113	-2.04*	.38
Other health concerns	5	4	4.27	3.65	3.29	3.33	113	-1.49	.28
Lack of trust in the healthcare system	6	8	3.95	3.75	2.61	3.34	113	-2.02*	.37
Difficult to find transportation	7	5	3.82	4.04	3.15	3.80	113	-.92	.17
Family responsibilities	8	9	3.39	3.62	2.40	3.45	113	-1.51	.28
Only if family and friends thought it was a good idea	9	11	3.25	3.99	1.67	3.18	110.93[a]	-2.35*[a]	.42
Physically unable	10	10	3.16	3.64	2.29	3.13	113	1.37	.25
Fear of being the only person of my race	11	13	2.78	3.78	.67	1.68	82.94[a]	-3.93***[a]	.67
My neighborhood is not safe	12	12	2.45	3.48	1.38	2.62	109.05[a]	-1.87[a]	.34
Believe the program will be helpful[b]	13	7	1.84	2.70	2.65	2.91	113	1.56	.29

Note. B = Black Participants; W = White Participants.
[a]The *t* and *df* were adjusted because variances were not equal. [b]Reverse coded
*p < .05; **p < .01; ***p < .001

As shown in Table 3.4 the independent samples t-tests for barriers to participation in an at home self-management program (ASMP toolkit) yielded similar results to that of the community-based arthritis self-management program. Specifically, Blacks were more likely to report lack of trust in the healthcare system, fear of being the only person of their race in the program, only participating if family and friends thought it was a good idea, and cost as potential barriers to participating in the at home self-management program in comparison to their counterparts. We found medium effect sizes for each statistically significant group difference, ranging from .50 -.52. Recommendation of the doctor was no longer statistically significant. While no statistical tests were conducted, groups differed somewhat in the rank order of barriers to participation in the ASMP toolkit intervention. Blacks still reported cost as the greatest barrier to participation in the ASMP toolkit.

Arthritis intervention preferences. Table 3.5 displays mean differences between Blacks and Whites on preferences for intervention content. Significant group differences were found on all of the intervention content variables examined except for teaching you to improve physical functioning and teaching you about non-traditional treatment options. Intervention content was more highly favored by Blacks on all significant variables. In other words, Blacks were more likely to think the variables would be helpful if included in an arthritis intervention. Effect sizes for statistically significant findings ranged from .39-.78. Groups were not similar on the rank order of content preferences for an arthritis intervention.

Table 3.4 Barriers to Participation in ASMP Toolkit (home-based intervention)

	B	W	Black Participants (N = 60)		White Participants (N=55)				
Variable	Rank	Rank	M	SD	M	SD	df	t	d
Cost	1	3	5.84	4.28	3.18	3.79	113	-3.52**	.50
Only if recommended by my doctor	2	5	3.79	3.93	2.75	3.50	113	-1.50	.28
Hard to find the drive or determination	3	1	3.78	3.56	4.06	3.51	113	.41	.08
Difficult to find time	4	2	3.73	3.87	3.31	3.40	113	-.62	.11
Other health concerns	5	4	3.46	3.57	3.02	3.35	113	-.68	.13
Physically unable	6	6	3.31	3.70	2.33	3.33	113	-1.49	.28
Believe the program will be helpful[b]	7	7	3.16	3.10	2.04	3.27	113	1.88	.35
Lack of trust in the healthcare system	8	9	3.02	3.72	1.39	2.35	100.86[a]	-2.83**[a]	.50
Only if family and friends thought it was a good idea	9	10	2.75	3.67	1.15	2.39	102.32[a]	-2.97**[a]	.50
Family responsibilities	10	8	2.58	3.56	1.62	2.70	109.27	-1.64	.30
Fear of being the only person of my race	11	11	2.16	3.46	.68	1.61	85.1[a]	-2.97**[a]	.52

Note. B = Black Participants; W = White Participants.

[a]The *t* and *df* were adjusted because variances were not equal. [b]Reverse coded

*p < .05; **p < .01; ***p < .001

Table 3.5 Preferences on Intervention Content

	B	W	Black Participants (N = 60)		White Participants (N=55)				
Variable	Rank	Rank	M	SD	M	SD	df	t	d
Teach you helpful exercises	1	5	9.23	2.11	8.02	2.73	101.59[a]	-2.66**[a]	.49
Get the most out of the healthcare system	1	3	9.23	1.57	8.11	2.33	93.32[a]	-3.01**[a]	.55
Teach you about your type of arthritis	2	10	9.20	1.70	7.83	2.63	91.16[a]	-3.29**[a]	.60
Reduce your pain	3	2	9.18	2.08	8.29	2.44	113	-2.12*	.39
Problem solving-skills for arthritis related problems	4	6	9.13	1.88	7.93	2.81	93.17[a]	-2.68**[a]	.50
Treatment decisions	5	4	9.06	1.96	8.03	3.20	113	-2.70**	.48
Problem solving skills in general for health related problems	6	7	9.01	1.96	7.91	2.70	98.03[a]	-2.48*[a]	.46
Nutrition and healthy and eating	7	11	8.95	2.20	7.56	2.87	100.88[a]	-2.88**[a]	.53
Improve physical functioning	7	1	8.95	2.25	8.33	1.83	113	-1.62	.30
Arthritis healthcare options/ resources other than PCP	8	8	8.89	1.92	7.88	2.67	97.39[a]	-2.31*[a]	.43
Make meals you eat already in a healthier way	9	15	8.88	2.42	7.24	2.94	113	-3.28**	.59
Arthritis medications that are available	9	13	8.88	2.12	7.40	3.14	93.22[a]	-2.95**[a]	.54
Various types of arthritis	10	18	8.87	2.07	6.82	3.19	91.28[a]	-4.05***[a]	.72
Talk to professionals about your arthritis	11	14	8.75	2.46	7.29	2.87	106.85[a]	-2.91**[a]	.53
Information about the use of medications	12	12	8.62	2.60	7.49	3.00	113	-2.16*	.40
Decrease negative emotions	12	19	8.62	2.68	6.80	3.46	101.48[a]	-3.13**[a]	.57
Set personal treatment goals and a plan of action	13	17	8.48	2.34	6.98	3.13	99.60[a]	-2.90**[a]	.53
Choose a doctor	14	16	8.47	2.69	7.16	3.10	113	-2.45*	.45
Non-traditional treatment decisions	15	9	8.40	2.76	7.86	2.84	113	-1.04	.20
Talk to family and friends about your arthritis	16	20	8.34	2.78	5.87	3.47	103.50[a]	-4.18***[a]	.73
Internet sources for arthritis care	17	22	8.08	3.07	5.16	3.92	102.35[a]	-4.43***[a]	.78
Discrimination in healthcare	18	21	8.05	3.16	5.86	3.97	103.13[a]	-3.26**[a]	.59

Note. B = Black Participants; W = White Participants.

[a] The *t* and *df* were adjusted because variances were not equal. *p < .05; **p < .01; ***p < .001

Regarding intervention structure and delivery, independent samples t-tests resulted in a statistical significant difference on 19 out of 22 variables (Table 3.6). In comparison to Whites, Blacks were more likely to see the need of the structure and delivery variables for an arthritis intervention. Effect sizes ranged from .43-.97. Blacks rated the preference to have the intervention mailed as the highest, whereas Whites responded most favorably to having the intervention led by someone who has arthritis themselves. No statistical tests were conducted to determine the significance of the rank order of preferences.

Utilization patterns. Participants were asked to rate their preferences of resources for arthritis information. The results of the independent samples t-tests between Blacks and Whites are shown in Table 3.7. In comparison to Whites, Blacks reported they would be more likely to seek information from all listed arthritis resources. There were significant differences between the groups on all variables except for the likelihood of one seeking arthritis information from a physician. Effect sizes for statistically significant findings ranged from .38-.72. Both Blacks and Whites rated physician, healthcare provider, and arthritis foundation as the places they would most likely go to for arthritis information. Amongst the list of resources, interestingly both groups report religious leaders as the resource they would least likely go to for arthritis information.

Table 3.6 Preferences on Intervention Structure and Delivery

	B	W	Black Participants (N = 60)		White Participants (N=55)				
Variable	Rank	Rank	M	SD	M	SD	df	t	d
Mailed	1	5	8.57	2.41	5.93	3.62	92.79[a]	-4.56***[a]	.80
Include discussion with other people who have arthritis	2	2	8.20	2.89	6.47	3.28	113	-3.00**	.54
Offer a class to a group teaching you to manage arthritis	3	3	7.89	3.30	6.42	3.40	113	-2.35*	.43
Given at a community or senior center	4	8	7.53	3.39	5.49	3.62	113	-3.11**	.56
Bring a friend for support and to learn with you	5	15	7.52	3.27	4.06	3.55	113	-5.45***	.91
Led by someone who has arthritis themselves	5	1	7.52	3.19	6.68	2.90	113	-1.48	.27
Video-Tape/ DVD	6	6	7.43	3.54	5.76	3.71	113	-2.46*	.45
Given in your neighborhood	7	4	7.40	3.60	6.24	3.52	113	-1.74	.32
Cassette Tape/CD	8	9	7.29	3.65	5.26	3.82	113	-2.92**	.53
Given in an instructions or lecture format	9	7	7.28	3.54	5.74	3.15	113	-2.46*	.45
Given at the local Arthritis Foundation	10	12	7.15	3.47	4.69	3.35	113	-3.86***	.68
Material on spiritual beliefs	11	13	7.10	3.53	4.55	3.77	113	-3.75***	.66
Given at a local health clinic	12	14	7.01	3.18	4.07	3.17	113	-4.95***	.84
Bring a family for support and to learn with you	13	16	6.95	3.86	4.00	3.55	113	-4.25***	.73
Include people in your same age group	14	11	6.63	4.44	4.76	3.72	113	-2.44*	.45
Given at a local church	15	17	6.39	3.86	3.00	3.16	116.64[a]	-5.17***[a]	.86
Include people of your race	16	18	5.60	4.47	2.59	3.33	108.61[a]	-4.12***[a]	.71
Be given by someone of the same gender	17	19	5.36	3.96	2.06	3.04	109.74[a]	-5.05*[a]	.85
Provide child care services	18	20	5.15	4.35	1.55	2.68	99.41[a]	-5.39***[a]	.88
Be limited by condition	19	10	5.12	4.19	4.84	3.44	111.66[a]	-.39[a]	.07
Given by someone of the same race	20	22	4.70	4.23	.98	1.95	84.45[a]	6.13***[a]	.97
Be limited by gender	21	21	4.15	4.00	1.38	2.38	97.46[a]	-4.55***[a]	.77

Note. B = Black Participants; W = White Participants.

[a] The *t* and *df* were adjusted because variances were not equal.

*p < .05; **p < .01; ***p < .001

Table 3.7 Preferences of Resources for Arthritis Information

Variable	B	W	Black Participants (N = 60)		White Participants (N=55)				
	Rank	Rank	M	SD	M	SD	df	t	d
Physician	1	1	8.71	2.49	7.97	2.36	113	-1.62	.30
Healthcare Provider	2	3	8.67	2.21	7.51	2.63	113	-2.55*	.46
Arthritis Foundation	3	2	8.65	2.22	7.57	2.53	113	-2.45*	.45
Someone with arthritis	4	4	7.35	3.23	5.74	3.01	113	-2.76**	.50
Books	5	5	7.02	3.41	5.28	3.30	113	-2.78**	.50
Relatives	6	9	5.69	3.75	3.14	2.83	109.07^{a}	-4.14***^{a}	.72
Internet	7	6	5.67	4.25	4.11	3.92	113	-2.04*	.38
Friend	8	7	5.66	3.76	3.70	3.24	113	-2.97**	.54
TV	9	8	5.32	3.77	3.17	3.02	111.05^{a}	-3.38**^{a}	.59
Radio	10	10	4.38	3.84	2.12	2.94	109.58^{a}	-3.57**^{a}	.63
Religious Leader	11	11	3.65	3.73	1.72	2.44	102.46^{a}	-3.30**^{a}	.58

Note. B = Black Participants; W = White Participants.
^{a}The *t* and *df* were adjusted because variances were not equal.
*p < .05; **p < .01; ***p < .001

To investigate the differences between Blacks and Whites familiarity of the Arthritis Foundation and the Arthritis Foundation Intervention Programs independent samples t-tests and Chi- Square analyses were conducted (Table 3.8). Although participants reported that they would be likely to seek information from the Arthritis Foundation, participants did not report being very familiar with the Arthritis Foundation (mean ± SD 2.73 ± 3.26 versus 2.89 ± 3.22; p = .27; Blacks versus Whites respectively) or report a great deal of use of the Arthritis Foundation resources (1.50 ± 2.83 versus 1.38 ± 2.70; p =.-22; Blacks versus Whites respectively). There was no significant difference between Blacks and Whites familiarity of the Arthritis Foundation, or use of Arthritis Foundation resources in general. When asked about specific Arthritis Foundation intervention programs, Pearson chi-square results indicated that Blacks were significantly less likely to have heard of the Arthritis Foundation Aquatics Program, and the Arthritis Foundation Tai-Chi program. In addition, results indicate that Blacks were more likely to have participated in the Arthritis Foundation People with Arthritis can Exercise program, but less likely to have participated in the Arthritis Foundation Tai-Chi program in comparison to Whites.

Table 3.8 Familiarity with the Arthritis Foundation and Programs

Variable	B Rank	W Rank	Black Participants (N = 60)	White Participants (N=55)	x^2
Heard of PACE (% Yes)	1	3	45.3	35.3	1.08
Heard Tai-Chi (% Yes)	2	1	34.8	71.7	13.54***
Heard of ASHC (% Yes)	3	4	20	13.5	.79
Heard of Aquatics Program (% Yes)	4	2	18.4	44.4	8.02**
Participated in PACE (% Yes)	1	3	16.9	3.8	4.92*
Participated in Tai-Chi (% Yes)	1	1	16.9	37.7	6.15*
Participated in ASHC (% Yes)	2	2	13.8	10.9	.22
Participated in Aquatics Program (% Yes)	3	2	11.9	11.3	.01

Note. B = Black Participants; W = White Participants.
*p < .05; **p < .01; ***p < .001

ASMP Toolkit Evaluation

Sample characteristics. Descriptive statistics for the sample are displayed in Table 3.9. Only Black and White participants were included in the analyses. Participants included individuals who self-reported a doctor-diagnosed case of OA. There were no significant race differences in the participant’s age, marital status or income. The majority of the participants, both Black and White, were widowed Whites were more likely to have a higher education level than Black participants.

Table 3.9 ASMP Sample Characteristics

Variable	Black Participants (N=34) M (SD)	White Participants (N=27) M (SD)	$t(x^2)$
Age (M in years)	73.80 (7.89)	74.50 (10.55)	.29
Education (M in years)	12.24 (2.43)	14.70 (2.30)	4.04***
High school or less (%)	73.5	33.3	(9.87)**
More than High School (%)	26.5	66.7	
Marital Status (%)			
Never Married	8.8	0	(10.9)
Divorced	8.8	29.6	
Widowed	58.8	44.4	
Living with Partner	0	11.1	
Married	23.5	14.8	
Gender (% female)	90.9	85.2	(.47)
Income	3.75 (2.51)	4.40 (2.46)	.87
< $5,000 – 9,999	37.5	15	(9.80)*
$10,000 – 19, 999	33.3	45	
$20,000 – 39,999	8.3	25	
$40,000 – 59,999	16.7	5	
≥ $60,000	4.2	10	

*p < .05; **p < .01; ***p < .001

Evaluation of materials. Table 3.10 shows that there were no significant differences between Blacks and Whites in the acceptability of the action plan information sheets, and one of the exercise CDs included in the ASMP toolkit. Blacks and Whites were similar on the rank order for the acceptability of the action plan but were not similar on questions pertaining to the exercise CD. As shown in Table 3.11

there were also no significant differences between the groups' acceptability of the problem solving information sheets that are included in the toolkit. However, independent samples t-tests for acceptability of the illustrated exercise guide yielded group differences on two items. Blacks were significantly more likely to say they would use the exercise guide for their arthritis, and more likely to tell a friend to use the exercise guide in comparison to Whites. Effect sizes for significant findings ranged from .62-.69. Interestingly, Blacks and Whites ranked the questions for the acceptability of the exercise guide in the same order. Blacks did not rank acceptability of the problem solving section similarly. No statistical test was conducted to determine significance of rank order.

Table 3.10 Acceptability of ASMP Toolkit (Action Plan and Exercise CD)

	B	W	Black Participants (N = 34)		White Participants (N=27)				
Variable	Rank	Rank	M	SD	M	SD	df	t	d
Action Plan									
The action plan was designed with people like me in mind	1	1	7.20	2.83	6.52	3.07	59	-.90	.23
An action plan will help my arthritis	2	4	6.98	2.60	5.86	3.06	59	-1.41	.36
Likely to follow an action plan	3	3	6.15	2.69	5.85	2.96	59	-.41	.11
Likely to create an action plan	4	2	5.97	2.92	6.26	2.78	59	.40	.10
Exercise CD									
Liked listening to the CD	1	3	8.09	2.60	7.55	3.02	59	-.75	.19
Found CD very helpful	2	5	7.90	2.87	7.02	3.52	59	-1.08	.28
Someone from my cultural/racial group can relate to the speaker	3	2	7.76	2.56	7.93	2.82	59	.24	.06
Exercise CD is meant for people like me	4	4	7.65	2.71	7.07	3.25	59	-.75	.19
Would tell my friends to use the CD for their arthritis	5	6	7.62	3.13	6.18	3.63	59	-1.65	.42
Feel confident I would use the CD at home on my own	6	7	7.52	3.31	5.99	3.71	59	-1.70	.43
Confident I can do the exercises on the CD even with my arthritis	7	1	7.18	2.92	8.07	2.40	59	1.29	.33

Note. B = Black Participants; W = White Participants.
*p < .05; **p < .01; ***p < .001,

Regarding the acceptability of the community resources section of the ASMP toolkit, independent samples t-tests resulted in no statistical differences between Blacks and Whites (Table 3.12). Participants were also asked to rate the acceptability of the ASMP toolkit relaxation CD. Significant differences were found on one item. Blacks were more likely to report that they would recommend the relaxation CD to their friends to use the CD for their arthritis in comparison to Whites (Table 3.12). Blacks did not rank the acceptability of the community resources and relaxation CD similarly.

Table 3.11 Acceptability of ASMP Toolkit (Problem Solving and Exercise Guide)

Variable	B	W	Black Participants (N = 34)		White Participants (N=27)				
	Rank	Rank	M	SD	M	SD	df	t	d
Problem Solving									
Problem-solving steps were designed with people like me in mind	1	4	8.32	2.04	7.03	3.03	59	-1.98	.50
Would use problem solving skills to reduce my problems in general	2	5	8.26	1.98	7.02	3.04	42.60[a]	-1.82[a]	.48
Found problem-solving to be very helpful	3	3	8.06	2.13	7.15	2.93	59	-1.41	.36
Would use problem-solving skills to reduce arthritis problems	4	2	7.91	2.35	7.19	2.83	59	-1.10	.28
Learning problem-solving skills would help my arthritis	5	1	7.83	2.56	7.50	2.93	59	-.46	.12
Exercise Guide									
Feel that someone from my cultural/racial group can relate to the pictures	1	1	8.21	2.48	7.43	2.40	59	-1.23	.31
Likely that exercise were meant for people like me	2	2	8.03	2.33	6.76	2.83	59	-1.93	.48
Exercise pictures were helpful	3	3	7.94	2.64	6.68	2.94	59	-1.76	.45
Would tell my friends to use the guide	4	4	7.71	2.77	5.81	3.10	59	-2.52*	.69
Likely to use guide at home for my arthritis	5	5	7.38	2.82	5.18	3.20	59	-2.85**	.62

Note. B = Black Participants; W = White Participants.
[a] The *t* and *df* were adjusted because variances were not equal.
*p < .05; **p < .01; ***p < .001

Table 3.12 Acceptability of ASMP Toolkit (Community Resources and Relaxation CD)

	B	W	Black Participants (N = 34)		White Participants (N=27)				
Variable	Rank	Rank	M	SD	M	SD	df	t	d
Community Resources									
Confident I can find community resources to help with my arthritis	1	3	9.76	14.06	6.75	3.27	59	-1.08	.08
Likely to use detective tools to find answers to my arthritis questions	2	2	7.30	2.70	6.82	3.20	59	-.63	.16
Detective tools were meant for people like me	3	1	7.12	2.73	7.03	3.13	59	-.11	.02
Confident I can find community resources to help me in general	4	4	6.75	2.93	6.62	3.20	59	-.16	.04
Relaxation CD									
Would tell my friends to use CD for their arthritis	1	8	8.16	1.87	6.42	3.28	39.14^{a}	-2.46^{*a}	.64
Found CD to be very helpful	2	6	8.03	2.30	7.02	3.36	44.07^{a}	-1.34^{a}	.36
Would use the CD at home on my own	3	7	7.92	2.60	6.50	3.37	47.90^{a}	-1.82^{a}	.47
Feel that someone from my cultural/racial group can relate to the speaker	4	1	7.85	2.40	8.03	2.38	59	.30	.08
Relaxation CD is meant for people like me	5	5	7.83	2.23	7.32	3.22	44.32^{a}	-70^{a}	.19
Can use the relaxation to benefit my arthritis	6	4	7.81	2.71	7.36	3.17	59	-.61	.16
Liked listening to the CD	7	2	7.80	2.22	7.51	3.08	59	-.44	.11
Can relate to the story on the CD	8	3	7.59	2.85	7.43	3.05	59	-21	.05

Note. B = Black Participants; W = White Participants.

[a] The *t* and *df* were adjusted because variances were not equal.

*p < .05; **p < .01; ***p < .001

When asked to rate the acceptability of the healthy eating portion of the toolkit, Blacks reported in comparison to Whites that they were more likely to change their eating habits based on the material learned, and more likely to understand how a change in their eating habits would benefit their arthritis. In addition, Blacks were more likely to believe that the healthy eating section was designed with people like them in mind in comparison to their counterparts (Table 3.13). Effect sizes for significant findings ranged from .60-.71. Blacks and Whites ranked the questions in the healthy eating section similarly. Also shown in Table 3.13, there were significant differences in the acceptability of the imagery CD that accompanies the ASMP toolkit. Blacks seemed to find the imagery CD more acceptable than Whites. Blacks were more likely to believe the CD was meant for people like them, more likely to find the CD helpful, more likely to feel confident that they would use the CD at home on their own, and more likely to recommend the use of the CD to their friends who have arthritis. For all of the statistically significant findings, effect sizes ranged from .57-.71.

Although very few differences were found between Blacks and Whites on the acceptability of each section of the toolkit, several group differences were found when participants were asked to rate their acceptability or the toolkit in general based on the parts they had seen or heard. Findings are reported in detail in Table 3.14. Blacks were more likely than Whites to feel the written material was offensive, more likely to feel the graphics were offensive in some way, and more likely to feel the audio was offensive in some way. Contrary to the findings concerning the offensiveness of the graphics and written material, Blacks were also more likely to report that the program materials were visually appealing, and the program material was easy to read in comparison to Whites.

The acceptability of the problems addressed in the toolkit, attending a traditional ASMP, the likelihood of exercising with the entire exercise CD was rated higher by Black participants in comparison to White participants. Effect sizes ranged from medium to very large.

Table 3.13 Acceptability of ASMP Toolkit (Healthy Eating and Imagery CD)

Variable	B	W	Black Participants (N = 34)		White Participants (N=27)				
	Rank	Rank	M	SD	M	SD	df	t	d
Healthy Eating									
Healthy eating section fits my needs	1	1	8.47	2.02	7.41	2.96	59	-1.66	.42
Seems healthy eating section was designed with people like me in mind	2	2	8.38	2.41	6.33	3.43	44.98[a]	-2.63*	.67
See how changing my eating would help my arthritis	3	3	8.04	2.45	6.26	3.32	46.47[a]	-2.33*[a]	.60
Likely to change my eating based on material learned	4	4	7.45	2.70	5.15	3.42	59	-2.94**	.71
Imagery CD									
Liked listening to the CD	1	2	8.17	2.23	6.89	3.20	59	-1.84	.47
Found the CD helpful	2	4	8.07	2.13	6.00	3.61	39.93[a]	-2.64*[a]	.68
Would tell my friends to use the CD for their arthritis	3	7	7.78	2.45	5.59	3.72	42.96[a]	-2.64*[a]	.68
Feel confident I would use the CD at home on my own	4	8	7.70	2.71	5.30	3.72	46.11[a]	-2.82**[a]	.71
Someone from my cultural/racial can relate to the speaker	5	1	7.75	2.11	7.04	2.78	59	-1.14	.57
CD is meant for people like me	6	6	7.64	2.50	5.88	3.49	45.56[a]	-2.29*[a]	.30
Can relate to the story on the CD	7	3	7.57	2.56	6.49	3.42	59	-1.41	.36
Confident I can use the CD to help with my arthritis	8	5	7.30	2.63	5.91	3.49	47.14[a]	-1.72[a]	.45

Note. B = Black Participants; W = White Participants.

[a] The *t* and *df* were adjusted because variances were not equal.

*p < .05; **p < .01; ***p < .001,

Table 3.14 Acceptability of ASMP Toolkit (In General)

Variable	B	W	Black Participants (N = 34)		White Participants (N=27)				
	Rank	Rank	M	SD	M	SD	df	t	d
In General									
Did you find the material easy to read	1	6	8.34	2.49	6.73	3.25	59	-2.20*	.55
Did you feel the print was big enough	2	5	8.12	2.95	6.83	3.64	59	-1.52	.39
Are the arthritis program materials visually appealing	3	8	8.07	2.20	4.42	3.35	42.90[a]	-4.88***[a]	1.11
Are the problems and concerns addressed problems you have with your arthritis	4	7	7.58	3.01	5.88	2.70	59	-2.30*	.57
Likely you would listen to and exercise with a 20 min. CD	5	9	7.41	2.82	4.15	3.18	59	-4.24***	.97
Would you attend the traditional ASMP	6	10	6.47	3.65	2.28	2.70	59	-4.97***	1.08
Is the written material in any way offensive[b]	7	3	5.83	4.17	8.74	2.26	52.76[a]	3.48**[a]	.78
Is the audio in any way offensive[b]	7	2	5.83	4.20	8.78	1.84	47.39[a]	3.40**[a]	.80
Are the pictures or graphics in any way offensive[b]	8	1	5.66	4.26	9.19	1.46	42.25[a]	4.53***[a]	.95
Anything in the materials that made you feel uncomfortable or was not acceptable[b]	9	4	5.39	4.17	7.24	3.78	59	1.79	.45

Note. B = Black Participants; W = White Participants.

[a] The *t* and *df* were adjusted because variances were not equal. [b]Reverse coded

*p < .05; **p < .01; ***p < .001,

Chapter Four: Discussion

In light of the fact that addressing health disparities has been the focus of the CDC, Department of Health and Human Services, and the National Arthritis Action Plan (CDC, 2010b), the current dissertation sought to examine ways that arthritis interventions (i.e., ASMP) could potentially address those disparities. Specifically, we sought to examine whether Blacks and Whites differ on their preferences for arthritis interventions and acceptability of the ASMP toolkit. To our knowledge this study is among the first to evaluate the needs of individuals with OA in this manner. Our first research question was to determine whether there were race differences between Blacks and Whites in arthritis knowledge and beliefs, barriers to healthcare, arthritis intervention preferences, and utilization.

Knowledge and Beliefs.

In this particular study, our findings showed that there were no race differences specific to knowledge and beliefs about arthritis. Blacks and Whites had similar perceptions about arthritis. Both groups reported that they thought that arthritis was somewhat due to normal aging, and could only get worse. Moreover, both groups only partially felt that something could be done about arthritis. These findings support results of previous research that have examined arthritis perceptions in older adults. Common misperceptions about arthritis tend to be highly prevalent among older adults (Appelt, Burant, Siminoff, Kwoh, & Ibrahim, 2007; Goodwin, Black, & Satish, 1999). According to Appelt et al. (2007), OA patients show a significant relationship between their age and beliefs about arthritis. Specifically, the older the patient the more likely they are to believe that arthritis is a natural part of aging, and that people should expect functional impairment and pain as they age. In addition, older individuals believed that once you have arthritis the disease will only worsen over time (Appelt et al., 2007). Goodwin and colleagues (1999) found that 39% of their sample of older adults had no opinion about the cause of arthritis, and approximately 22% of the sample stated that old age was the cause of arthritis. Such beliefs appeared to be tied to the participant's health care decisions. Participants who thought nothing could be done for arthritis were less likely to have a primary physician, and those believing that it was a result of old age were less likely to have received preventive care (Goodwin et al., 1999). Devoting efforts to further understand older adult's knowledge and perceptions about arthritis may aid in reducing the major public health problem associated with arthritis as well as arthritis health disparities.

Potential Barriers

Relatively little is known about whether or not individuals feel the need for a self-management program for arthritis and whether or not the perception of need or lack of need would serve as a barrier to participation. Our findings suggest that both Blacks and Whites perceive a similar level of need for an arthritis self-management program. Therefore, our findings suggest that lack of need for a self-management program is not a potential barrier to participation. In other words, individuals expressed a strong need for a program of this type which likely would increase participation. While findings vary (Chodosh et al., 2005; Warsi, LaValley, Wang, Avorn, & Solomon, 2003), a great deal of research has found self-management programs to be beneficial to individuals dealing with arthritis and complications associated with arthritis (Brady et al., 2003; Fries, Carey, McShane, 1997; Goeppinger et al., 2009; Lorig, 2003; Lorig et al., 2004; Lorig et al., 2005; Lorig, Ritter, Laurent, & Plant, 2008). While chronic conditions like OA are not immediately life threatening they are also not curable and may prove to be burdensome over time. Learning how to manage the condition across one's lifespan is imperative to quality of life. Regardless of the need expressed by individuals as in this study and the evidence of its effectiveness from previous research (Brady et al., 2003), self-management programs have not been widely accepted as a vital part of the health care system by health care providers (Lorig, 2003; Redman, 2004). In addition, although endorsed by the Arthritis Foundation and the CDC, it seems that arthritis self-management programs oftentimes are not promoted by clinicians (i.e., primary physicians, rheumatologists) as an option to treating arthritis (Redman, 2004). In fact previous research has referred to self care as the hidden health care system putting an emphasis on the fact that in spite of the lack of acceptance by clinicians, self care or self-management comprises the majority of health care (Keysor et al., 2003; Sobel, 1995). Specifically, patients self-manage up to 90% of their symptoms without any assistance from a healthcare provider (Sobel, 1995). These findings suggest that perceived need coupled with the benefits of arthritis interventions underscore the importance of an ASMP for both Blacks and Whites.

The hypotheses concerning barriers to participation in both the community-based ASMP and the ASMP toolkit intervention were only partially confirmed. Blacks were more likely than Whites to report lack of trust in the healthcare system, cost of the program, and fear of being the only person of their race as potential barriers to participating in both of the self-management programs. Based on the participants' responses, cost was the biggest barrier to participation for Blacks. These barriers are not unfamiliar when considering overall barriers to healthcare for Blacks and factors that have been documented in the literature as potential contributors to health disparities (IOM, 2003).

Previous research has documented concerns with socioeconomic status and healthcare parity. The fact that Blacks were more likely to see the cost of the program as a barrier may be a reflection of their SES and ability or lack thereof to pay for programs that are not covered by their insurance. Research has consistently documented the inequalities in SES between Blacks and Whites (IOM, 2003; Williams, Yu, & Jackson, 1993). According to the U.S. Census Bureau, approximately 25% of Blacks in comparison to approximately 8% of Whites are living at the poverty level (DHHR, 2009b). Moreover, Blacks in this study had a statistically significantly lower income in comparison to Whites. Based on these statistics and the characteristics of our sample it is understandable that Blacks would be more likely to see cost as a barrier to participating in the program, particularly if you feel that other issues are more pressing. Therefore, it is imperative to make self-management programs affordable to individuals with low or fixed incomes that otherwise would not participate. While similar access may not guarantee similar use of the ASMP, however, it will begin to provide equal opportunity.

Consistent with prior research Blacks are known to express distrust in the healthcare system (LaVeist, 2004). Lack of trust could hinder optimal healthcare. Cultural mistrust, which is the mistrust of Whites by Blacks in politics, interpersonal relations, education and training, and business and work, could also be a potential explanation as to why Blacks were more likely to report distrust in the healthcare system as a barrier to participating. Previous research has shown that among Blacks, perceived racism along with cultural mistrust had a negative impact on the trust of the healthcare provider and health care system (Benkert, Peters, Clark, & Keves-Foster, 2006; Benkert, Pohl, & Coleman-Burns, 2004). While this research study did not examine cultural mistrust and only examined trust as a barrier to participation with a single-item question, it does suggest that more research is warranted to analyze the correlation between trust and participation in the ASMP for Blacks with OA.

Blacks were also more likely to report that their fear of being the only person of their race in the program would serve as a barrier to participation. This and the above findings may be closely tied to the perceived discrimination that Blacks experience in general. Fear of being the only person of your race in the program may directly be a result of fear of racism and discrimination. Specifically, Blacks with OA have reported perceived discrimination due to race at a higher rate than Whites (54% versus 2%; McIlvane, Baker, & Mingo, 2008). Interestingly, the results of the needs assessment also show that Blacks were more likely than Whites to report that they would only participate in the community-based ASMP if recommended by their doctor or their family and friends thought it was a good idea, however, the findings did not remain the same for the ASMP toolkit. For the ASMP toolkit, there were no differences between Blacks and Whites basing their participation on the recommendation of their doctor. It may be that neither Blacks nor Whites see the need to obtain a doctor recommendation for an at home program. In other words, the skepticism of participating may decrease with the option of being able to participate at home on one's own time. Not only were there significant differences between Blacks and Whites concerning the aforementioned barriers, examination of effect sizes also suggested practical significance.

Little to no data is available on barriers to participation in the ASMP. However, based on the general health disparities literature and studies that examine barriers to participating in health related research we made directional predictions. Contrary to our predictions, there was no difference between Blacks and Whites reporting that family responsibilities, and transportation, served as a barrier to participating in the arthritis programs. Each of these factors have been shown to interfere with either healthcare or participation of minorities in health related programs or research (Banks-Wallace & Conn, 2002; Kimsey, Ham, & Macera, 2001; Ryall et al; 2003; Walcott-McQuigg & Prohaska, 2001 Williams & Jackson; 2005). Findings may say something about the recruitment efforts of the study. Specific to transportation many participants were recruited from places in which they traveled to get there (e.g., participants were asked to meet me at their church). Future research is warranted to further understand why differences were not found.

Arthritis Intervention Preferences

In the current study, differences in preferences regarding the content and structure and delivery of an arthritis self-management intervention were examined. Based on the findings Blacks were significantly more likely to prefer most items (i.e., 20 out of 22 of the items measuring preference of intervention content, and 19 out of 22 of the items measuring preference of intervention structure and delivery). It appears that Blacks preferred everything more than Whites, however these findings may not be a result of true differences, but more so a result of response styles. Response styles to consider are acquiescence bias (e.g., Yea-Saying) or extreme response style (ERS; Furr & Bacharach, 2008) Acquiescence bias occurs when individuals have a greater tendency to respond positively irrespective of the content. ERS occurs when an individual has a tendency to choose an extreme response choice of the scale.

Some research has suggested that there may be cultural differences that explain the use of ERS. In other words some cultures may be more likely to have an extreme response style causing some research findings to reflect measurement artifact (Leung & Bond, 1989). Moreover, response bias is common in research that relies on a Likert scale such as this study (Clarke, 2001). In addition, some research has found greater levels of ERS in Blacks when compared to Whites (Bachman, O'Malley, & Freedman-Doan, 2010; Clarke, 2000). It is speculated that ERS is the basis for the differences seen in this study concerning intervention content and structure and delivery. Variations in response style may lead to a misinterpretation of race or cultural differences. Therefore no conclusions have been drawn concerning differences between Blacks and Whites on arthritis interventions preferences. However, we did find it informative to observe which items were rated the highest. For example, Blacks seemed to prefer an intervention that would be mailed, and least likely to prefer an intervention that was limited by gender. Whites seemed to prefer an arthritis intervention that would be led by someone with arthritis, and least likely to prefer an intervention that was specifically given by someone of the same race. . Many items were ranked similarly within each group; therefore it is difficult to determine the meaningfulness of the ranking of preferences without further statistical analyses. Future research is needed in this area.

Utilization Patterns

With regard to arthritis information, both groups rated that they were more likely to look for arthritis information from their physician, health care provider, and surprisingly the Arthritis Foundation. The finding concerning the Arthritis Foundation was surprising in that both groups also reported that they were not very familiar with the Arthritis Foundation or the resources available through the Arthritis Foundation. Blacks reported being more likely than Whites to look for arthritis information from the internet, friends, healthcare provider, someone with arthritis, television, radio, relatives, books, religious leaders and the Arthritis Foundation. It is again speculated that the differences are a result of Blacks being more likely to have an extreme response style in comparison to Whites. As a result, it appears they have rated everything more favorably including factors that they normally would have less access to in comparison to Whites (e.g., internet; Forkner-Dunn; 2003). It also is important to note the question used in the questionnaire stated, “would you look for information for your arthritis from the following resources?” It did not ask the participants, “do you look for arthritis information from the following resources?” The manner in which the question was asked may explain the participants’ response. Even if one is unfamiliar with the Arthritis Foundation, It seems understandable that someone would say they would seek information on arthritis from the Arthritis Foundation.

One of the complaints in previous research concerning arthritis interventions was the lack of knowledge about the programs and participation in the programs (Brady et al., 2003). Our findings support the findings of previous research yielding similar concerns. Less than 30% of the participants in the White and Black group had heard of the Arthritis

Self-Help Course (also referred to as the ASMP). Blacks were significantly less likely than Whites to have heard of the Arthritis Foundation Aquatics and Tai-Chi programs. Moreover, less than 20% of Blacks and Whites had participated in three out of the four of the Arthritis Foundation Programs. Interestingly, Blacks were significantly more likely to have participated in People with Arthritis can Exercise and less likely to have participated in Tai-Chi.

ASMP Toolkit Evaluation

The goal of the final research question was to determine whether there were race differences in the acceptability of the ASMP toolkit between Blacks and Whites. Findings from this study showed that on the sections that participants were asked to review, there were only race differences on the acceptability of some of the sections of the ASMP toolkit. The action plan information sheet, exercise CD, problem solving information sheet, and community resources information sheet were reviewed similarly by Blacks and Whites. Specific to the action plans, the question that asked was the action plan designed with people like me in mind resulted in the highest means for both Blacks and Whites. In comparison to Whites, Blacks were more likely to report they would use the illustrated exercise guide at home for their arthritis, and more likely to tell their friends to use the illustrated exercise guide and relaxation CD for their arthritis. Blacks seemed to find the healthy eating section and the imagery CD more acceptable than Whites. Participants were not only asked to rate the acceptability of sections of the toolkit, but based on what they saw and heard rate the acceptability of the toolkit in general. Again, conclusions could not be drawn due to ERS. To date very little is known about the acceptability and effectiveness of the ASMP toolkit in Blacks. Previous research has suggested that Blacks may find the toolkit unappealing (Goeppinger et al., 2009). Our findings suggest that Blacks may find existing components acceptable. Further research is warranted to address response bias and support the study findings.

Chapter Five: Conclusions

In the over 20 years that ASMP has been in existence very minimal research has focused on the needs, acceptability or effectiveness of the program in Blacks. Over the past 10 years the CDC has funded state arthritis programs. The arthritis funded program that has received the most recognition has been the ASMP, however, little has been done to determine the acceptability of the ASMP among Blacks. In recognition of this gap in the literature, we sought to examine the needs of Blacks with arthritis specific to the ASMP. In addition, we sought to examine the acceptability of existing tools used in the ASMP toolkit arthritis intervention. Responses to the surveys used in this study clearly indicate that differences do exist in the perceptions of both the community-based ASMP and the ASMP toolkit, and utilization of arthritis resources (Table 5.1 and Table 5.2). More powerful were the differences found between Blacks and Whites in the potential barriers to participation in the programs (Table 5.1). It is necessary that we take the information used in this study to structure interventions that would adequately address potential barriers and begin to move forward by testing the acceptability, feasibility, and effectiveness of arthritis interventions. It is our hope that the current study will contribute to the arthritis intervention literature by beginning to understand the needs and preferences of Blacks with arthritis and designing or adapting interventions that will meet those needs.

Implications and Recommendations

While the data associated with our study did not determine causality for arthritis heath disparities nor did it definitively determine how to design culturally sensitive arthritis interventions, valuable information has been gained about the differences between Blacks and Whites and their preferences for an arthritis intervention (Table 5.1 and Table 5.2). This valuable information can inform the design of an intervention which should later be tested for feasibility, acceptability, accessibility, and ultimately effectiveness. Due to the exploratory nature of this study, we are careful not to draw definitive conclusions. However, valuable recommendations can be made based on our findings. This study was designed to build a basis for in-depth examinations of the needs of Blacks with OA specific to arthritis interventions. We believe this study to be an important piece of the puzzle in the area of arthritis health disparities and in designing culturally sensitive effective arthritis interventions.

For healthcare professionals, service providers, and task forces that are specifically interested in the impact of arthritis and the acceptability of arthritis interventions in minority samples, the findings presented in this study may offer important insights. Specifically, it is important to understand how barriers may impact the utilization a healthcare program. One barrier found in our study was that Blacks were more likely to fear being the only person of their race to participate in the programs. The fear expressed by Blacks is consistent with research indicating that minorities are more likely than Whites to refuse needed health services (IOM, 2003), and that very few studied arthritis self-management interventions have included Blacks. However, this is a barrier that could be addressed by ensuring that those trained to deliver the ASMP are from diverse backgrounds, and that the programs are offered in areas that would attract both White and minority participants.

Cost was a barrier that seemed to rise to the top for Blacks not only in comparison to Whites but also in comparison to other barriers. When programs are being developed access and affordability of the programs should be considered. This is particularly true for older minorities who have a greater likelihood to be living on a fixed income. Research has been conducted to show the cost benefits from the ASMP; however; the cost benefits are retrospective. In other words the ASMP cost benefits currently come in the form of a decrease in doctor visits, and a decrease in emergency room visits after one has participated in the program. It is suggested that in addition to retrospective cost benefits, prospective cost benefits should be considered (e.g., subsidizing the cost to participate in the ASMP) as it would decrease a major barrier to participation.

Lack of trust and the recommendation of friends and family were also barriers that rose to the forefront of our findings when comparing Whites and Blacks. Considering the fact that communities and family members often serve as gatekeepers to participation in health related research or programs (Rooks & Whitfield, 2004), it is possible that such a barrier could be addressed with an adapted intervention using the community-based participatory research methodology. Trusted community members may be able to build a liaison between the target population and the healthcare providers. The importance of community liaisons were exemplified in our recruitment efforts as some participants would not even discuss the study with us until the liaison had assured them that it was a reputable study and that no harm would be brought to them by participating.

Table 5.1 Race Differences between Blacks and Whites on Intervention Preferences

Potential Barriers	**Preference of Content**	**Preference of Structure and Delivery**	**Preferences for Arthritis Resources**
-Cost	-All factors except a program that teaches you how to improve physical functioning, and about non-traditional treatment options	All factors except a program led by someone with arthritis themselves, a program that includes people of your same age group, and a program given in your neighborhood	-Internet
-Lack of trust in the healthcare system			-Friend
-Fear of being the only person of your race			-Healthcare Provider
-Only if family and friends agree that participating in the program is a good idea			-Someone with arthritis
-Only if recommended by my doctor			-TV
			-Radio
			-Relatives
			-Books
			-Religious Leader
			-Arthritis Foundation

Note. Black participants report higher scores on all listed differences.

Table 5.2 Race Differences between Blacks and Whites on Acceptability of ASMP Toolkit

Illustrated Exercise Guide	**Relaxation CD**	**Healthy Eating**	**Imagery CD**	**General**
-Would tell my friends to use the guide	-Would tell my friends to use the CD	-Seems healthy eating section was designed with people like me in mind.	-Found the CD helpful	-ASMP toolkit materials are visually appealing
-Likely to use guide at home for my arthritis		-Can see how changing my eating would help my arthritis	-Would tell my friends to use the arthritis for their arthritis	-Problems and concerns addressed in the ASMP toolkit are problems I have with my arthritis
		-Likely to change my eating based on material learned	-Feel confident that I would use the CD at home on my own	-Likely to listen to and exercise with the entire 20min exercise CD
			-CD is meant for people like me	-Would attend traditional ASMP ASMP material is offensive -The ASMP audio is offensive -Pictures or graphics are offensive

Note. Black participants were more likely than Whites to find the listed factors more acceptable

Overall, specific individual parts of the toolkit seemed to be similarly acceptable by both Whites and Blacks. However, there were some significant differences in acceptability of the materials. Blacks rated the healthy eating section more acceptable than Whites. In addition, Blacks were also more likely to report that they would tell their friends to use the exercise guide, and more likely to use the guide at home for their arthritis. It seems as if the illustrated guide attempted to include drawings of individuals from various ethnic background including Blacks. As cited in Weintraub, Maliski, Fink, Choe, & Litwin (2004), previous research has shown that culturally sensitive health education materials (e.g., materials including pictures of Blacks), is more likely to translate into positive behavior changes and outcomes.

Blacks were more likely to report that they would tell their friends to use the relaxation CD for their arthritis, and they found the guided imagery more acceptable over all in comparison to Whites. Findings specific to the relaxation and the imagery CD, may be closely related to other research that has looked at the use of mind-body interventions in Blacks (e.g., guided imagery, prayer, positive imagery, relaxation; Katz & Lee, 2007). Blacks may have found this CD to be familiar to ways they already manage their condition. While it has been found that prayer is the most common type of mind-body intervention used by Blacks (Katz & Lee, 2007), the use of meditation in general may be favored

Based on our findings and previous research, evidence does not support a need for a tailored ASMP, however, there are some practical issues that could be addressed to make the program more culturally sensitive for Blacks. First, address social and environmental factors that serve as potential barriers to participation (e.g., cost, lack of trust), develop materials that are suitable and appealing to the target audience, and collaborate with community partners. Changes to ensure the cultural sensitivity of the intervention could benefit minorities and potentially reduce the racial/ethnic health disparities associated with this condition. Culturally sensitive interventions must promote accessibility and be designed in an acceptable manner taking in consideration the values, preferences, and needs of the target population.

While no definitive conclusions can be drawn due to suspected ERS, we do speculate that some of findings specific to intervention preferences warrant additional research. In the current study, we found that Blacks were more likely than Whites to prefer intervention content including learning about making meals that they already eat (e.g., specific to your culture) in a healthier way, internet sources that are focused on arthritis care, various types of arthritis, specifically the type of arthritis of which they have been diagnosed, problem solving skills in general for health related problems, talking to your family and friends about arthritis, discrimination in healthcare, how to choose a doctor, and getting the most out of the health care system. It is plausible to think that adding such components to the intervention may yield better self-management and self-efficacy for Blacks. For example, having the skills to manage discrimination in healthcare may provide people with the confidence to interact more with their healthcare providers and to get better understanding out of their doctor visits resulting in better treatment outcomes. Minor changes such as adding a component on managing discrimination may impact the effectiveness of the intervention within the target population.

Again, it is critical that we do not overstate our findings and acknowledge that the extreme response style may be considered a major reason for the differences in content preferences found in this study. However, the findings of our research are in line with findings from the research done by Goeppinger et al. (2007) in that there is a need to strengthen the content of the ASMP by including information on cultural dimensions of eating, how to communicate with health care providers from a cross-cultural perspective, information on faith and spirituality, and the importance of mutual help and social support. Future research is warranted in this area.

Analyses revealed that Blacks and Whites also differ on their preferences of the structure and delivery of an arthritis self-management intervention. Some of the preferences already exist in either the ASMP or the ASMP toolkit. While the results seem to be due to Blacks being more likely than Whites to choose an extreme response style, differences may be a result of the lack of knowledge of existing programs that include such components. In other words, it may not be a case of Blacks preferring specific structural and delivery features over Whites; it may be a case of them wanting a program in general.

Systematic adaptations should be made to the toolkit, ASMP, and other arthritis interventions so that culture is considered. It is likely that adaptations have begun to take place (Goeppinger et al., 2007; Goeppinger et al., 2009) but are not systematically documented in the arthritis intervention literature. It is suggested that adaptations (e.g., cost, include community liaisons, offer in minority neighborhoods) be documented and tested to determine whether such changes yield benefits in acceptability and in successful recruitment. It is important to ensure that the programs are culturally sensitive not only to increase the use of the programs, but increase the positive clinical outcomes within a disadvantaged group. We must continue to make strides toward being more culturally sensitive and realize there is no one-size-fit-all intervention. It is vital that we move closer to providing interventions that not only will be acceptable but effective to everyone by making an attempt to consider the culture of many.

Study Limitations

The present study has a number of limitations that should be noted. First, individuals in this study were asked to self-report a doctor diagnosed case of arthritis. Frequently, as experienced in our recruitment efforts individuals do not know the type of arthritis they have. Individuals will report anything from “the regular kind” to “not the crippling kind.” While self-reported data is continually used by the BRFSS, it has been found to be less accurate when asking individuals to specify the type of arthritis. In fact, the CDC strongly discourages collecting self-reported data on arthritis type (CDC, 2009c). However, varying types of arthritis may result in various experiences which could potentially serve as a confounding variable to study findings. Healthcare providers should remain vigilant about educating individuals on not only the fact that they have arthritis but the type

Moreover, while self report has been used as a method to determine national prevalence rates for arthritis, the use of both clinical criteria and radiological scales would be the ideal method to confirming an OA diagnosis. Using clinical criteria and radiological scales would be considered a gold standard and would strengthen the validity of the research.

Another limitation was that of the response style of Black versus White participants. A response bias of this type can obscure the between group differences. Future research should create a questionnaire or a measure that will minimize the effect of response bias. Specifically, one solution is to design and use a balanced scale. A scale of this type will have questions worded both positively and negatively to minimize the effect of ERS.

It is important to note that the findings that we report concerning the evaluation of the toolkit were not obtained under an ideal dissemination of the intervention. Participants were only presented with various components of the toolkit. An ideal situation would include time for participants to review all materials at home (e.g., The Arthritis Self Help Book, information sheets, all exercise CDs, the complete relaxation and imagery CD) and then to respond to the acceptability of the materials. Unfortunately, time and cost prevented the research from being conducted in this manner.

The current study is based on the ASMP. While there are some concerns about the strength of the effectiveness of the intervention, the ASMP is supported by the CDC, and widely publicized on their website as an effective intervention program (CDC, 2010b). However, other arthritis interventions have been found to have a greater effect size specific to outcome measures in comparison to the ASMP (Dixon et al., 2007). While it would have been ideal to concentrate on many of the various arthritis interventions, many have restrictions that keep them from being easily administered in the community. Future research should not only focus on increasing the cultural sensitivity of the ASMP but also strengthen the efficacy so that it is comparable to other arthritis interventions and still readily available to the community.

In addition, a major limitation of the study was that the ASMP community-based course is not offered in the city in which the research was conducted. There are no trainers available. This is a limitation in that upon completion of the study our recruited participants wanted to know more about the study and how to participate in the full length ASMP. It was unfortunate to have to respond that the program is currently not being offered. This is not only a limitation in our immediate study, but in general when considering the ASMP. A review article reported that in spite of the effectiveness of the intervention less that 1% of the population actually participated in the intervention (Brady et al., 2003).

While the recruitment efforts of minorities in our study based on the ASMP was successful, it is important to note that the small sample size particularly in the evaluation of the materials may have affected our findings. The small sample size may have resulted in a lack of sufficient statistical power needed to detect differences between Black and White participants, particularly those who participated in the evaluation of materials. A statistical power analysis should be conducted in the future to determine the sample size needed for a study of this type. Current findings need to be confirmed with replication and larger samples. The use of a convenience sample limits the generalizability of this study. However, using a convenience sample for an exploratory design allows for basic information that serves as a basis for conducting future research with a representative sample. Our study was also predominately female. Future research should include similar number of males and not only look at race differences but also race x gender differences.

In addition, there were significant demographic differences between Black participants and White participants. The analyses included in this study did not adjust for such differences. Additional analyses (e.g., ANCOVA), could be conducted to account for intergroup variation that is associated with demographic factors such as age, education, and health status. Analyses of this type will determine if adjusting for demographic variables would alter the findings and better explain the group differences.

Lastly, while this study is examining cultural sensitivity, there is no measure of culture. In the future it will be important when considering cultural sensitivity to include measures that would examine how culture influences the participants' preferences, barriers, and utilization. Such a scale would add to the argument of the importance of making practical adaptations to existing intervention to ensure cultural sensitivity.

Future Directions

Taken together this dissertation study underscores the importance of cultural sensitivity in arthritis interventions. Although the need to address arthritis health disparities between Blacks and Whites is widely recognized, very little has been done in the way of addressing the disparities with existing arthritis interventions. This exploratory study has focused on an initial effect to address the needs of Blacks with arthritis. Arthritis is a an important condition and a growing public health issue, it is important that we minimize the impact in cost, disability, and prevalence, by developing effective interventions that can be successfully disseminated to the community. Future research should utilize both clinical criteria, radiological scales, and self-report to ensure diagnosis of OA.

This research was conducted to learn about the differences of intervention preferences between Blacks and Whites with arthritis. Future work is needed to take this further by determining if small changes like the ones recommended in this study will enhance recruitment to, and the effectiveness of, the ASMP in Blacks. Future research should include Blacks in culturally sensitive arthritis interventions asking participants to rate their experiences, determine if attending the course was beneficial, assess whether there was an improvement of one’s understanding about arthritis and ways to treat arthritis, and determine if information was easy to understand. In addition, future research should determine if the intervention or program leader was helpful, topics discussed were important, the timing and location were convenient, and lastly would they recommend the program to others with arthritis.

The lack of awareness of the ASMP and the lack of availability of local trainers speaks volumes to policy concerns at a variety of levels. As federal dollars are continuing to be allocated toward the development of state arthritis programs such as the ASMP, a mechanism should be put into place to ensure that the programs are not only available on paper but as an actual service. Oftentimes the programs are listed on the various websites as helpful existing programs; however, there is no system in place to guarantee that the ASMP is being offered. The lack of awareness begs the need for an emphasis on translation. A stronger collaboration is needed between the scientists who determine the effectiveness of the interventions and the governmental agencies that financially support the programs to ensure the dissemination. Programs are not beneficial to the healthcare of our society if they are not utilized. This is true for culturally sensitive interventions. A culturally sensitive intervention on the shelf does not address the continued health disparities between Blacks and Whites with OA.

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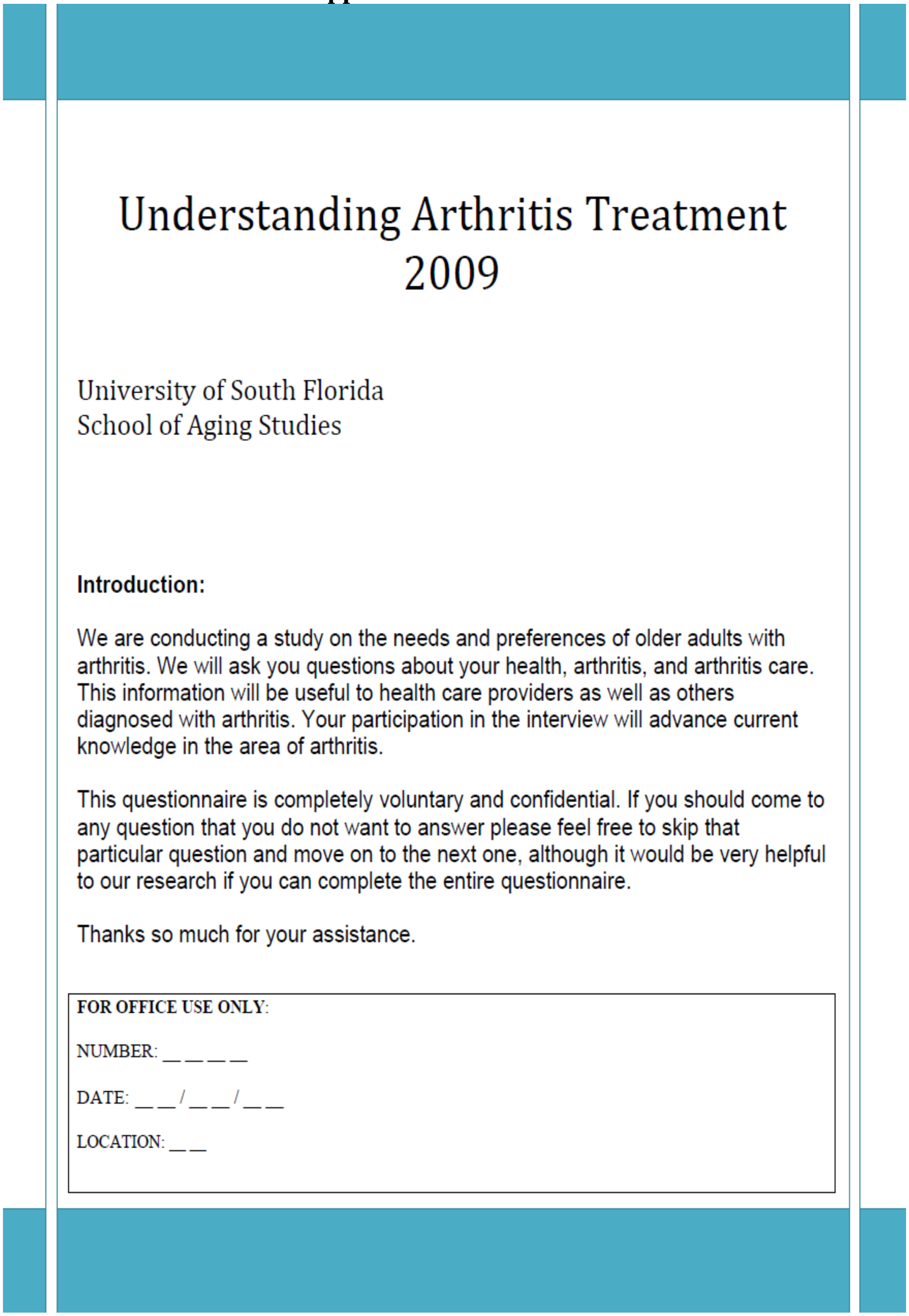
Appendices

Appendix A: Needs Assessment



Understanding Arthritis Treatment 2009

University of South Florida
School of Aging Studies

Introduction:

We are conducting a study on the needs and preferences of older adults with arthritis. We will ask you questions about your health, arthritis, and arthritis care. This information will be useful to health care providers as well as others diagnosed with arthritis. Your participation in the interview will advance current knowledge in the area of arthritis.

This questionnaire is completely voluntary and confidential. If you should come to any question that you do not want to answer please feel free to skip that particular question and move on to the next one, although it would be very helpful to our research if you can complete the entire questionnaire.

Thanks so much for your assistance.

FOR OFFICE USE ONLY:

NUMBER: __ __ __ __

DATE: __ __ / __ __ / __ __

LOCATION: __ __

Thank you for agreeing to participate by filling out this questionnaire. You will be asked questions about your arthritis, arthritis care, and health in general. Certain questions may seem irrelevant or not important; however, all questions are included to ensure we obtain the most information possible. Questions are asked in a manner that will improve accuracy. We apologize in advance if questions seem repetitive, appear to not make sense, or seem obvious. All information is collected in order to gain new information in the area of arthritis and understand the needs of those with arthritis. If there are no questions, please begin.

Section A

Please Start by Telling Me a Little About Yourself:

Could you please tell me your date of birth? __ __ / __ __ / __ __ __ __ (M/D/Y)

1. Please **circle** the highest year of school completed?

Primary School High School College/University

1—2—3—4—5—6—7—8—9—10—11—12—13—14—15—16—17+

2. What is your current marital status? **(Please check the box that applies to you)**

☐Married

☐Living with partner

☐Widowed

☐Divorced

☐Separated

☐Never Married

Section B

The next questions will ask you about the status of your health in general. Please be open and honest. Answer each question to the best of your ability. Please check the box that applies to you.

1. In general, would you say your health is

☐Excellent
☐Very Good
☐Good
☐Fair
☐Poor

2. Are you limited in any way in any activities because of physical, mental, or emotional problems?
☐Yes
☐No

Section C

The next section will include questions about arthritis in general. Please be open and honest in your responding.

1. What is the main kind of arthritis that you have? Please answer Yes or No for each kind of arthritis. **(Please Circle 1 for Yes and 2 for No)**

	YES	**NO**
Rheumatoid Arthritis	1	2
Osteoarthritis/Degenerative Arthritis	1	2
Other **(Please Specify)** ________________________________	1	2

2. How many years have you had arthritis related symptoms?
(write in the number of years in the space below)
___________________ year(s) ___________________ (months)

3. How many years ago were you diagnosed with Osteoarthritis by a doctor?
(write in the number of years in the space below)

________________ year(s) ________________ (months)

For the following questions, check the box that applies to you.

4. Please think about the past 30 days, keeping in mind all of your joint pain or aching and whether or not you have taken medication. **DURING THE PAST 30 DAYS**, how bad was your joint pain **ON AVERAGE**? Please answer on a scale of 0 to 10 where 0 is no pain or aching and 10 is pain or aching as bad as it can be.

No Pain **Extreme Pain**

☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

5. Do you consider arthritis a normal part of getting older?

Not at All a Part of Normal Aging **Normal Aging**

☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

6. Do you think anything can be done about arthritis once you have it?

Don't believe at All **Definitely Believe**

☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

7. Do you think that once you get arthritis it can only get worse not better?

Don't believe at All **Definitely Believe**

☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

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Section D

Arthritis self-help programs are programs that are geared toward giving people information and skills to improve the negative effects of arthritis. Sometimes people would like to participate in healthcare programs such as an arthritis self-help program, but are not able to do so for various reasons. We are interested in learning more about things that may either interest you, or keep you from participating in arthritis health programs. In some of these questions we will ask you to imagine services that might be available. Please give your best judgment about how you think you would view such programs.

1. Do you believe there is a need for an arthritis self-help program for people who have been diagnosed with arthritis?
   - ☐Yes
   - ☐No

2. Please explain why or why not.

   ____

   ____

   ____

   ____

Please read the statement described below as if it is happening to you.

Imagine that you have been diagnosed with arthritis and have been asked to participate in an **Arthritis Group Education Course**. The course will be offered at the local community center and will be taught by a person who has arthritis and has been trained to offer this course. The course will cost you $30. You will be asked to come to the center once a week from 10:00am – 12:00 noon for six weeks. In addition, to the weekly meetings you will receive *The Arthritis Helpbook* (a textbook for the course), Arthritis Foundation brochures, and a year's subscription to the *Arthritis Today* magazine. During the six weeks you will develop an exercise program just for you, discuss arthritis medications, learn how to manage your pain, learn how to solve arthritis-related problems, and learn how to communicate with your health care providers. You will be responsible for getting yourself to and from the community center.

How much do you believe each of the following statements? Please check the box for the response that best applies to you.

1. I believe that the program will be helpful

Don't believe at All **Definitely Believe**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

2. I believe it would be hard for me to find the drive or determination to work on the program

Don't believe at All **Definitely Believe**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

3. I believe my lack of trust in the health care system would prevent me from participating

Don't believe at All **Definitely Believe**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

4. I believe it would be difficult to find time to participate in the arthritis program

Don't believe at All **Definitely Believe**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

5. I believe my family responsibilities (caring for spouse, grandchildren, and other relatives) will keep me from participating in the program

Don't believe at All **Definitely Believe**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

6. I believe it would be difficult to afford the cost of the program

Don't believe at All **Definitely Believe**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

7. I believe my other health concerns are more important than participating in an arthritis health care program

Don't believe at All **Definitely Believe**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

8. I believe that I have a fear that I would be the only person of my race in the program

Don't believe at All **Definitely Believe**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

9. I believe that I would only participate if my family and friends thought it was a good idea.

Don't believe at All **Definitely Believe**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

10. I believe I am physically unable to participate

Don't believe at All **Definitely Believe**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

11. I believe that I would only participate if it was recommended by my doctor

Don't believe at All **Definitely Believe**

☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

12. I believe it would be difficult to find transportation to the local community center

Don't believe at All **Definitely Believe**

☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

13. I believe that I would avoid a neighborhood program because my neighborhood is not safe.

Don't believe at All **Definitely Believe**

☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

Now we want you to answer the same questions about another type of program. Please read the statement described below as if it is happening to you.

You have been diagnosed with arthritis and have been informed that you can participate in an **At Home Arthritis Management Program**. The information will be mailed to you. The cost of the information is $30. You will be able to go through the information at your own pace. The mailed package will include *The Arthritis Helpbook* (a textbook for the course), information sheets describing arthritis problems and solutions, a self-test, and a relaxation and exercise CD. The self- test will help you determine the areas that you will need to focus on to develop a personalized arthritis health care plan. You will be responsible for scoring the test yourself. The information sheets and textbook will include information on pain, physical limitations, fatigue, health concerns, exercise, medications, healthy eating, finding community resources, dealing with your emotions, and how to work with your doctor and the health care system.

How much do you believe each of the following statements? Please check the box for the response that best applies to you.

1. I believe that the program will be helpful

Don't believe at All **Definitely Believe**

☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

2. I believe it would be hard for me to find the drive or determination to work on the program

Don’t believe at All **Definitely Believe**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

3. I believe my lack of trust in the health care system would prevent me from participating

Don’t believe at All **Definitely Believe**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

4. I believe it would be difficult to find time to participate in the arthritis program

Don’t believe at All **Definitely Believe**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

5. I believe my family responsibilities (caring for spouse, grandchildren, and other relatives) will keep me from participating in the program

Don’t believe at All **Definitely Believe**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

6. I believe it would be difficult to afford the cost of the program

Don’t believe at All **Definitely Believe**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

7. I believe my other health concerns are more important than participating in an arthritis health care program

Don’t believe at All **Definitely Believe**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

8. I believe that I have a fear that I would be the only person of my race in the program

Don’t believe at All **Definitely Believe**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

9. I believe that I would only participate if my family and friends thought it was a good idea.

Don’t believe at All **Definitely Believe**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

* * *

10. I believe I am physically unable to participate

Don’t believe at All **Definitely Believe**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

* * *

11. I believe that I would only participate if it was recommended by my doctor

Don’t believe at All **Definitely Believe**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

In the past, very little research has asked individuals like you what they like or dislike about arthritis self-help programs, or what would encourage you to participate or not participate in such programs. We are interested in learning about what you would like to see in an arthritis program designed to help with your arthritis.

If you were to participate in an arthritis self-help program which of the following components would you find helpful if included? Please check the box that applies to you.

Do you think it would be helpful for an arthritis self-help program to:

1. Teach you about available arthritis healthcare options or resources other than a primary care physician

Not Helpful at All **Extremely Helpful**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

* * *

2. Help you set personal treatment goals and a plan of action for meeting those goals

Not Helpful at All **Extremely Helpful**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

* * *

3. Teach you about internet sources focused on arthritis care

Not Helpful at All **Extremely Helpful**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

* * *

4. Teach you about various types of arthritis

Not Helpful at All **Extremely Helpful**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

5. Teach you specifically about your type of arthritis

Not Helpful at All **Extremely Helpful**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

- -

6. Teach you about nutrition and healthy eating

Not Helpful at All **Extremely Helpful**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

Do you think it would be helpful for an arthritis self-help program to:

7. Teach you how to make meals that you already eat but in a healthier way

Not Helpful at All **Extremely Helpful**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

8. Give you information about the use of medications and how they work

Not Helpful at All **Extremely Helpful**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

9. Tell you about arthritis medications that are available

Not Helpful at All **Extremely Helpful**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

10. Teach you problem solving skills for arthritis-related problems

Not Helpful at All **Extremely Helpful**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

11. Teach you problem solving skills in general for health-related problems

Not Helpful at All **Extremely Helpful**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

12. Teach you how to decrease negative emotions (anger, fear, frustration, depression, isolation)

Not Helpful at All **Extremely Helpful**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

13. Teach you how to improve physical functioning

Not Helpful at All **Extremely Helpful**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

14. Teach you skills to help reduce your pain

Not Helpful at All **Extremely Helpful**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

Do you think it would be helpful for an arthritis self-help program to:

15. Teach you how to talk to your family and friends about your arthritis

Not Helpful at All **Extremely Helpful**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

16. Teach you how to talk to health professionals about your arthritis

Not Helpful at All **Extremely Helpful**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

17. Teach you helpful exercises for your condition

Not Helpful at All **Extremely Helpful**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

18. Talk to you about non-traditional treatment decisions (e.g., liniment, glucosamine)

Not Helpful at All **Extremely Helpful**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

19. Talk to you about how to handle discrimination in health care

Not Helpful at All **Extremely Helpful**

☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

20. Teach you how to get the most out of the healthcare system

Not Helpful at All **Extremely Helpful**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

21. Talk about how to make treatment decisions

Not Helpful at All **Extremely Helpful**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

22. Teach you how to choose a doctor

Not Helpful at All **Extremely Helpful**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

The next set of questions asked you about what you would like included in an arthritis self-help program. Next, we would like to know, in your opinion, what is the best way to offer an arthritis self-help program such as the best format, the best time, and the best place. Please check the box that applies to you.

How much would you like the arthritis self-help program to:

1. Be mailed to you (e.g., brochures, videos)

Not at All **Extremely**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

2. Offer a class to a group that teaches how to manage arthritis

Not at All **Extremely**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

3. Include material or address issues related to your spiritual beliefs

Not at All **Extremely**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

4. Allow you to bring your friend for support and to learn with you

Not at All **Extremely**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

5. Allow you to bring a family member for support and to learn with you

Not at All **Extremely**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

6. Be given using a Cassette Tape or CD to listen to

Not at All **Extremely**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

- -

7. Be given using a Video-Tape or DVD to watch

Not at All **Extremely**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

How much would you like the arthritis self-help program to:

8. Be given by someone of the same race

Not at All **Extremely**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

9. Be given by someone of the same gender

Not at All **Extremely**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

10. Include discussions with other people who have arthritis

Not at All **Extremely**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

11. Be given in an instructional or lecture format

Not at All **Extremely**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

12. Be given at a local church

Not at All **Extremely**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

13. Be given at a community or senior center

Not at All **Extremely**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

14. Be given at the local Arthritis Foundation

Not at All **Extremely**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

15. Be given at a local health clinic

Not at All **Extremely**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

How much would you like the arthritis self-help program to:

16. Be limited by gender (women or men only)

Not at All **Extremely**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

17. Provide child care services

Not at All **Extremely**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

18. Be given in your neighborhood

Not at All **Extremely**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

19. Include people of your race

Not at All **Extremely**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

20. Include people in your same age group

Not at All **Extremely**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

21. Be led by someone who has arthritis themselves

Not at All **Extremely**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

22. Be limited by condition (others with the same type of arthritis as you)

Not at All **Extremely**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

Section E

The following questions will ask you about locating information on arthritis. Below you will find a list of places or people one may go to find information about arthritis, please tell us the likelihood of you going to the following places or people to get information about your arthritis. Please check the box that best applies to you.

Would you look for arthritis information:

1. On the Internet

Not Likely at All **Extremely Likely**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

2. From a Friend

Not Likely at All **Extremely Likely**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

3. From a Healthcare Provider

Not Likely at All **Extremely Likely**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

4. From a Physician

Not Likely at All **Extremely Likely**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

5. From someone with arthritis

Not Likely at All **Extremely Likely**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

6. On the TV

Not Likely at All **Extremely Likely**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

7. On the Radio

Not Likely at All **Extremely Likely**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

8. From Relatives

Not Likely at All **Extremely Likely**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

9. In Books

Not Likely at All **Extremely Likely**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

10. From a Religious Leader

Not Likely at All **Extremely Likely**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

11. From the Arthritis Foundation

Not Likely at All **Extremely Likely**

☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

12. Other **(Please Specify)________________________**

Not Likely at All **Extremely Likely**

☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

Section F

Next, I would like to ask you some more questions about arthritis. The following questions will ask you about arthritis programs and services. There are no right or wrong answers. Please be open and honest in your response. Please check the box that applies to you.

The next set of questions asks you about the Arthritis Foundation.

1. How familiar are you with the Arthritis Foundation?

Not at All **Extremely**

☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

2. How often have you used the Arthritis Foundation resources?

Not at All **Quite a Bit**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

i. If you have used any Arthritis Foundation resources, which resources have you used________________________?

****

3. Have you ever **heard** of any of the following programs?
(Please Check Yes or No)

	YES	**NO**
Arthritis Self Help Course	☐	☐
People with Arthritis Can Exercise	☐	☐
Arthritis Foundation Aquatic Program	☐	☐
Tai-Chi	☐	☐

4. Have you ever **participated** in the **Arthritis Self Help Course?**
☐Yes
☐No

A. If **No**, Why?____

B. If **Yes**, How useful did you find the program?

Not Useful at All **Very Useful**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

5. Have you ever **participated** in the **People with Arthritis Can Exercise?**
☐Yes
☐No

A. If **No**, Why?____

B. If **Yes**, How useful did you find the program?

Not Useful at All										**Very Useful**
☐0	☐1	☐2	☐3	☐4	☐5	☐6	☐7	☐8	☐9	☐10

****

6. Have you ever **participated** in the **Arthritis Foundation Aquatic Program?**

☐Yes
☐No

A. If **No**, Why?____

B. If **Yes**, How useful did you find the program?

Not Useful at All										**Very Useful**
☐0	☐1	☐2	☐3	☐4	☐5	☐6	☐7	☐8	☐9	☐10

****

7. Have you ever **participated** in a **Tai Chi** class**?**

☐Yes
☐No

A. (If No, Why____)

B. If **Yes**, How useful did you find the program?

Not Useful at All										**Very Useful**
☐0	☐1	☐2	☐3	☐4	☐5	☐6	☐7	☐8	☐9	☐10

****

Section G

The next set of questions asks you about arthritis treatments. How often would you say you use the following home remedies to treat your arthritis? Please circle the answer that best applies to you.

	Not at All	**Occasionally**	**Some of the Time**	**Most of the Time**
Copper Bracelets	1	2	3	4
Heat compress applied to the area	1	2	3	4
Cold compress applied to the area	1	2	3	4
Ginger	1	2	3	4
WD-40	1	2	3	4
Icy Hot, Ben Gay or any other liniment, herbal creams, or rubbing lotions	1	2	3	4
Bee Venom	1	2	3	4
Advil, Tylenol, Aspirin or something similar	1	2	3	4
Massage	1	2	3	4
Acupuncture	1	2	3	4
Magnets	1	2	3	4
Vitamins	1	2	3	4
Glucosamine or Chondroitin	1	2	3	4
Prayer	1	2	3	4
Green Rubbing Alcohol	1	2	3	4
Sliced Potatoes	1	2	3	4
Kerosene	1	2	3	4
Other **(Please Specify)** ________________ ________________ ________________	1	2	3	4

Section H

1. Which do you feel best describes your race/ethnicity? **Please check the one that best applies to you.**

- ☐White (Not Hispanic)
- ☐Black/African American (Not Hispanic)
- ☐Hispanic
- ☐Asian
- ☐Native American
- ☐Other

If Other please specify.

____

3. Were you born in the U.S.?

- ☐Yes
- ☐No

4. What is your gender?

- ☐Male
- ☐Female

5. Please check the box that best describes your approximate family annual gross income (before taxes and insurance). This should include the following sources; wages, pensions, dividends, and any additional household income. **(Please check the box that best applies to you)**

- ☐ Less than $5,000
- ☐$5,000 - $9,999
- ☐$10,000 - $14,999
- ☐$15,000 - $19,999
- ☐$20,000 - $29,999
- ☐$30,000 - $39,999
- ☐$40,000 - $49,999
- ☐$50,000 - $59,999
- ☐$60,000 - $79,999
- ☐$80,000 - $99,999
- ☐$100,000 and over

Thank you for completing this questionnaire

Appendix B: ASMP Toolkit Evaluation

Arthritis Self-Help Program Evaluation

University of South Florida
School of Aging Studies

We are conducting a study evaluating the Arthritis Self-Help Program by asking for your opinion. We will ask your input about various parts of an existing arthritis self-help program. This information will be useful to health care providers as well as others diagnosed with arthritis. Your participation in the interview will advance current knowledge in the area of these programs.

This questionnaire is completely voluntary and confidential. If you should come to any question that you do not want to answer please feel free to skip that particular question and move on to the next one, although it would be very helpful to our research if you can complete the entire questionnaire. You may ask questions at any time.

Thanks so much for your assistance.

Subnum: __ __ __ __

Date: ____/____/____

Location: ___ ___

Thank you for agreeing to participate. In order to provide the best arthritis care possible it is important that we get your opinion on existing arthritis health care programs. You will be asked to read and listen to portions of an existing arthritis self-help program. You will then be asked to respond openly and honestly to a list of questions. Certain questions may seem irrelevant or not important; however, all questions are included to ensure we obtain the most information possible. We apologize in advance if questions seem repetitive, appear to not make sense, or seem obvious. All information is collected in order to gain new information in the area of arthritis self-help programs and understand the needs of those with arthritis. If there are no questions, please begin.

Please Start by Telling Me a Little About Yourself:

1. Could you please tell me your date of birth? _ _/_ _/_ _ _ _ (M/D/Y)

- -

2. Please circle the highest year of school completed?

Primary School High School College/University
1—2—3—4—5—6—7—8—9—10—11—12—13—14—15—16—17

3. **

4. What is your current marital status
    - ☐Married
    - ☐Living with partner
    - ☐Widowed
    - ☐Divorced
    - ☐Separated
    - ☐Never Married

The Arthritis Self-Management program is a community–based program geared toward giving people information and skills to improve the negative effects of arthritis such as pain. The Arthritis Self-Management Program has been shown to be effective (e.g., decreasing pain and disability). The Arthritis Self-Management Program includes the basic information for you to put together a personal plan to manage your arthritis. Skills taught include pain management, relaxation, exercise, goal-setting, and action planning.

While the classic Arthritis Self-Management program is a two-hour, one day a week, in class program, there is also a mailed version of the program. The mailed version is referred to as the Arthritis Self-Management Program Toolkit, and can be purchased for approximately $60 and used at home on your own time.

We will show you various pieces of the Arthritis Self-Management Program Toolkit. You will be asked about your opinion on each piece. The program was not designed by myself or any of the researchers included on this project. Please be open and honest in your responses. All comments and responses, both negative and positive are welcome. Your opinions will aid in strengthening existing arthritis self-help programs.

The next session teaches you about action planning as a tool for self-management. Please Read the Next Page and Answer the Questions that FolloW.

Action Plan

A realistic Action Plan is your most important tool for self-management. It can also be one of the most difficult tools to develop. When you decide what you want to do and how you will do it, you teach yourself an important self-management skill.

Make your personal Action Plan about something that **you** want to do – not the things that other people think you should do! Your answers on the "Self Test" may help you decide what is most important right now. An Action Plan includes the following:

1. **What** you are going to do
   Will you eat or drink differently? Will you walk?

2. **How much** you are going to do
   Perhaps you will decide to stop eating fried food, or practice a relaxation exercise, or walk up and down stairs instead of taking the elevator?

3. **When** you are going to do it (what time of day)
   Perhaps you will decide not to eat fried food at lunch? Practice a relaxation exercise as soon as you get home from work? Walk up the stairs to your office when you come to work, and when you leave?

4. **How many times a week** you are going to do it
   Try your new plans three or four times a week, not every day. You are more likely to be successful if you give yourself a break now and then. Everybody has days when they don't feel like doing anything! **(Note: Taking your medication is an exception. You must take your medicine exactly as directed.)**

Example of an Action Plan

Use this general pattern to develop your personal Action Plan:

"I will eat grilled or broiled food (*what*) when I visit a fast food restaurant (*how much*) for lunch (*when*) twice a week (*how many times a week*)."

This week I will:

- Eat grilled chicken instead of fried chicken
- When I meet my friends for lunch at the fast food restaurant
- Two times this week

Write down **your personal Action Plan**. Have your Plan reflect your goals -- what you think you *can* do now and what you *want* to do now.

Now, ask yourself a question. **How confident am I that I can complete this Action Plan?** Give yourself a number between 0 (not at all confident) and 10 (totally confident).

If your answer is 7 or higher, your Action Plan is probably realistic. If your answer is below 7, reassess your Action Plan. Ask yourself why you aren't confident that you can complete the activities you have planned. Then think about how to solve the problem/s and change your Plan so that you will be successful in fulfilling your Plan.

Getting the Most from Your Action Plan

Develop a plan for ***you****, based on what you know you can do and what you want to do...not what someone else thinks you should do!*

- Carry out your Action Plan. If it doesn't work at first, don't give up. Identify the problem. Try something else. Modify your Plan. Get help. (See the Information Sheet on the seven steps of Problem Solving.)
- Check the Action Plan Calendar in *The Arthritis Helpbook*, p. 51. Make copies of the Calendar page.
- Write down your Action Plan. This makes it easy to keep track of your progress and helps you identify any problems.
- Post your Action Plan Calendar in a place where you will see it every day, such as your bathroom mirror or refrigerator door.

Based on what I read about the action plan:

1. I am likely to create an action plan?

Not at All Likely **Extremely Likely**

☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

2. I am likely to follow an action plan?

Not at All Likely **Extremely Likely**

☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

- -

3. I can see how an action plan would help my arthritis?

Not at All **Extremely**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10
****

4. It seems that the action plan was designed with people like me in mind?

Not at All **Extremely**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10
****

Exercising in the correct way will make it easier for you to manage and live with your condition. Now, take the time to listen to the exercise CD.
(4 minutes of the CD will be played)

Please Answer the Following Questions.

1. After listening to the CD, I feel confident that I can do those exercises even with arthritis?

Not at All Confident **Extremely Confident**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10
****

2. It is likely that the exercise CD is meant for people like me?

Not at All Likely **Extremely Likely**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10
****

3. I feel that someone from my cultural or racial group can relate to the speaker on the exercise CD?

Not at All True **Extremely True**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10
****

4. I liked listening to the CD?

Not at All True **Extremely True**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10
****

5. I found the CD to be very helpful?

Not at All **Extremely**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

6. I feel confident that I would use the exercise CD at home on my own?

Not at All **Extremely**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

7. I would tell my friends to use the CD for their arthritis?

Not at All **Definitely**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

The next session teaches you problem solving skills to overcome various everyday problems. Please Read the Next Page and Answer the Questions that Follow.

Problem Solving

"Sometimes I feel overwhelmed with problems. What can I do?"

Everybody has problems. Sometimes we feel like they are just too much to handle. Living with a chronic disease can make things feel even harder. Problems can be opportunities to change things that aren't working for us. Solving problems helps us feel better and improves our lives!

Try the seven steps below to help you decide what isn't working for you, and find changes that you can make to improve your life.

Problem Solving Steps

1. **Identify the problem.** The real problem may not be what you think first. Do you often feel tired and assume that it is fatigue? Maybe it isn't fatigue. Maybe it's something you can do something about. Perhaps you aren't sleeping well at night because of pain and stiffness.

   <u>Example of a problem to be solved:</u> Pain and stiffness at night.

2. **List many ways of solving the problem.** Write down lots of possibilities. Brainstorm. List any idea that comes into your mind – no matter how odd or silly it sounds. List as many ideas as possible and think about them. Which ones might work? If you are not sleeping well because of pain and stiffness, you could try taking your pain medicine just before bedtime, using a heated mattress pad, or taking a warm bath right before bed.
3. **Try one idea at a time.** Give yourself time to try the various ideas, one at a time. New approaches may take a while to make a difference. Consider borrowing or renting items, such as heating pads or heated mattresses, before buying them. Try them out to see if they work.
4. **Evaluate the results.** Has the solution you tried made the problem better? Maybe it has. Maybe not. If not, go back to Step 2 and pick another solution to try.
5. **Keep trying new ideas until you find one or more that work!**
6. **Always look for new ideas.** Ask family and friends for ideas and help. Talk with your doctor. Look for community resources in the phone book or on the internet. Use your detective skills.
7. **Some problems can't be solved immediately.** If you try every idea you can think of and nothing really helps, you may have to accept that your problem can't be solved right now. If this happens, work on improving another problem, and leave the complicated one for another day. Work on something else and keep going!

People with arthritis and fibromyalgia find problem solving one of the most important tools for living a healthy life. Choose something that is causing you problems and practice the seven steps today. Read the material on problem-solving (pp. 57-64) in Chapter 8, "Outsmarting Arthritis," of *The Arthritis Helpbook.*

Based on what I read about problem solving:

1. I found the problem-solving approaches to be very helpful?

Not at All Helpful **Extremely Helpful**

☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

2. It is likely that I would use the problem solving skills to reduce my arthritis problems?

Not at All Likely **Extremely Likely**

☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

3. It is likely that I would use the problem solving skills to reduce the problems I have in my life in general?

Not at All Likely **Extremely Likely**

☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

4. I can see how learning problem solving skills would help my arthritis?

Not at All **Extremely**

☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

5. It seems the problem solving steps were designed with people like me in mind?

Not at All **Definitely**

☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

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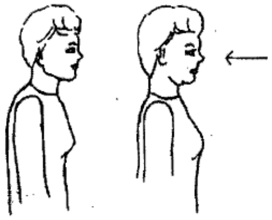
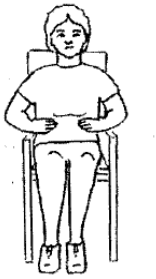
Below you will find parts of the illustrated guide to go along with the exercise CD. Please take the time to view the material.

Low Intensity Exercise

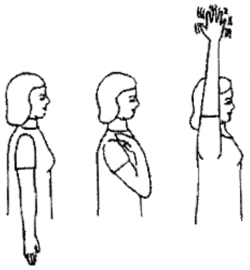


1. Chin in: place hand on chin and push in towards neck

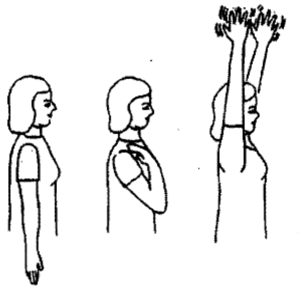
2. Neck stretch: turn your head from side to side



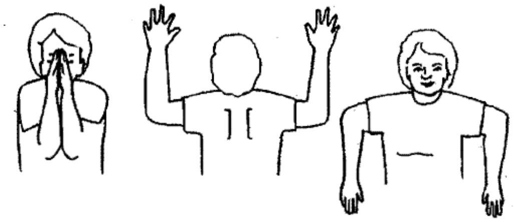
3. Deep breathing: place your hands over your ribs



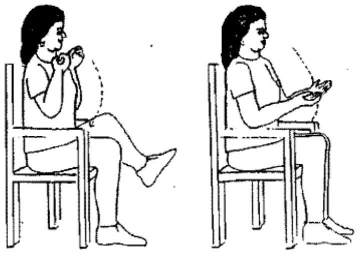
4. Bend and reach: touch your hand to your shoulder then extend above your head (do on both sides)



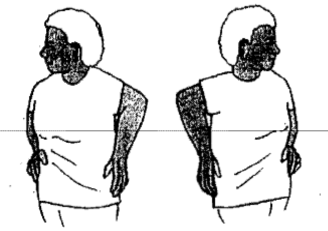
5. Bend and reach: touch both your hands to your shoulder then extend above your head



6. Raise the palms of your hands in front of you as if praying, separate your hands and bring your elbows behind your shoulders



7. Make a gentle fist and lift towards shoulders as if carrying weights

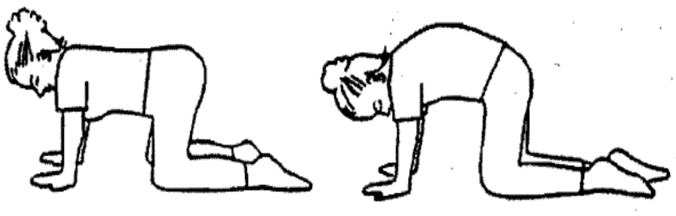


8. Waist twist: in a seated position, place your hands on your hips and turn from side to side

More Vigorous Exercise

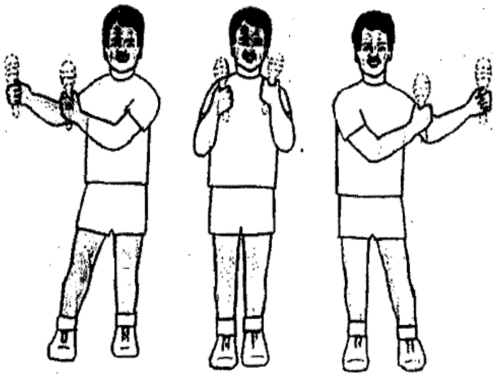
1. Neck stretch: turn your head from side to side

36. Waist rock and roll: laying down, twist from the waist with your arms extended at your sides, keep your upper back and shoulders flat on the floor/mattress



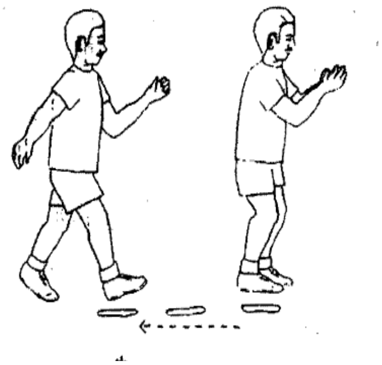
Aerobic Section

19. Dance



20.Dance: shake an imaginary tambourine

21.March in Place



Based on the exercise material I viewed:

1. I feel the exercise pictures were helpful?

Not at All Helpful **Extremely Helpful**

☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

2. I am likely to use the illustrated guide at home to exercise for my arthritis?

Not at All Likely **Extremely Likely**

☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

3. I would tell my friends to use the illustrated exercise guide?

Not at All **Definitely**

☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

4. I feel that someone from my cultural or racial group can relate to the exercise pictures?

Not at All **Definitely**

☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

5. It seems likely that the exercises included were meant for people like me?

Not at All Likely **Extremely Likely**

☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

The next session teaches you about how to find resources that will help you accomplish various goals and tasks in your life. Please Read the Next Page and Answer the Questions that Follow.

Finding Community Resources: A Treasure Hunt

Finding help these days is like going on a scavenger hunt. It requires problem solving, detective skills, and persistence! Read Chapter 10 ("Finding Resources") in *The Arthritis Helpbook* for more details.

Problem Solving

What problem do you need help solving? This is the first step. Once you decide what problems you need to solve, you may decide to ask for help. Can your family and friends help? Do you need expert advice and assistance? Chapter 19 ("Feelings and Communication") of The Arthritis Helpbook, pages 291 to 299, includes good ideas about how to ask for help…and how to say "no" when you really don't need or want some types of "help!"

Detective Skills

What if you are having trouble finding the help that you need? Use your detective skills to get answers to your questions. Let's look at an example of a problem and practice exploring solutions.

Problem: Meal Preparation

Perhaps you decide that you need help preparing meals. How can you solve this problem?

Ask yourself questions: Is your kitchen "friendly" to people with physical limitations? Do you need to remodel your kitchen so that you can work in it sitting down? Can you buy frozen, prepared meals that only require re-heating? Do you need meals delivered to your home? How much will each of these options cost? Do you have the money to pay for them? Will your health insurance help with the costs? Is the cost of any of these options based on ability to pay?

Don't be shy about asking questions. List all your questions and then get out your Detective Tools to find the answers!

Detective Tools

- The Yellow Pages in your telephone directory
- Referral agencies
- The want ads, events calendar, and classified section in your newspaper
- Public libraries
- Church or religious groups
- The person in your community who knows everyone and everything
- A list of organizations for your disease, including state chapters, such as the Arthritis Foundation
- Your doctor, case-manager, insurance plan, hospital, health department, or health center
- The internet or web

Based on what I read about community resources:

1. I feel confident that I can find community resources to help with my arthritis?

Not at All Confident **Extremely Confident**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

2. I feel confident that I can find community resources to help me in general?

Not at All Confident **Extremely**
Confident ☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8
☐9 ☐10

****

3. I am likely to use detective tools to find the answers to questions I may have about arthritis?

Not at All Likely **Extremely**
Likely ☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9
☐10

****

4. It seems the detective tools listed were meant for people like me?

Not at All True **Extremely True**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

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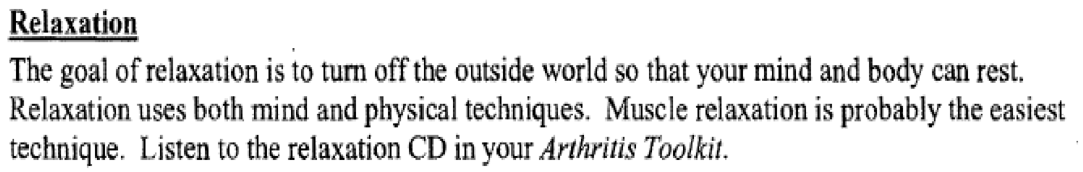
Stress management techniques such as relaxation, which will be explained below, could be used to manage your arthritis. Relaxation can result in muscles becoming less tense, less painful, and may also help you rest better.



Relaxation

The goal of relaxation is to turn off the outside world so that your mind and body can rest. Relaxation uses both mind and physical techniques. Muscle relaxation is probably the easiest technique. Listen to the relaxation CD in your *Arthritis Toolkit*.

Now take the time to listen to the Relaxation CD. (4 minutes of the CD will be played)

1. After listening to the CD, I feel confident that I can use the relaxation CD to benefit my arthritis problems?

Not at All Confident **Extremely Confident**

☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

2. I feel that the relaxation CD is meant for people like me?

Not at All **Definitely**

☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

3. I feel that I can relate to the scenario (story) on the relaxation CD?

Not at All **Extremely**

☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

4. I feel that someone from my cultural or racial group can relate to the speaker on the exercise CD?

Not at All **Extremely**

☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

5. I liked listening to the CD?

Not at All **Extremely**

☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

6. I found the CD to be very helpful?

Not at All **Extremely**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10
****

7. I feel confident that I would use the relaxation CD at home on my own?

Not at All **Extremely**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10
****

8. I would tell my friends to use the CD for their arthritis?

Not at All **Definitely**
☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10
****

Eating well can help you manage your condition. The next session teaches you about how to eat in a healthy way. Please Read the Next Page and Answer the Questions that Follow.

Healthy Eating

There are a lot of myths about food and arthritis

Do some foods cure arthritis? No. Do some foods cause it? Not as far as we know. But the things you eat can affect how you feel. Eating the wrong foods can make you feel tired. Eating a healthy diet will give you more energy and help you deal with your illness. What you put in your mouth does make a difference!

Fatigue

Eating unhealthy foods, or skipping meals, can cause tiredness and fatigue. Processed food like white bread, white rice, cakes, pastries, and sugars can make the fatigue of arthritis worse. Being overweight can also cause fatigue. Limit the amount of processed food you eat. Replace it with fresh fruits and vegetables.

Overweight

Extra pounds put extra stress on your hips, knees, ankles and feet. Every additional pound on your body puts **several** additional pounds of stress on your joints!

Flare-ups and Food

Most foods don't cause flare-ups, but every person is a little different in the way they react to food. If you notice that you feel worse after eating a particular food, don't eat it.

What is healthy eating?

There is no mystery to healthy eating. Remember these tips:

- Eat a variety of foods at each meal.
- Try to eat about the same amount of food at each meal, especially if you also have diabetes.
- Try to eat at about the same times every day.
- Eat 5-7 portions of fruits and/or vegetables every day. A "portion" is one-half cup. In general, eat 2 1/2 to 3 1/2 cups of fruits and vegetables each day.
- Eat small amounts of saturated fats. Those are the fats that are solid at room temperature, including butter, cream cheese, and the fat on meats and poultry.
- Eat small amounts of trans fats, which are found in most store-bought baked goods and many fried foods.
- Limit your salt and sodium intake as much as possible. Try to eat no more than one teaspoon of salt or sodium a day. Remember that many foods have lots of sodium in them even before you add more at the table!
- Limit the amount of empty-calorie foods you eat, including snack foods, sodas, chips, candy, cake, cookies, and other foods that are mostly sugar.

You can find more about healthy eating in Chapter 15 of *The Arthritis Helpbook*.

I know that I need to lose weight but it is so hard!

Good for you for recognizing that you need to lose weight! You can find detailed help in *The Arthritis Helpbook*, Chapters 11 ("Exercise for Fitness and Better Living") and 15 ("Healthy Eating"). Here are some quick tips:

The "200 Plan"

- Every day, **eat** 100 fewer calories and **exercise** to use up 100 more calories. This "200 Plan" will take off 20 pounds a year.
- What's an easy way to **eat 100 fewer calories** a day? Cut out one slice of bread, or a medium size cookie, or the amount of butter or margarine you put on a slice of toast, or half a candy bar.
- What's an easy way to **use up 100 more calories** a day? Add 20-30 minutes to your regular exercise routine, such as walking, bicycling, dancing, or gardening.

Make small changes. Leave something on your plate. (Your mother is not watching!) Leave butter off your toast or mayo off your sandwich. Have your salad dressing on the side. When you get a sweet craving, suck on hard candy instead of eating a candy bar.

Instead of frying food, bake, broil, or cook your food in the microwave.

Don't go on a diet! Even if you lose weight you will probably gain it all back. Instead, make small changes that you will be able to continue for a lifetime.

Use your Action Plan as a guide. Identify your favorite snack foods – the ones that you know are not healthy. If you try to stop eating them completely you may feel deprived and end up binging. Instead, make an Action Plan to eat less of those "junk foods." For example, if you are drinking two sodas a day, make an Action Plan to drink only four sodas a week. If you are eating chocolate every day, cut back to eating chocolate only twice a week.

Share your Action Plan with friends and family so that they can help you. You might even want to make weight loss a family project!

Give yourself lots of encouragement and love!

Based on what I read about healthy eating:

1. I feel the healthy eating section fits my needs?

Not at All **Extremely**

☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

2. I am likely to change my eating based on the material learned in the healthy eating section?

Not at All Likely **Extremely Likely**

☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

3. I see how changing my eating would help my arthritis?

Not at All True **Extremely True**

☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

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4. It seems that the healthy eating section was designed with people like me in mind?

Not at All Likely **Extremely Likely**

☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

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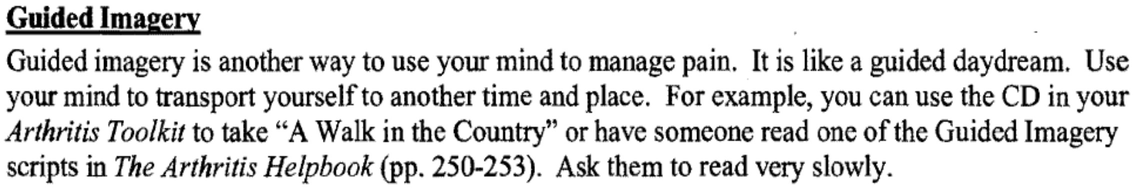
Stress management techniques such guided imagery, which will be explained below, could be used to manage your arthritis. Guided imagery can result in muscles becoming less tense, less painful, and may also help you rest better.



Guided Imagery

Guided imagery is another way to use your mind to manage pain. It is like a guided daydream. Use your mind to transport yourself to another time and place. For example, you can use the CD in your *Arthritis Toolkit* to take "A Walk in the Country" or have someone read one of the Guided Imagery scripts in *The Arthritis Helpbook* (pp. 250-253). Ask them to read very slowly.

Now take the time to listen to the Guided Imagery CD. (4 minutes of the CD will be played)

1. After listening to the CD, I feel confident that I can use the guided imagery CD to help my arthritis problems?

Not at All Confident **Extremely Confident**

☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

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2. I feel that the guided imagery CD is meant for people like me?

Not at All **Definitely**

☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

3. I feel that I can relate to the scenario (story) on the guided imagery CD?

Not at All **Extremely**

☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

4. I feel that someone from my cultural or racial group can relate to the speaker on the guided imagery CD?

Not at All **Extremely**

☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

5. I liked listening to the guided imagery CD?

Not at All **Extremely**

☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

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6. I found the guided imagery CD to be very helpful?

Not at All **Extremely**

☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

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7. I feel confident that I would use the guided imagery CD at home on my own?

Not at All **Extremely**

☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

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8. I would tell my friends to use the guided imagery CD for their arthritis?

Not at All **Definitely**

☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

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The last questions will ask you about the arthritis self-help program in general. Based on each part of the program that you saw

1. Is there anything in the materials that you made you feel uncomfortable or that you felt was not acceptable?

Not at All **Definitely**

☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

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2. Is the written material in any way offensive?

Not at All **Extremely**

☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

3. Are the pictures or graphics in any way offensive?

Not at All **Extremely**

☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

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4. Is the audio in any way offensive?

Not at All **Extremely**

☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

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5. Are the arthritis program materials visually appealing?

Not at All **Extremely**

☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

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6. Are the problems and concerns addressed in the program problems that you have with your arthritis?

Not at All **Extremely**

☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

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7. On average the total length of an exercise section on the CD is 20 minutes long. Is it likely that you would listen and exercise with an entire section on the CD?

Not at All Likely **Extremely Likely**

☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

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8. Would you attend a class one day a week for six weeks covering the material presented here in greater detail?

Not at All Likely **Extremely Likely**

☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

- -

9. Did you find the arthritis program material easy to read, for example the page on problem solving?

Not at All **Extremely**

☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

****

10. When reading the program material on arthritis did you feel the print was big enough, for example the page on problem solving?

Not at All **Definitely**

☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

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2. Which do you feel best describes your race/ethnicity? **Please check the one that best applies to you.**

☐White (Not Hispanic)
☐Black/African American (Not Hispanic)
☐Hispanic
☐Asian
☐Native American
☐Other
If Other please specify.

____

3. What is your gender?

☐Male
☐Female

4. Please check the box that best describes your approximate family annual gross income (before taxes and insurance). This should include the following sources; wages, pensions, dividends, and any additional household income. **(Please check the box that best applies to you)**

☐ Less than $5,000
☐$5,000 - $9,999
☐$10,000 - $14,999
☐$15,000 - $19,999
☐$20,000 - $29,999
☐$30,000 - $39,999
☐$40,000 - $49,999
☐$50,000 - $59,999
☐$60,000 - $79,999
☐$80,000 - $99,999
☐$100,000 and over

THE END

Thank you for your help

Appendix C: Progressive Muscle Relaxation CD Script

Make yourself as comfortable as possible. Uncross your legs, ankles, and arms. Allow your body to feel completely supported by the surface beneath you. You may want to close your eyes, as a way of closing out any unnecessary distractions.

Begin by taking a deep breath, breathing in through your nose, filling your chest and breathing all the way down to the abdomen. When you are ready to breathe out, breathe out through pursed lips slowly and completely. As you breathe out, let as much tension as possible flow out with your breath. Let all your muscles feel heavy, and let your whole body just sink into the surface beneath you.

This exercise will guide you through the major muscle groups from your feet to your head, asking you to first tense and then relax those muscles. If you have pain in any part of your body today, do not tense that area. Instead just notice any tension that may already be there and let go of that tension.

Become aware of the muscled of your feet and calves. Pull your toes back up toward your knees. Hold your feet in this position…noticing the sensations…Now relax your feet and release the tension. Observe any changes in sensations as you let go of the tension.

Now tighten the large muscles of your thighs and buttocks. Hold the muscles tense. And as you do, be aware of the sensations…And now release these muscles, allowing them to feel soft, as if they are melting into the surface beneath you.

Now turn your attention to your abdomen and chest. Tense these muscles by holding in your abdomen and tightening the muscles on your chest wall. Notice a tendency to hold your breath as you tense these muscles. Now release the tension. You may feel a natural desire to take a deep breath to release even more of the tension, and so do that now. Breathe in deeply through your nose, and when you breathe out, allow your abdomen and chest to soften.

Now, stretching your fingers out straight, tighten the muscles of your hands and arms. Release and feel the tension flowing out and the circulation returning.

Next, press your shoulder blades together, tightening the muscles in your upper back, shoulders, and neck. This is a place many people carry tension…And relax. You may notice that your muscles feel a little warmer and more alive.

Finally, tighten all the muscles of your face and head…Notice the tension around your eyes and in your jaw. Now release the tension, allowing the muscles around your eyes to soften and your mouth to remain slightly open as your jaw relaxes. Notice the difference.

Now take another deep breath, and when you're ready to breathe out, allow any remaining tension to flow out with your breath and your whole body to be even more deeply relaxed. And now just enjoy this feeling of relaxation for a little while…In this quiet state, notice the heaviness of your muscles…and the rhythm of your breathing…as you breathe in and breathe out…

Remember this pleasant feeling. You can quiet your mind and body in this way anytime you do this exercise. With practice, you will be able to create this feeling just by taking a deep breath.

As you prepare to end this exercise, picture yourself bringing this feeling of quiet and calm to whatever you are going to do next. And then take one more deep breath and, when you are ready, open your eyes.

Appendix D: Guided Imagery CD Script

You are giving yourself some time to quiet your mind and body. Allow yourself to settle comfortable, wherever you are right now. If you wish, you can close your eyes. Breathe in deeply, through nose, expanding your abdomen and filling your lungs. Pursing your lips, exhale through your mouth slowly and completely, allowing your body to sink heavily into the surface beneath you…And once again breathe in through your nose and all the way down to your abdomen, and then breathe out slowly through pursed lips – letting go of tension, letting go of anything that is on your mind right now and just allowing yourself to be present in this moment…

Imagine yourself walking along a peaceful old country road. The sun is warm on your back…the birds are singing…the air is calm and fragrant.

As you walk along, your mind naturally wanders to the concerns and worries of the day. Then you come upon a box by the side of the road and it occurs to you that this box is a perfect place to leave your care behind while you enjoy this time in the country. So you open the box and put into it any concerns, worries, or pressures that you are carrying with you. You close the box and fasten it securely, knowing that you can come back and deal with those concerns whenever you are ready.

You feel lighter as you progress down the road. Soon you come across an old gate. The gate creaks as you open it and go through.

You find yourself in an overgrown garden – flowers and growing where they have seeded themselves, vine climbing over a fallen tree, soft green wild grasses, and shade trees.

Breathe deeply, smelling the flowers…listen to the birds and insects…feel the gentle breeze warm against your skin. All of your senses are alive and responding with pleasure to this peaceful time and place.

When you are ready to move on, you leisurely follow a path behind the garden, eventually coming to a more wooded area. As you enter this area, your eyes find the trees and plant life restful to look on. The sun is filtered through the leaves. The air feels mild and a little cooler. You become aware of the sound and fragrance of a nearby stream. You pause and take in the sights and sounds, breathing deeply of the cool and fragrant air several times…And with each breath, you feel more refreshed.

Continuing along the path for a while, you come to the stream. It is clear and clean and it flows and tumbles over the rocks and some fallen logs. You follow the path along the creek for a way, and after a while you come out into a sunlit clearing, where you discover a small waterfall emptying into a quiet pool of water.

You find a comfortable place to sit for a while, a perfect spot where you can feel completely relaxed. You feel good as you allow yourself to just enjoy the warmth and solitude of this peaceful place.

After a while, you become aware that it is time to return. You arise and walk back down the path, through the cool and fragrant trees, out into the sun-drenched overgrown garden…One last smell of the flowers, and out the creaky gate.

You leave this country retreat for now and return down the road. You notice you feel calm and rested. You know that you can visit this special place whenever you wish to take some time to refresh yourself and renew your energy.

About the Author

Chivon A. Mingo received a Bachelor of Science Degree in Psychology and a minor in Gerontology from Georgia State University in 2003. In 2005, she received a Master of Arts Degree in Gerontology from the University of South Florida. Ms. Mingo was awarded the McKnight Doctoral Fellowship and entered the Ph.D. in Aging Studies program at the University of South Florida in 2005.

While in the Ph.D. program at the University of South Florida, Ms. Mingo was employed as a Graduate Teaching Associate, teaching undergraduate Life Cycle (Developmental Psychology) and Race, Ethnicity, and Aging (Minority Aging) courses. She has served as a Graduate Research Assistant on two grant-funded research projects under the auspices of Dr. Jessica McIlvane, and as the Principal Investigator on two projects outside of her dissertation research, one of which was funded by the Florida Chapter of the Arthritis Foundation. Ms. Mingo has co-authored five peer-reviewed journal articles, and presented her work at several national conferences including the Gerontological Society of America, and the National Medical Association.