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## The Effects of Telephone Intervention on Arthritis Self-Efficacy, Depression, Pain and Fatigue in Older Adults with Arthritis

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THE EFFECTS OF TELEPHONE INTERVENTION ON ARTHRITIS SELF-  
EFFICACY, DEPRESSION, PAIN, AND FATIGUE IN OLDER ADULTS WITH  
ARTHRITIS

A Dissertation

Submitted to the Graduate Faculty of the  
University of New Orleans  
in partial fulfillment of the  
requirements for the degree of

Doctor of Philosophy  
in  
The Departments of Curriculum & Instruction  
and Human Performance & Health Promotion

by

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## ABSTRACT

The current study was conducted to examine the effects of telephone intervention on arthritis self-efficacy, depression, pain and fatigue in older adult patients in different clinical settings. Eighty-five subjects from two clinics were randomly assigned to either the control ( $n = 45$ ) or intervention ( $n = 40$ ) groups. The study was a mixed quantitative/qualitative design. Each subject completed several pre-tests including the Arthritis Self-Efficacy (ASE) scale, the Geriatric Depression scale (GDS), and numeric rating scales for both pain and fatigue. All subjects received an informational packet on self-management of arthritis and developed an action plan and personal goals for self-management of their arthritis over the next six weeks. Subjects in the intervention groups also received a brief educational session on the packet and were called once weekly for the next five weeks. The calls followed a script, addressing different sections of the informational packet. The calls were designed to be both instructional and motivational. Subjects in the control groups were not contacted until the sixth week. At that time all subjects were called and the assessment tools were re-administered.

Quantitative data analysis (repeated measures ANOVA) showed a significant increase in ASE scores over time for both intervention and control groups. Qualitative data analysis revealed the emergence of several major themes that were supported by the

subjects' responses. The telephone interventions helped many of the participants initiate exercise programs for the first time in their lives. Participants also indicated that they were determined to adhere to these programs, that they would make other lifestyle changes that would assist their arthritis self-management, and that the telephone interventions were helpful in facilitating medical care for arthritis exacerbations and other medical problems.

Telephone intervention was helpful in promoting adherence to exercise programs and other lifestyle changes that may assist older patients in the self-management of their arthritis, and was helpful in facilitating medical care.

Arthritis education classes have been developed which have been shown to enhance the self-management of arthritis in older patients. Telephone intervention may be an alternative means of enhancing self-management for these individuals.

## CHAPTER ONE

### INTRODUCTION

People with arthritis sometimes liken their condition to “living in a pool of wet cement.” This description vividly captures the image of living with arthritis. Arthritis comes in many different forms and can vary greatly in terms of severity, but it almost always leaves its patients feeling stiff and in pain. Arthritis is not curable, but learning to manage arthritis successfully can help to lighten the burden it imposes on those who have it and may also improve their quality of life.

The American population is older than it ever has been. In 1997, 13 percent of the U.S. population was 65 years of age and over (U.S. Center for Disease Control, 2000). Of the 34 million Americans in this age group, nearly 4 million were 85 years or older. The elderly population is growing faster than the rest of the U.S. population, with the 85 and older population group increasing at the fastest rate. As Americans live longer, they are likely to experience at least one chronic illness during their lifetime. The most prevalent self-reported chronic condition in adults over 65 is arthritis (Services, 2002). Arthritis is the leading cause of disability in the United States. However, the pain and limitations of arthritis can be lessened through appropriate management. The purpose of this study was to examine a method by which older adults might be able manage their arthritis more

effectively. This method consisted of using a telephone intervention as a method of increasing self-efficacy in older adults as they attempt to manage their arthritis.

Arthritis in its various forms is a chronic and essentially incurable disease. Most forms of arthritis are characterized by a slow and progressive decline in function and mobility. This overall decline, however, is often marked by transient periods of improvement and setbacks. These may range from having exceptionally good or bad weeks to dramatic swings in symptoms within a 24-hour period. The disease takes an emotional as well as a physical toll on the patient. Because of the changing, yet chronic nature of arthritis, patients must take an active role in the management of the illness. They need to acquire or learn methods of managing the disease to remain as functional as possible. Typically, patients must assume much of the responsibility of the disease management.

Self-care may be enhanced by information provided to the patient (Lorig & Holman, 1993). However, knowledge alone is insufficient. Patients must also believe they are capable of managing the symptoms and implications of the illness. Consequently, a key component of self-care is self-efficacy, which was first defined by Bandura and is a central concept of the Social Learning Theory (also known as the Social Cognitive Theory, or SCT) (Bandura, 1977, 1981; Bandura, Adams, & Beyer, 1977). By definition, self-efficacy is someone's confidence in his or her ability to perform a specific behavior or to change a certain cognitive state (Lorig & Holman, 1993). Interventions to improve self-efficacy may not significantly alter the physical status of someone with arthritis, but their perception of their condition may be altered. This change in perception could lead to a decreased focus on the disability and pain aspects of their condition. In other words, they may not have improved physically but their perception is that they have. They may

believe that they have greater mastery or control over their condition. Their focus may shift from what the disease prevents them from doing to what they are able to do in spite of their symptoms. Barlow & Barefoot (1996) describe the role of self-efficacy in arthritis management below:

*“In the context of arthritis, self-efficacy refers to a perceived ability to manage pain, fatigue and physical functioning on a daily basis. Given equal disease severity, perception of arthritis self-efficacy (confidence in self-management) can differentiate between those who are incapacitated by their disease and those who continue to live full and active lives. Regarding the nature of outcomes of patient education, there is increasing evidence that educational programmes do not have a great impact on physical functioning amongst people with arthritis. Rather, the main benefits appear to center on psychological well being (e.g., depression) and confidence in self-management of the condition (i.e., self-efficacy.)” (page 258).*

Structured intervention work has been shown to increase efficacy in patients with arthritis (Barlow, Turner, & Wright, 2000; Lorig, Gonzalez, Laurent, Morgan, & Laris, 1998; Lorig & Holman, 1993; Lorig & Holman, 1989; Lorig, Sobel, Ritter, Laurent, & Hobbs, 2001). The common thread in all of these studies is that the patients who completed self-management courses described a greater sense of control over their arthritis. The information and skills gained in the courses had given them confidence (i.e., self-efficacy) to ultimately change behavior. Their changes in behavior were mainly linked to increased confidence in management of the pain and improvement of their level of function.

Most of the studies performed have utilized well-structured patient education programs such as the Arthritis Self-Management Program (ASMP) (Lorig, Seleznick et al., 1989). The ASMP and other similar patient education programs are typically presented in weekly one to two hour sessions over a 6-10 week period (Lorig & Holman, 1989; Lorig, Lubeck, Kraines, Seleznick, & Holman, 1985; Lorig, Mazonson, & Holman,

1993; Lorig et al., 2001). Studies using this format have shown that the ASMP is effective in increasing self-management behaviors (Lorig & Laurin, 1985; Taal et al., 1993). In a study of the long-term benefits of participation in the ASMP, it was found that four years after completion of the ASMP patients with diagnoses of rheumatoid arthritis (RA) or osteoarthritis (OA) had less pain. These patients also demonstrated reduced use of medical services compared to patients who had not participated in the ASMP (Lorig et al., 1993). A limitation of the research related to the benefits of self management programs is that most of these studies were conducted on samples who were typically Caucasian and well-educated (often college degree and beyond) (Lorig et al., 1985; Lorig et al., 1993; Lorig et al., 2001). Demographic information on range of income was not often provided in most of these studies. Range of income is often identified as part of the classification of socioeconomic status (SES).

None of the research reviewed has documented whether the ASMP is as effective in a group of patients characterized by lower educational and socioeconomic levels. It is reasonable to hypothesize that older adults who belong to the lower SES group may be less likely to participate in a program as structured and long-term as the ASMP; however none of the literature reviewed has investigated this hypothesis. Transportation and financial considerations may make the logistics of attending the courses problematic. In addition, lower literacy rates among this group may be a barrier to successful participation in a program like the ASMP (Criswell & Katz, 1994; Davis, Michielutte, Askov, Williams, & Weiss, 1998; Gordon, Hampson, Capell, & Madhok, 2002; Young et al., 2000).

An important avenue of research might consider whether these barriers could be less of a problem if a less structured and shorter patient education program might improve efficacy in patients with low self-efficacy states. An unanswered question remains: could an alternative means of intervention affect changes in arthritis self-efficacy? Direct phone calls to patients may represent a viable alternative to structured programs. Prior research has shown that substitution of phone care for some selected clinic visits in older patients with a variety of diagnoses significantly decreased utilization of medical services (Wasson et al., 1992). In a study of sedentary older adults free of cardiovascular disease, a telephone-based program was found to be as or more effective in adopting home exercise programs (King, Haskell, Taylor, Kraemer, & DeBusk, 1991). Although research has demonstrated the effectiveness of the phone intervention method in various aspects of health care, this technique has not been applied to arthritis self-management or as a means to influence self-efficacy.

#### *Purpose Statement*

The purpose of this experimental study was to examine the effects of telephone intervention on arthritis self-efficacy in older arthritis patients in different clinical settings. The independent variables were whether or not the participant received follow-up phone calls over a six-week period and the different clinical settings in which the study participant received care. The dependent variables were scores on the Arthritis Self-Efficacy Scale (ASE), the Geriatric Depression Scale (GDS), and participant self-ratings on numeric pain and fatigue scales. In addition, the qualitative data recorded during the telephone intervention were analyzed for the emergence of major themes in order to explain the importance of the intervention to the participants.



### *Theoretical Framework*

Prior research in the area of self-management has shown that the Social Cognitive Theory (SCT), with its emphasis on self-efficacy, was the most relevant theory for this study and provided the theoretical framework for it. The SCT provides a basis for learning strategies and interventions and provides a framework for explaining how individuals acquire and maintain behaviors (Schuster, Petosa, & Petosa, 1995). This theory will be examined in greater detail in Chapter Two.

The role of self-efficacy in changing health status has become increasingly important. It has long been thought that for health education to be successful, health behaviors must change to improve health status. Self-efficacy may be an important factor in changing health behavior and therefore affecting health status (Lorig & Laurin, 1985). The focus on changing self-efficacy is the basis for self-care programs such as the Arthritis Self-Management Program (ASMP).

According to Bandura (Bandura, 1986b), self-efficacy is influenced by four factors: (1) performance attainment, (2) vicarious experiences, (3) verbal persuasion, and (4) psychological states. Performance attainment has been shown to be the largest influence on self-efficacy because it is based on actual skill mastery. Further relevance of this framework for the proposed study is that by its nature the telephone intervention may represent several forms of influencing self-efficacy. For example, telephone intervention can be identified as a form of verbal persuasion. Telephone interventions can also influence self-efficacy by means other than verbal persuasion. If the caller was an arthritis patient who could share their experiences with the individual being called, vicarious experiences could be utilized. It might also be argued that the phone calls might

have an inspirational/motivational component, thereby affecting the patient's psychological status. The question is whether this type of intervention can significantly affect self-efficacy. As discussed earlier, much of the research on patient education has involved relatively lengthy and structured interventions. Such interventions are not possible for all patients. Consequently, the present study focused on more of a minimalist approach, i.e. is there a lesser amount of intervention that may still significantly affect arthritis self-efficacy?

### *Need for Study*

Arthritis self-efficacy has been shown to play an important role in helping patients manage their arthritis (Barlow & Barefoot, 1996). Relatively sophisticated patient education/intervention programs such as the ASMP have been shown to enhance arthritis self-efficacy (Lorig et al., 1998; Lorig et al., 2001). However these studies have mainly examined the effects of the ASMP on a homogeneous population (i.e., well-educated, middle to upper income individuals). These individuals may be more likely to be willing and/or able to commit to a program like ASMP that requires a weekly 1-hour commitment of attending class for up to 8 weeks. There is a need to examine whether a less time-intensive program (e.g., telephone interventions) might also have an effect on arthritis self-efficacy. Such an intervention might be useful in assisting individuals in more successfully managing their arthritis in a more time-efficient manner. This study was needed to examine the relationship between telephone intervention and arthritis self-efficacy. Health care providers may use this information to design programs that may enhance the arthritis self-efficacy of patients who are unable to attend more structured patient education classes.

### *Statement of the Problem*

Individuals with chronic illness need to be active managers of their care. Research shows that those with higher efficacy are more effective in managing their condition (Lorig & Holman, 1993). It has been shown that efficacy may be increased through relatively intensive patient educational programs, but such a program may not be possible for all patients or clients.

The effect of telephone intervention on arthritis self-efficacy has not been examined in the literature. The relationship between telephone interaction and arthritis self-efficacy is important. Arthritis self-efficacy has been shown to play an important role in how well an individual adapts to and manages their arthritis (Barlow & Barefoot, 1996). While several studies have examined the role telephone intervention plays in adherence to various health behaviors (Castro, King, & Brassington, 2001; King et al., 1991; Maisiak, Austin, & Heck, 1996), the studies did not examine the relationship between the telephone interventions and arthritis self-efficacy.

### *Research Questions*

1. What are the effects of telephone interventions on arthritis self-efficacy? Does the effect of the intervention group vary by site (LSU vs. Charity)?
2. What are the effects of telephone intervention on ratings of depression on patients (who have been diagnosed with arthritis)?
3. What are the effects of telephone intervention on patients' (who have been diagnosed with arthritis) perception of pain?
4. What are the effects of telephone intervention on patients' (who have been diagnosed with arthritis) perception of fatigue?

5. What are the effects of telephone intervention on patients' attempts to reach various functional/activity goals in the self-management of their arthritis?

### *Research Hypotheses*

1. The telephone intervention will enhance arthritis self-efficacy in the intervention groups from both clinical settings as shown by increases in their Arthritis Self-Efficacy (ASE) scores.
2. The telephone intervention will have a positive effect on depression ratings for patients in both clinical settings.
3. Intervention groups will have reduced perception of pain as shown by their scores on the pain numeric rating scale.
4. Intervention groups will have reduced perceptions of fatigue as shown by their scores on the fatigue numeric rating scale.
5. Participants in the intervention groups will show evidence of progress toward their stated goals as shown by qualitative data analysis.

### *General Methodology*

The basic design of this study was an experimental, pretest-posttest control group design. Participants were randomly assigned to one of two groups. Each group was given the same pretest measurements, intervention was given to one group, and then posttest measurements were taken on each group. The study was also a combined quantitative and qualitative design. The differing methods of data collection and analysis utilized in this study necessitated a combined study design. The sample consisted of volunteers from two different clinical settings: the Rheumatology Clinics at Charity Hospital of New Orleans and at the LSUHSC Lion's Clinic in New Orleans. Participants were randomly assigned

to control or intervention groups. All participants underwent pre-test measurements on arthritis self-efficacy and levels of function. Participants also described their baseline perceptions of levels of pain and fatigue and were screened for depression. In addition each participant stated a goal (related to managing their arthritis) that they wished to achieve in the next six weeks. Participants in the intervention groups received follow-up informative telephone calls weekly for the first four weeks of the study and a final call in the sixth week of the study. At the end of six weeks all participants were re-tested with the same measures (arthritis self-efficacy, depression, pain perception and fatigue perception). Each participant also described what progress had been made toward reaching his or her stated goal.

#### *Study Overview*

Arthritis self-efficacy has been shown to be very important in managing and functioning with arthritis (Barlow & Barefoot, 1996). It has also been shown that telephone interventions may have an impact on how an individual manages their arthritis (Castro et al., 2001; King et al., 1991; Maisiak et al., 1996). However, the effects of telephone intervention on arthritis self-efficacy have not been investigated, especially in individuals who may not have health insurance or may have a lower socioeconomic status. The study investigated the effects of telephone intervention on arthritis self-efficacy in older arthritis patients who receive their primary health care in different clinical settings.

### *Definition of Terms*

1. Self-efficacy- An individual's confidence in their ability to perform a task. A component of the Social Cognitive Theory. Self-efficacy was measured in this study by use of the Arthritis Self-Efficacy scale (ASE).
2. Arthritis self-efficacy- an individual's perceived ability to manage the pain, fatigue and disability associated with arthritis on a daily basis. Arthritis self-efficacy was measured in this study by use of the Arthritis Self-Efficacy scale (ASE).
3. Arthritis- The general term given to describe inflammation of a joint. Also used to describe a chronic condition of joint inflammation. There are dozens of types of arthritis.
4. Auto-immune- A situation where the body's immune system recognizes a normal body component as a foreign body and attacks it with the intention of destroying it.
5. Osteoarthritis- (OA) The type of joint inflammation that is associated with a mechanical deterioration of joint surfaces; also associated with joint "wear and tear". OA may be progressive but is limited to joint involvement.
6. Rheumatoid arthritis- (RA) The type of joint inflammation that describes an auto-immune destruction of joint surfaces. RA is usually a progressive disease that may also affect other body organs and systems in addition to the joints.
7. Fibromyalgia- A condition (not well understood or easily diagnosed) that produces chronic and widespread pain throughout the body, often involving virtually every joint and muscle. Fibromyalgia ranges in severity from being an annoyance to being disabling.

8. Rheumatology – The study of pathological conditions of the joints, muscles, tendons, bones or nerves.
9. Co-morbidity – Other medical conditions (in addition to the primary diagnosis) that the patient may have.
10. Symmetric polyarthritis – Arthritis that affects both upper and lower extremities, with at least two joints that are painful and swollen.
11. Self-management/self-care – (in arthritis) the broad term used for describing how a patient with arthritis takes care of various aspects of his/her life. While self-management does not exclude having the assistance of others, it usually refers to having the patient function as independently as possible. Self-management may include managing the medical aspects of the condition (medication, treating pain/swelling, exercise, etc.) as well as managing the psychological aspects (relationships, emotional state, etc.) and practical aspects (adapting work and home activities, etc.).

### *Limitations*

The following factors were limitations to the study:

1. Participants from the LSU Clinic may not have insurance and participants from the Charity Hospital may have insurance; this may have affected generalization about insurance status and arthritis self-efficacy.
2. Communicating by phone with participants in the intervention groups might have been logistically difficult. The use of telephone intervention did present certain challenges; many calls had to be attempted several times before being successfully completed. However, of the 92 participants who entered the study, only four had to

be dropped from the study when they could no longer be reached by phone.

3. Participants may have had other communications (with their physicians, etc) during the period of the study that may affect their level of arthritis self-efficacy.
4. Levels of participant activity during the study period largely relied on self-reporting; the reliability of this may be questioned.

### *Delimitations*

The following factors were delimitations to the study:

1. Initially the study was limited to adults 55 or older with a primary diagnosis of either osteoarthritis or rheumatoid arthritis.
2. Participants needed to state that they had telephone communication and would be willing to communicate with the experimenter during the course of the study.

### *Summary*

Arthritis is a disease process that commonly affects older adults. Self-efficacy is a concept that describes one's confidence in their ability to perform a task. It may be applied to managing a chronic disease such as arthritis, and increased levels of self-efficacy have been associated with more positive outcomes in the management of arthritis. This study investigated the effects of telephone intervention on arthritis self-efficacy and its subsequent outcomes. Chapter Two presents a review of relevant literature. Chapter Three describes the Methodology used in the study. Chapter Four presents the study's results, and Chapter Five discusses the findings and their possible implications.



## CHAPTER TWO

### REVIEW OF LITERATURE

#### *Overview*

This chapter presents a review of the literature pertaining to self-efficacy and management of chronic disease in older adults. The initial section will detail the relationship between self-management of chronic illness, and more specifically, arthritis and self-efficacy. The pathologic process of arthritis will be briefly reviewed to provide additional context for the self-management behaviors. Social Cognitive Theory will be reviewed as well as the development of the intervention itself. An overview of efficacy and adherence to health behaviors in the healthy older adult population and a comparison to the same topics in older adults with arthritis will be presented. Level of formal education, socioeconomic status and ethnicity and their impacts on older adults with arthritis and their efficacy to manage arthritis will be explored. Learning styles, and their impact on patient education, will be examined. Further, the effectiveness of telephone interventions in health care will also be reviewed and evaluated.

### *Chronic Illness and Self-Management*

Chronic illness may be described as a medical condition which will affect individuals for a period of time that may range from months or years to the remainder of their lives. Many different diseases may be included in this classification. Arthritis, in its various forms, is an example of a chronic disease. Arthritis is essentially incurable and its effects can vary greatly among patients with arthritis. While it is rarely if ever fatal, the effects of arthritis can range from mildly annoying to quite painful to completely incapacitating. Patients with arthritis are usually under some form of medical management for their disease, especially when the disease exacerbates or worsens, as it often does. However patients are rarely hospitalized for arthritis care. Even if they are under medical supervision they may go months or even years between visiting and communicating with their health care providers. During these periods the individual may need to find a way to deal with their arthritis on a daily basis. The patient with arthritis may be left to his or her own devices to devise strategies to deal with the pain, fatigue, and other stresses that their condition leads to. According to Lorig (Lorig et al., 1996), self-management may include tasks such as

1. understanding the disease well enough to recognize symptoms and prevent an acute worsening of the condition;
2. understanding the medications used in the management of the condition;
3. using exercise as an outlet for the physical and psychological stresses of their condition;
4. communicating and interacting effectively and appropriately with their health care providers as needed;

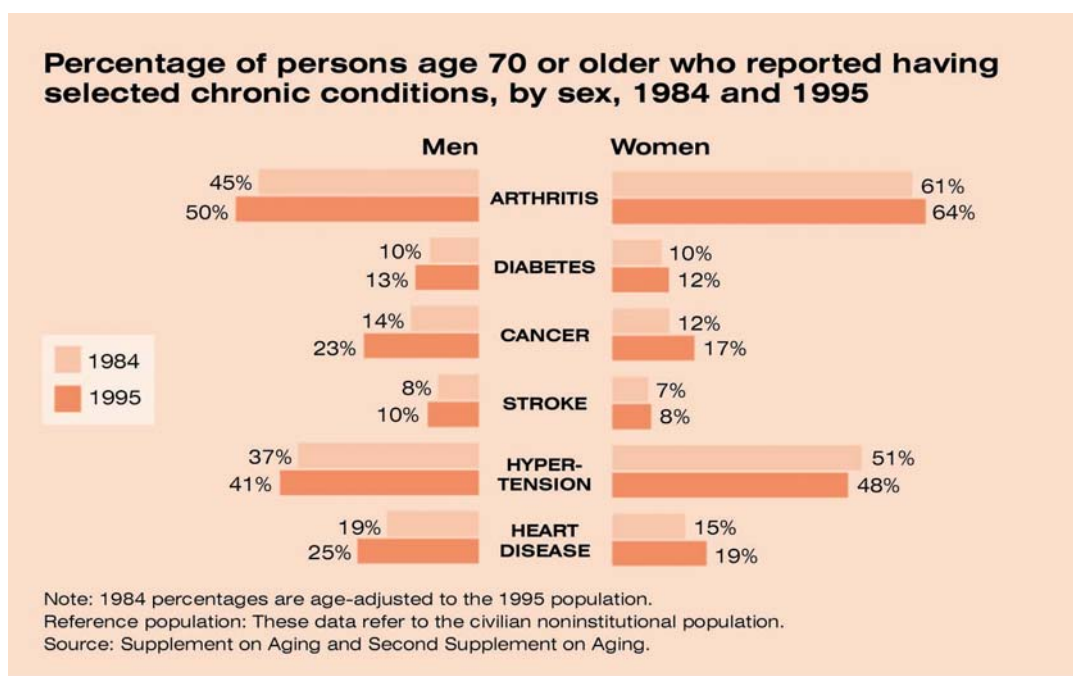
5. using healthy lifestyle behaviors including proper nutrition, avoiding smoking, etc.;
6. effectively dealing with the psychological and emotional stresses of their condition by using relaxation techniques, counseling, etc.;
7. seeking and utilizing community resources that may be helpful to the patient and his/her family, etc.

Self-management can be individualized depending on the functional capability of the patient and the severity of his or her condition. Enhancing the individual's ability to manage their disease effectively can positively impact their health outcomes (Lorig et al., 1996).

#### *Pathological Processes of Osteoarthritis and Rheumatoid Arthritis*

Arthritis is the most common chronic disease affecting older adults (Figure 1).

Figure 1: *Percentages of persons reporting chronic illness*



Arthritis is a general term that means inflammation of the joints. Over 200 types of arthritis have been identified but all are linked by their potential to produce pain and functional disability. A brief description of the pathological processes involved in two kinds of arthritis, rheumatoid arthritis (RA) and osteoarthritis (OA), follows.

As described in the Merck Manual (Berkow & Fletcher, 1992), rheumatoid arthritis is a chronic syndrome that is usually characterized by symmetrical inflammation of the joints of the upper and lower extremities. About one percent of all populations is affected, women two to three times more commonly affected than men. Onset of RA may occur at any age but is most common between the ages of 25 and 50. RA potentially results in destruction of the surfaces that line the joints and of the structures around the joints, and may lead to significant and even extreme pain and disability. RA is characterized as an autoimmune disease. The body's immune system, which usually fights infections and disease, for some unknown reason targets the body's joint and surrounding structures as a foreign body and attempts to destroy those structures. Up to 75% of patients with RA may improve somewhat with conservative (medical) treatment during the first year of the disease. However, at least 10% of patients with RA are eventually disabled despite full treatment.

While RA is described as an inflammatory disease, osteoarthritis is more of a mechanical problem (Berkow & Fletcher, 1992). OA is often simply described as wear and tear on the joints and is the most common form of all joint disorders. Virtually all people over the age of 35 or 40 experience some degenerative changes in their weight-bearing joints (usually referring to the bones in the ankle, knee and hip joints and the spine). OA is nearly universal by the age of 70 but a relatively small percentage of the

population become symptomatic. Men and women are equally affected by OA. While OA is primarily a problem that is concentrated in one's joints, it can cause major side effects and complications that can manifest in other body systems. Weinberger and colleagues described some of the most common problems experienced by patients with OA. These include depleting their prescription medicines before their next physician visit, experiencing gastrointestinal problems (often a side effect of the medications they are taking to treat the arthritis), and simply having trouble getting to primary care (Weinberger, Tierney, & Booher, 1989). Arthritis, while a chronic disease, is often intermittent in nature. The disease flare-ups, or exacerbations, may be unpredictable in terms of timing and severity. Arthritis may affect patients in very different ways. Management techniques that might be very effective for one patient may not help someone else with the same condition.

#### *Functional Levels in Older Adults with Arthritis*

The effects of arthritis on functional levels in the older adult population are well documented. Baker (Baker et al., 2001) and Ettinger (Ettinger, Burns, Messier, & et al., 1997) discussed the potentially devastating effects of knee osteoarthritis on older adults, discussing the declines in physical function and the associated effects on quality of life. Other studies have examined the role of arthritis as a source of morbidity, disability and loss of function in older adults (Hopman-Rock & Westhoff, 2000; Petrella & Bartha, 2000). The impact of arthritis, while not directly life-threatening in most cases, can greatly diminish quality of life.

Self-management plays a very important role in enhancing functional levels in older patients with arthritis. A number of strategies can help the individual on a daily basis.

Key skills such as being able to manage their pain (through medication, exercise, or relaxation techniques) and being able to effectively communicate with their physician and other health care providers can help patients function at as high a level as possible. Learning to adapt to their environment can also be helpful (e.g., modifying kitchen and other household utensils and appliances to meet their specific needs, etc.).

### *Arthritis Self-Management*

Research has demonstrated that knowledge about disease processes is a key component to more effective self-management. Barlow (Barlow, Williams, & Wright, 1999) found that patients with rheumatoid arthritis expressed a strong need for information about the disease process and how to manage it. Weinberger (Weinberger, Tierney, & Booher, 1989) showed that information provided to patients with osteoarthritis resulted in lower perceptions of pain and functional disability. This was true both for patients who had been newly diagnosed (less than one year) and those patients who had well-established cases (more than ten years). Lorig and Sobel (2001) found that a self-management program for patients with chronic diseases (including arthritis) resulted in less fatigue and disability, fewer limitations and better self-reported health, as well as fewer hospital visits compared to a control group over a six month period. Findings in this study were especially significant because they demonstrated the effectiveness of self-management in individuals with more co-morbidities, or more complex medical conditions. Patients with chronic diseases such as arthritis often have other medical problems that may even be more severe than the arthritis itself (Weinberger, Tierney, & Booher, 1989). The practical significance is that skills learned in the self-management of one illness may also aid the individual in managing other medical conditions.

### *Social Cognitive Theory*

The theoretical foundation for this study was Social Cognitive Theory (SCT). The predominant cognitive framework, as described by Bandura (1977), is that people tend to learn mainly by doing rather than from others. This form of active learning is especially relevant and important in the management of a chronic disease such as arthritis because the clinical manifestations of arthritis are idiosyncratic. Patients with arthritis usually need to find out for themselves what management techniques are effective. The more effective they are in managing their arthritis the more confident (efficacious) patients are likely to be. Successful management of the disease will vary between individuals. While the course of the disease may show transient or day-to-day fluctuations in terms of severity of symptoms, the larger issue is that the disease must be managed for the remainder of the individual's life. In fact, in clinical settings the patient is often counseled on how to manage all aspects of the disease (i.e., physical and emotional) for the long-term. While the temporary decreases in symptoms can make life more pleasant and the flare-ups can diminish quality of life, patients are advised on trying to maintain as steady a state as possible. SCT also utilizes self-motivation, which involves standards against which one's performance may be measured. As performance improves, individuals may expect more of themselves. This tendency may seem contradictory to the steady state concept mentioned above, but in a practical sense it is logical. Most forms of arthritis are progressive as well as incurable. For patients to maintain a relatively steady functional state as the challenges of the disease increase, it may be necessary for them work harder in order to adapt to their new functional baseline.

A basis of the SCT is that behavior is affected by environmental influences, personal factors, and attributes of the behavior itself (Bandura et al., 1977). Environmental influences may include the physical environment/surroundings as well as any other external factors that may influence an individual's behavior (e.g., opinions or actions of others, other demands the individual may be facing, etc.). Personal factors may include things like how the individual feels about the behavior, their physical and/or emotional state, etc. Attributes of the behavior itself may describe the degree of difficulty involved with the behavior, any potential ramifications of the behavior on the individual, etc. Any of these three attributes (environmental influences, personal factors and behavior attributes) may affect each of the other two.

An important aspect of Social Cognitive Theory is efficacy expectations. An efficacy expectation is an individual's conviction that one can successfully execute the behavior required to produce the outcomes. Efficacy expectations have come to be known as self-efficacy (e.g., arthritis self-efficacy). Efficacy expectations must be differentiated from outcome expectations. An outcome expectation is an individual's estimate that a given behavior will lead to certain outcomes. The relationship between the two is that the strength of one's convictions in their own effectiveness is likely to affect whether they will even try to cope with given situations. This relationship has obvious relevance in dealing with a chronic disease that is likely to present increasingly difficult challenges to maintaining an individual's quality of life. If individuals believe they lack the ability to cope with a given situation, they are likely to avoid that situation. Such avoidance may produce self-imposed limitations on level of function and potentially further diminish quality of life. Brus et al, in their review of the literature on patient compliance, stated



that the outcome expectation of a specific treatment for a patient with arthritis might be influenced by two factors. These include their perception of the cause of the RA and what makes the RA symptoms worse (Brus, van de Laar, Taal, Rasker, & Wiegman, 1997). The example given was of a patient with rheumatoid arthritis who believes that diet is an important cause of his or her RA. This individual may have high outcome expectations of the effect a dietary change may have on his or her arthritis. In turn this expectation level may influence their level of compliance to the diet.

Further, it is important to make the distinction between self-efficacy and self-confidence. As Dzewaltowski pointed out (Dzewaltowski, 1994), self-efficacy implies direction of confidence; the greater the efficacy the greater the individual's confidence that they will succeed in the task. Self-confidence itself does not imply direction: the individual can be equally confident that they will succeed or fail at the task.

Another aspect of this concept is that individuals will persist longer in their efforts if they have stronger perceived self-efficacy. This perceived self-efficacy is very relevant to patients with arthritis. If individuals believe that they can perform a certain activity in spite of their pain level, they are more likely to attempt and succeed at the activity than if they did not have such a strong level of belief (or self-efficacy).

Bandura (1977) also believed that if individuals persist in activities that are relatively safe (even though they may not initially be successful) their self-efficacy would tend to be reinforced. The relevance to arthritis management is that an individual may first participate in activities that are well within their comfort level. As they begin to gain confidence in their ability to perform these tasks their self-efficacy will be reinforced. They will then be more likely to increase their activity levels as noted above.

Bandura made it very clear that efficacy alone is not enough to be successful.

Incentives and capabilities are also keys to being successful. While a patient with arthritis may believe that he or she may be capable of performing a task, that belief alone may not be enough. The patient needs to have a reason to attempt the task, something that makes it worth the discomfort they may experience. The potential benefit of successfully performing the task should outweigh the risk (e.g., discomfort, increased level of fatigue) of attempting it. The patient's psychological state may influence their level of motivation. Depression can be a factor; a depressed patient may have less incentive to increase their activity level especially if there may be increased discomfort associated with that effort.

Efficacy expectations (one's belief that they can perform a task) are largely based on the *magnitude* of the task, the *generality* of the task (the individual's efficacy may carry over to or from similar situations), and the *strength of the individual's convictions* that his/her efficacies may make a difference in whether or not they are successful.

According to Bandura (Bandura, 1986b), an individual's efficacy is derived from four different sources:

1. *Performance accomplishments* – efficacy is based on what the individual has done.

Occasional failures that are later overcome by determined self-effort can eventually improve self-efficacy. A patient with arthritis may believe that his knee pain will not allow him to work in his garden. He persists with his effort and eventually finds that he is now able to do so. His self-efficacy is likely to be strengthened and he may attempt future activities as a result. Gonzalez and colleagues (Gonzalez, Goeppinger, & Lorig, 1990) describe performance operations as skill mastery. The key element of skill mastery is that a skill is broken up into smaller components that the individual

can master. For example, a patient with arthritic knees wants to be able to work in the garden. Several smaller components may comprise the larger goal. The patient first may work on successfully descending the stairs to the back yard. The next step may be successfully walking down the slope toward the garden. Subsequent components may include being able to sit in a chair beside the garden, progressing to sitting on a lower stool, then kneeling, etc. Their success in mastering the smaller components (and eventually the broader skill) can help them to become more efficacious in that area. Gonzalez et al also discuss the importance of goal setting, or contracting, as a way to foster mastery. The goals must be driven by the patient to optimize chances of successfully meeting them. An effective means of monitoring progress on a patient contract is to make a follow-up phone call to the patient.

2. *Vicarious experiences* - the individual may feel that “if someone else can do it, so can I”. An individual may see a neighbor or a friend perform a task or participate in an activity that may serve as a form of motivation, especially if the one modeling the activity has a similar (or even lower) level of ability to perform the given activity. Efficacies derived from vicarious experiences may be weaker than those described in performance accomplishments. Gonzalez describes vicarious experiences in terms of modeling (Gonzalez et al., 1990). In terms of enhancing arthritis self-efficacy, modeling can be done in several different manners. As described above, the patient can see/hear how someone with similar problems has been able to successfully manage those challenges. As Gonzalez points out, health educators sometimes make a mistake and select the wrong types of model. An example of this might be using as a model an older patient with arthritis who has had two hip replacements but has

resumed ballroom dancing and outdoor hiking with her grandchildren. While these accomplishments are impressive, they may not be realistic goals for many patients with arthritis after hip replacement surgery. A better model might be an individual who has had the surgery and, despite some pain and discomfort, has managed to overcome those problems and perform functionally on a daily basis. Gonzalez also discussed the importance of using appropriate models in patient education materials whenever possible. For example an older adult rather than a young person should model a video designed to show older patients with arthritis who have fallen how they might get up from the floor.

3. *Verbal persuasion* – talking with someone may influence his or her behavior. This is one of the areas on which the study focused: can phone interventions affect the self-efficacy in people with arthritis? Verbal persuasion as a source of self-efficacy has not been examined in this context. Verbal persuasion may be a very useful and practical means of developing self-efficacy in this population. Gonzalez (Gonzalez et al., 1990) points out that the persuasion must be realistic for it to contribute to successful changes in one's self-efficacy. A way that this might be accomplished without increasing the arthritis patient's fear is to give them short-term goals that are at a slightly higher level than their present level. For example, if the patient with arthritis relates that they can now walk two blocks without having increased knee pain, the verbal persuasion might consist of encouraging them to increase that to three blocks in the next two weeks. The patient might see this as realistic and be confident (efficacious) that they have the ability to reach that goal.

4. *Emotional arousal* – the state of emotional arousal can affect perceived self-efficacy in coping with threatening situations. Individuals may believe that high levels of emotional arousal will usually negatively affect their performance. Bandura (1977, p. 199) addressed this: “By conjuring up fear-provoking thoughts about their ineptitude, individuals can rouse themselves to elevated levels of anxiety that far exceed the fear experienced during the actual threatening situation.” Additionally, people often rely on their own interpretation of their physiological states to judge their own capabilities (Bandura, 1982). Gonzalez (Gonzalez et al., 1990) describes the importance of an arthritis patient reinterpreting their physiological signs and symptoms. For example, a patient with arthritis may interpret the *normal* amount of physical stress associated with exercise as an indication that their arthritis is getting worse. This may then negatively affect their efficacy for the exercise; they think they are exacerbating the disease and then choose to remain even less active. This decision can precipitate a negative cycle often seen in patients with arthritis: they have pain and stiffness; any amount of physical activity gives them the *perception* of increased pain and stiffness so they self-limit their activities. As a result they *do* become stiffer and the cycle continues. Health educators must seek to determine how their patients are feeling about their situation and what perceptions/misperceptions they may have about their status. Finally, it is critical that mixed messages not be sent to patients with arthritis. For example, if they have been told that their arthritis is from “wear and tear” on their joints and they are now being asked to exercise with those joints, it is understandable that the patients would be confused. Controlled exercise can actually be beneficial to

an arthritic joint, but this information must be conveyed to the patient in a clear manner.

Modeling behavior may be useful in demonstrating effective ways of handling painful, negative, or threatening situations (and in so doing can improve self-efficacy and teach effective coping skills). Learning to manage difficult situations is important because avoiding stressful activities may impede the development of coping skills. The individual who avoids dealing with difficult situations will lack the skills and competencies to deal with the situation and may therefore have even more of a basis to fear participating. This behavioral control not only allows one to manage aversive situations but affects how the person may perceive the environment. Since perception is so closely related to self-efficacy this perception can be critical to the level of efficacy that may develop.

In the context of dealing with a chronic disease like arthritis, self-efficacy has been found to be a very important tool for the patient (Lorig et al., 1996). Lorig expands on Bandura's concept of self-efficacy, pointing out that chronic diseases require more than just knowledge of what to do. Self-efficacy can include the individual developing his or her coping skills and developing cognitive strategies for managing a chronic disease, as well as believing in the ability to carry out such an integrated plan. Individuals also must have motivation to do so; i.e., they must believe that developing and carrying out such a plan will result in a positive outcome.

Lorig (Lorig et al., 1985) showed that patient interventions (i.e., developing a self-help program) in managing arthritis improved aspects of both health behavior and pain. Lorig was later surprised to discover the changes in health behavior were not directly responsible for the changes in pain (Lorig, Seleznick et al., 1989). Lorig found that most

of the changes in behavior were related to the patient's sense of control over their symptoms (i.e., a reduction in pain). Lenker first reported this relationship to the sense of control in 1984 (Lenker, Lorig, & Gallagher, 1984). Lorig operationally defined this sense of control as perceived self-efficacy (Lorig, Chastain, Ung, Shoor, & Holman, 1989).

#### *Factors Relating Efficacy to Short and Long-Term Adherence*

Another area of investigation examined factors relating efficacy to short and long-term adherence to exercise in the elderly population. Bandura (1977) defined self-efficacy as an individual's belief that he or she has the ability to successfully perform or complete a task. In a series of related studies based on the same sample and data, McAuley examined various aspects of the effects of exercise efficacy on short and long term adherence to exercise (McAuley, 1992, 1993; McAuley, Lox, & Duncan, 1993). In the first study in the series, McAuley used a social cognitive framework to examine perceptions of personal efficacy regarding adherence to exercise behavior and how those perceptions would apply to a sample of sedentary middle-aged adults over a course of a five-month exercise program (McAuley, 1992).

The sample consisted of 103 sedentary middle-aged adults. Participants in this quasi-experimental study received the same instruction and introduction into an exercise program. The exercise program was a low-impact aerobic program that met three times/week. Participants' self-efficacy was measured along with various physiological measurements. The study showed that during the early (adoption) phase of an exercise program, efficacy played an important role in getting the participants to implement a regular exercise behavior.

However as the exercise program continued over its five-month course, efficacy became less of a factor in adherence. The previous behavior (established frequency of behavior) was the key predictor of continued compliance. The overall conclusion was that self-efficacy is important in getting individuals started on an exercise program but continued adherence depends more on getting into the habit of regular exercise and making a behavioral change. At the end of this study McAuley hypothesized about what happens when the formal program ends, and what factors may be important for continued adherence to the new exercise behavior when the formal instruction/exercise sessions ends.

McAuley's question led to his next study, a quasi-experimental study that examined the role of self-efficacy in the maintenance of exercise participation four months after termination of the exercise program (McAuley, 1993). The same participants were used as in the first study. A structured telephone interview was given to the participants four months after formal program participation ended. Participants also received a Seven-Day Physical Activity Recall questionnaire. Self-efficacy predicted exercise behavior over a four-month follow-up period when other exercise factors (capacity, previous behavior, etc.) were controlled. Participants who were more physically fit (aerobically), who had greater self-efficacy regarding exercise, who did not perceive the exercise sessions to be too demanding, and who had regularly attended the exercise sessions were more consistent in maintaining their exercise programs four months after termination than those who did not fit those categories.

McAuley's third study in this series had two purposes: (1) To determine whether the physiological changes and physical self-efficacy changes brought about by the five



month exercise program had been maintained nine months after program termination, and (2) To determine what role self-efficacy may have played in the maintenance of the exercise program during the nine months after its termination. In this study, 44 of the original 103 participants made themselves available for testing nine months after the formal five-month exercise program ended. The authors stated that they believed this sample to be representative of the original, larger sample (McAuley, 1992). Collection measurements were made on physiological and efficacy measures as well as exercise behavior. The study showed significant declines in both physiological variables and self-efficacy nine months after termination of the program. In addition, repeating the graded exercise testing at that time did increase the participants' efficacy levels to the same statistical level they had achieved at the conclusion of the five-month exercise program. Exercise self-efficacy was found to be the only predictor of exercise adherence during the nine-month follow-up period.

To summarize the three studies, self-efficacy has been shown to be the main factor in helping an individual initiate an exercise program and in helping the individual continue with the program after the formal supervision has ended. During the intermittent period (in the middle of a long exercise program) efficacy is not as important as the habitual behavioral changes that have taken place. This study had several limitations. The small sample size was due to attrition over the nine-month follow-up period. While the authors stated that they thought this small sample was representative of the larger sample that had started the study, they presented no evidence to demonstrate the sampling equivalency. This lack of evidence could make it difficult to generalize the results. The authors also made the point that the participants who did volunteer to be retested nine months later

were ones who had probably been much more likely to continue with their exercise program.

Conn attempted to develop and examine the predictive ability of a model of exercise among older adults (Conn, 1998). Constructs of the model included self-efficacy expectation, outcome expectation, perceived barriers, perceived health, lifelong leisure exercise participation and age. The study consisted of 147 independently living adults aged 65 or older. Each participant was interviewed individually and asked to try and recollect their “personal events time line”. Using the time line as a basis they were then asked to try and reconstruct their level of personal activity during each decade of their adult lives. They were then administered scales to address the above noted constructs. Of all the variables examined, self-efficacy expectations had the strongest direct effect on exercise behavior in older adults. Barriers to exercise and age had significant negative effects on self-efficacy and, therefore, indirect negative effects on exercise behavior. Health status had a significant negative effect on barriers and also an indirect effect on exercise behavior. Conn further validated the importance and relevance of Bandura’s Social Cognitive Theory and self-efficacy. There were several limitations to this study. The author noted a major limitation: the subjects were asked to retrospectively reconstruct their leisure exercise activities up to 70 years earlier. There are obvious problems with verifying the accuracy of this information. Additionally, racial and educational characteristics of the sample were not provided. This may be a problem, especially since educational level has been shown to be a primary predictor of exercise behavior (Clark, 1995).

*Ethnicity and Arthritis*

Researchers have also examined the often complex role that ethnicity plays in the management of arthritis. In a recent study, Ibrahim et al examined how elderly white and African-American patients with severe hip and/or knee osteoarthritis rated their quality of life (QOL) (Ibrahim, Burant, Siminoff, Stoller, & Kwoh, 2002). After controlling for covariates (e.g., age, marital status, income, etc), African-American ethnicity significantly negatively impacts QOL compared to white ethnicity. In other words, older African-Americans with arthritis were significantly less likely to rate their QOL as excellent or good than were their white counterparts. This is obviously a complex issue and the authors were not sure why their sample responded as it did. The two largest predictors of QOL were the Geriatric Depression score and the Western Ontario McMaster Osteoarthritis Index score, or WOMAC. The study did have several notable limitations. A single question was used to measure participants' quality of life. The question may have been too broad to accurately assess the topic. In addition the authors state that there may have been inaccurate interpretations of the responses to the quality of life question (e.g., classification of quality of life based on a response of "excellent" vs. "very good" may have been inconsistent or inaccurate).

In an earlier study, Ibrahim et al compared elderly African-American and white patients with osteoarthritis of the knee or hip with respect to their perceptions of the efficacy of traditional and complementary treatments and their self-care practices (Ibrahim, Siminoff, Burant, & Kwoh, 2001). African-American patients were found to be more likely to perceive traditional modes of treatment as helpful but were less likely to perceive joint replacement surgery as a good option. Also, African-American patients

were more likely than white patients to use self-care measures were (e.g., home remedies) and prayer as an option for managing their arthritis. In other words, African-American patients with arthritis might be more amenable to self-care. The authors concluded that there are significant differences in the way older African-American and white males with arthritis perceive the efficacy of traditional and non-traditional treatment approaches to management of arthritis. These differences reflect cultural and ethnic differences and should be considered by health care providers in their interactions with these individuals.

Escalante et al compared the proportion of Hispanics among recipients of hip replacements for primary articular (joint surface) disorders, recipients of knee replacements for the same reason, and persons hospitalized for other reasons (Escalante, Espinosa-Morales, del Rincon, Arroyo, & Older, 2000). It was found that there are significant differences in utilization of hip and knee replacement surgery among ethnic groups. This study adjusted ethnic comparisons for socioeconomic status and access to care and still found that Hispanics were less likely to be recipients of total hip replacement surgery. This was not true of total knee replacement surgery or hospitalization for other reasons. The authors were not clear about the reasons for these findings but did suggest that further studies are indicated.

The role of ethnicity and patient health education has also been examined. In a review of the literature, Marin and colleagues summarized the outcome of health education efforts among populations that, due to their cultural heritage, have received limited services (Marin et al., 1995). The authors looked at the complexity of background factors that define any target population. All of these factors may influence the individual members of that population in a manner that may affect their ability and/or desire to

engage in health behaviors. These factors may also play a role in the individual's ability and/or desire to engage in and benefit from health educational programming. Health educators must take all of these factors into account when developing health education programs for under-served populations. A program that may be successful for one target population may not be expected to be equally effective for another.

### *Socioeconomic Status and Arthritis*

Socioeconomic status (SES) has been shown to be associated with arthritis in several ways: effect on functional status, severity of progression, health outcomes, and type of patient care delivered. While SES does seem to be a factor in the course and outcome of arthritis after it has been diagnosed, SES does not seem to be a risk factor in whether or not an individual may initially develop the disease. Bankhead et al evaluated the role of SES factors in susceptibility to rheumatoid arthritis in Britain (Bankhead, Silman, Barrett, Scott, & Symmons, 1996). The authors found that there was no relationship between incidence of rheumatoid arthritis and socioeconomic status. The results of this study may be generalized to the United States with caution. While there has been evidence of relationship between SES and progression and prognosis of RA, there does not seem to be a relationship between SES and initial incidence of the disease. The relevance of these findings is that rheumatoid arthritis seems to equally affect individuals of all socioeconomic statuses.

The incidence of osteoarthritis has been found to be more prevalent among those of lower socioeconomic statuses (Dexter & Brandt, 1993). As Dexter and Brandt point out, this finding makes sense as individuals with less education often find themselves in more

physically demanding jobs, which may lead to the higher incidence of joint wear and tear (and eventual development of degenerative osteoarthritis).

Socioeconomic status has also been examined as a predictor of eventual outcomes in patients with arthritis. Maiden et al, in a 12-year longitudinal study, assessed the relationship between SES and mortality in patients with rheumatoid arthritis in England and Scotland (Maiden, Capell, Madhok, Hampson, & Thompson, 1999). It was found that in patients with rheumatoid arthritis, increasing socioeconomic deprivation is associated with higher rates of mortality. Maiden concluded that lower socioeconomic states are often associated with poorer health behaviors (e.g., smoking, poorly balanced diets, housing, pollution, etc). In addition, the psychological burden of a chronic disease like rheumatoid arthritis may lead to even further stress and add to many of the cardiovascular risk factors (lack of exercise, obesity, etc). This is especially relevant since cardiac/circulatory disease was the leading cause of death in patients with rheumatoid arthritis in this study. The authors questioned the generalizability of their findings but believed it probable that there would be parallels in other Western countries. In an editorial, Pincus and Callahan considered the impact of rheumatoid arthritis on mortality rates (i.e., shortening the patient's life-span) (Pincus & Callahan, 1986). The authors examined various aspects of RA and how it impacts the patient's prognosis. Level of formal education has been shown to be a significant predictive marker for increasing both mortality and morbidity with RA. This is also true of lower socioeconomic status. Level of formal education has also been shown to be a predictive marker for frequency of RA and other chronic diseases. The relationship between formal education and arthritis will be discussed in greater detail in the next section.

The role that SES plays in the course of rheumatoid arthritis may be complex.

Berkanovic et al examined the role of socioeconomic status and recently diagnosed rheumatoid arthritis (Berkanovic et al., 1996). The authors sought to examine the role of SES in physical pain, depressive symptoms and functional status in patients who were newly diagnosed with RA and who were classified as having severe disability. The authors tried to control for the effects of health status and non-SES related social structure (age and gender), so that they could examine any independent effects of SES on pain, functional status and depressive symptoms. In addition, health status was described as a combination of disease status and comorbidities. The results of this study were somewhat contradictory. Age, gender and SES were found to be independent predictors of functional disability and depressive symptoms. However, age, gender, SES and health statuses were unrelated to pain. Additionally, neither disease activities nor comorbidities (related disease activity) could be explained by income or by level of education. There may be a number of possible explanations for this. One is that because the occupation of respondents' head of households was not included, the SES measurement in this study may not have been accurate. In addition, the mean education and household incomes of the respondents in this study were above the U.S. mean and may affect generalizability of the results. Another factor is that the respondents in this study were generally younger and were very early in their disease process. It was hypothesized that these individuals exhibited more depressive symptoms because their disease came at an unexpected time in their lives and they were still dealing with the shock, denial and anger of their diagnosis.

Young and colleagues assessed how socioeconomic deprivation influences the presentation, treatment, and outcome of patients with rheumatoid arthritis (Young et al.,

2000). It was found that while there is no evidence that lower SES contributes to the initial development of RA, it does correlate with more severe signs and symptoms (e.g., joint swelling) early in the progression (within six months from onset of symptoms) than in patients from higher SES. Also, progression of the disease over the first three years tended to be greater in patients from low SES. Upon beginning medical intervention for their arthritis, patients with lower SES did not improve as much after initial Health Assessment Questionnaire scores (HAQ) as did higher SES patients. Low SES patients who were most affected tended to be women and older patients. These findings suggest that patients who are diagnosed with RA in the early stages and are known to have low SES status may need to be targeted for more aggressive intervention (including patient education and support).

The role of socioeconomic status on levels of functional disability in patients with arthritis has also been examined. McEntegart and colleagues attempted to determine what role social deprivation had on disease severity, functional disability, and outcome in English patients with RA (McEntegart et al., 1997). The authors found that patients who had rheumatoid arthritis and lived in the most deprived areas tended to have the poorer functional status. This status was defined as their scores on the Health Assessment Questionnaire, or HAQ. The HAQ is a measure of functional disability and is also predictive of morbidity and death rates in five to ten years (McEntegart et al., 1997). Thus neither the current functional status nor the outlook for functional improvement is good for these individuals from socially deprived areas. The authors proposed that patients from more deprived areas do not consult their doctor until their symptoms become more severe; their counterparts in more affluent areas are more likely to consult



their physicians sooner and for less severe symptoms. The poor functional outcome may be related to factors such as crowded living conditions, smoking and other poor health behaviors (poor diet, association of overcrowding with infection, etc). In summary, the data showed a definite trend toward more severe disease activity and poorer functional status in patients from more socially deprived areas (in England). It should be noted that there was a lack of demographic information given in this study (e.g., gender, educational level, etc). Therefore generalizing the results, especially from Great Britain to the United States, might be somewhat difficult.

In a nine-year longitudinal study, Reisine et al evaluated the association of demographic, disease, workplace, social, and household factors with the ability of patients with rheumatoid arthritis to remain employed over time (Reisine, Fifield, Walsh, & Feinn, 2001). It was found that continuing to work was more closely associated with the patient's age, characteristics of the job, i.e. physical demands, prestige (blue vs. white collar), educational level and time missed from work rather than the disease factors. It is notable that clinical data were collected only during first three years of the study, and the patients' medical conditions may have changed over the remainder of the study. The relevance of these findings is that patients with RA may continue to work if the job situation is appropriate for them to do so. Kessler et al found that while cancer was by far the leading cause of impairment and missed days of work due to a chronic medical condition, arthritis was one of the comorbidities that were associated with higher than expected levels of impairment (Kessler, Greenberg, Mickelson, Meneades, & Wang, 2001).

The role that SES may play in treatment of patients with arthritis has also been

examined. Dexter and Brandt examined the relationships between socioeconomic status and medical care in older patients with symptomatic osteoarthritis of the hip or knee (Dexter & Brandt, 1993). The medical care examined was the prescription and encouragement in the performance of therapeutic joint exercises. When stratifying education and level of impairment, care was comparable for all groups except for individuals who were more impaired and had greater than a high school education. These individuals received better physician instruction in terms of exercise and were the only group with a self-reported frequency of exercise that would approach a therapeutic level (at least three times/week). This discrepancy in level of physician attention occurred despite the fact that African-Americans and less educated patients had more physician contact than their better-educated counterparts. This increased physician contact did not translate into more medical advice about exercise. These findings may be related to the assertiveness of the different groups. The more educated patients (when more severely impaired) may tend to be more proactive about their care. In turn, this may translate into their being more assertive about asking for exercises and their physicians responding to that interest by providing the patients with more detailed exercise instruction and supervision.

#### *Level of Formal Education and Arthritis*

The relationships between adult literacy levels, formal education and arthritis have been examined. Davis and colleagues reviewed the literature and screening assessments relative to adult literacy and discussed their applications in different health care settings (Davis et al., 1998). The conclusion was that about twenty-one percent of Americans are functionally illiterate (read at lower than an eighth grade level) with another twenty-seven

percent of the population having marginal literacy skills. These findings have obvious relevance to patient education, home exercise and disease management programs (especially written materials), and prescription information and labels. Gordon and colleagues attempted to determine the prevalence of illiteracy on patients with rheumatoid arthritis and the impact of illiteracy on the severity and functional levels of the disease (Gordon et al., 2002). The authors utilized the Rapid Estimate of Adult Literacy in Medicine instrument, or REALM. The participants in the British study were 99% white and had an average age of 56 (range 19 – 77); no other demographic information was provided. The findings were that fifteen percent of the sample had REALM scores equivalent to functional illiteracy (and demonstrated the need for low-level literacy materials such as patient education handouts, etc). This REALM score correlates with seventh to eighth grade reading levels in the United States. It was shown that the illiterate patients had significantly more hospital visits than the literate patients did but there was no difference in functional levels. Low literacy rates have been shown to be significantly associated with lower socioeconomic statuses (Gordon et al., 2002). These findings support the idea those patients from lower socioeconomic statuses and less literate patients may benefit from telephone interventions. Individuals from lower SES may be less likely to comply with written educational materials provided for self-management at home.

Formal education may be a prognostic indicator for rheumatoid arthritis (Pincus & Callahan, 1985). In a longitudinal nine year study, higher mortality in patients with rheumatoid arthritis was significantly correlated with lower levels of formal education. While the authors noted that this finding was consistent with higher levels of mortality

and lower educational levels in the general population, they believed that this study was the first to control for many confounding factors (e.g., age, smoking history, years of disease duration, functional levels, etc). In other words, they believed that the association between formal education and mortality in the individuals studied was significant. The authors did not believe that formal education could necessarily directly explain the mechanism of mortality in patients with rheumatoid arthritis. Rather, they believed that level of formal education could serve as a composite for variables such as access to medical care, income, levels of responsibility for their own health care, problem solving abilities, willingness to be adherent with medical advice and management. Katz agreed with Pincus' findings, concluding that lower levels of formal education should not be seen as a direct cause of increased mortality and morbidity in arthritic patients but rather as a composite of numerous factors that are responsible for poor health outcomes (Katz, 1998). Leigh and Fries investigated occupation, income and education as independent covariates, or risk factors, for prevalence and severity of arthritis (Leigh & Fries, 1991). It was shown that years of formal education completed is perhaps the single variable that best describes SES; this in turn is associated with the prevalence and perhaps the progression of arthritis. However, occupations are also a significant part of the problem and must be considered as such. Specific physical occupations such as football, ballet, construction, etc. are often linked with specific types of arthritis. Finally, in a descriptive survey, Callahan et al examined the relationship between health status and level of formal education in patients with five different types of rheumatic diseases (including rheumatoid and osteoarthritis) (Callahan, Smith, & Pincus, 1989). It was found that the level of formal education was significant; in all five-disease categories, patients who had

not completed high school had poorer clinical status than did patients who had completed high school. Significant differences were seen on 24 of 30 comparisons according to education levels; the only other variable associated with significant differences was age (two comparisons).

While level of formal education may be used as a prognostic marker for arthritis, it may also play a role in arthritis management and treatment. Criswell and Katz attempted to determine whether treatment received for rheumatoid arthritis is systematically different among individuals with different levels of formal education (Criswell & Katz, 1994). In other words, do individuals with different levels of formal education receive different treatment? They found that in general, individuals with low levels of education did not receive different medications (i.e., specific medications for arthritis) or receive specific patterns of medication. There was a significant difference, however, in patterns of hospital use and surgical treatment. Patients with higher levels of education were more likely to be hospitalized and undergo surgery for treatment for their rheumatoid arthritis. This difference was true even after statistically controlling for variables such as age, race, gender, income, marital status, insurance and co-morbidities. The association of education levels with outcomes of treatment for rheumatoid arthritis may at least be partially explained by better educated patients using health services in an increased manner compared to less educated patients with arthritis.

The level of formal education can impact occupational status in patients with arthritis as well as individuals who do not have the disease. In an extensive population based survey of over 5600 individuals, Mitchell, Burkhauser and Pincus examined three relevant areas: (1) the disability and work status of patients with symmetric polyarthritis

compared to those without; (2) the differences in income between both groups, and (3) how much of the income difference can be explained by the arthritis (compared to age, level of education, etc.) in people with and without the disease (Mitchell, Burkhauser, & Pincus, 1988). Population-based data were used to try to determine the magnitude of arthritis-related work disability. The authors use symmetric polyarthritis as a surrogate for rheumatoid arthritis. Symmetric polyarthritis describes an individual who has pain and/or swelling in at least four joints, including at least two pairs on each side. The authors found that a significantly higher percentage of the population with symmetric polyarthritis had work disability compared to the population without the disease (26% in women, 47% in men). However, after applying regression analysis it was determined that only about one-third of the income gap between individuals with and without arthritis could be explained by the presence of the disease. The other major additional explanatory variables included age, formal education level, and comorbidity (or the presence of other diseases and/or health problems).

#### *Patient Education and Arthritis*

Patient education, as defined by Lorig and Gonzalez, is defined as “a set of planned educational activities intended to improve patients’ health behaviors and/or health status, or retard deterioration from disease” (Lorig & Gonzalez, 1992). The role of patient education in the treatment and management of arthritis has been examined extensively in the literature. In a 1995 editorial, Lorig examined the dilemma facing patient education in the management of arthritis (Lorig, 1995). The primary problem is that patient education is “tremendously underutilized” despite the fact that it has been shown to be a cost-effective treatment (without the side effects associated with many medications). In

addition, patient education may be added to the other medical interventions an arthritic patient receives. Lorig discussed the three primary causes for this underutilization. The first is that patient education programs are not often part of the normal delivery of medical practice in the treatment of arthritis. In other words, the physician usually does not have the time or the educational expertise to conduct such a program. Another problem is that many patients with arthritis do not receive medical care for their condition (i.e., seeing a doctor or a physical therapist). Most patients who do participate in educational programs do so through the efforts of their care providers. Therefore not receiving any care or intervention may be a barrier to receiving the educational intervention. A third significant problem with implementing patient education in the management of arthritis is the lack of funding for such programs. Funds are scarce, and often governments and other funding agencies must choose between funding intervention programs or research programs. While the cure for arthritis is a desired goal, it is difficult to cut funding for intervention programs that can result in immediate reduction in patient symptoms (e.g., programs that may help finance anti-inflammatory or pain medications for patients who would not otherwise be able to afford them). However it may be easier to reduce funding of an educational program that does not demonstrate the same immediate patient benefits as the medication does. As Lorig concludes, “the problem is that patient education is still considered a nice extra, not an effective treatment” (p. 706). Lorig’s editorial may also relate to the present study. One reason for the underutilization of patient education in the management of arthritis is that some patients simply do not participate in currently existing programs. The reasons for this lack of participation may be logistical, financial or otherwise. Investigating the effectiveness of alternative and

more patient friendly means of education should be done. Funding has also been cut for patient educational intervention programs for other conditions, such as diabetes (Rickheim, Weaver, Flader, & Kendall, 2002).

Goeppinger and Lorig's review of the literature discussed the role of patient education on eventual outcomes for patients with arthritis. They concluded that "...Only a few of the studies measured changes in knowledge alone. Exercise continued to be the most widely measured behavioral outcome, although self-care behaviors generally and specific pain relief and stress reduction behaviors were also studied. And, the trio of clinical outcomes termed the 'gold standard' of arthritis outcomes research – pain, function/disability, and depression – were consistently measured and either found to be improved (pain and depression) or unchanged (function/disability)" (Goeppinger & Lorig, 1997). Goeppinger and Lorig drew three major conclusions about the cumulative effects of the development of arthritis patient education. The first was that patients identified their problems, and educational interventions (using theoretical frameworks) were developed that focused on those problems. This was a change from the more traditional approach to patient education, where it was externally decided what patients needed and programs were then established based on those perceived needs. A second conclusion was that while community based arthritis education programs were found to be effective in certain populations (i.e., more educated and higher SES groups) there was a lack of evidence in the literature for its effectiveness in less educated minority groups. The need for further research in this area continues to exist in 2003. Finally they concluded that the educational interventions in existence need to continue to be evaluated in a detailed and systematic manner in order to ascertain which components of these



programs may be most responsible for improvements in functional outcomes

Formal patient education is not usually done unless it is part of the medical management of arthritis. The educational component usually augments the larger treatment plan. The effectiveness of patient education in enhancing the effectiveness of the medical management and patient satisfaction with their treatment has been studied. Branch et al performed an experimental study in an attempt to determine whether a patient educator could have a positive impact on the patient's health status, knowledge of their disease and satisfaction with their care (Branch, Lipsky, Nieman, & Lipsky, 1999). Branch discussed arthritis patients' widespread dissatisfaction with the care they receive from their physicians, and attempted to determine if intervention from a patient educator combined with standard medical care could improve patient knowledge and increase satisfaction with their care. All patients received baseline measurements for arthritis self-efficacy and functional status. The control group received no intervention over the next eight weeks, and then repeated their measurements. The intervention group received a 10-30 minute personal visit with a patient educator, followed by one follow-up phone call one week later. During the personal visit the patient educator provided information about the diagnosis, peer support and counseling. The follow-up phone call was used to determine whether or not the patient had any questions since their physician visit. Eight weeks after the physician visit the intervention group exhibited greater knowledge of arthritis. This was evidenced by their scores on a basic arthritis knowledge test, an instrument that contained six questions (e.g., "What type of arthritis do you have?"; "What medications/interventions are being used for your arthritis?"; "Name two things you can do – other than taking medication – to help with your arthritis?", etc.). In

addition, the intervention group was more satisfied with their care than the control group (as shown by their scores on a *Satisfaction with Services* questionnaire). There was no change in functional status or arthritis self-efficacy. A substantial number of the control group (16%) who did not have any intervention with the patient educator spontaneously requested a future meeting with the educator. Branch noted that even after a short period of time (eight weeks) the results showed that patient educators could have a significant impact in rheumatology care, primarily by helping to increase a patient's knowledge about their condition and satisfaction with their care. Branch also proposed that these changes might have been greater if the patient had more interactive experiences with the patient educator than just one phone call. Branch discussed the relevance of the follow-up phone call. It was noted that open-ended phone calls tend to be more effective in helping patients to discuss their life stresses. It was believed that it was not possible to determine whether the positive effects noted in the control group at the end of the study were due to the phone calls, the personal interaction with the patient educator, or some combination of the two. It was again noted that while there was not a significant change in functional status (i.e., no change on the functional status measurement) the patients in the intervention group indicated that they had received better overall care. The relevance to the current study is that the study utilized repeated phone interventions rather than just one, and there was not a difference in personal interactions with the patient educator between the control and intervention groups. Branch concluded that arthritis patient educators might play a vital role in helping patients with both newly diagnosed and chronic arthritis in understanding and managing their condition. Branch's study provided virtually no demographic or descriptive information about the sample studied, making

generalization difficult.

Patient education can be important in enhancing patient satisfaction with their care, but education may also offer aid in diminishing pain and increasing function. Superio-Cabuslay and colleagues compared the effects of educational interventions and the effects of non-steroidal anti-inflammatory medications (NSAIDS) on pain and functional disability in patients with OA or RA (Superio-Cabuslay, Ward, & Lorig, 1996). NSAIDS are drugs (e.g., Motrin) that are commonly used for pain relief with inflammatory conditions. Nineteen patient education trials were analyzed. From these trials, two meta-analyses were performed. One examined patient education trials using controls. The other examined the placebo controlled effects of using NSAIDS for arthritis management. The authors found that patient education interventions can significantly enhance medical management of arthritis. It was shown that for patients with rheumatoid arthritis, educational intervention can provide an additional 20% to 30% of pain relief and an additional 30% to 40% improvement in functional disability to that already provided the patient by NSAIDS. In patients dealing with osteoarthritis, patient education interventions can provide another 20% to the pain relief achieved with the use of NSAIDS (education did not have a significant effect on functional disability in patients with OA). The authors believe that these results further strengthen the case for the increased utilization in patient education in the management of arthritis.

Goeppinger and Lorig examined the importance of community-based arthritis education programs. They noted that these programs not only benefit the patients, but clinicians as well. Clinicians may benefit indirectly by being able to refer their patients to arthritis education programs that are established, accessible and affordable. These

programs may supplement the more traditional medical interventions that the patients may be receiving for their arthritis (Goeppinger & Lorig, 1997).

### *Learning Styles and Patient Education*

Chase reviewed major learning styles and how they might be relevant to teaching and learning in the home healthcare setting (Chase, 2001). It has been shown that most adults have a predominant learning style. Some individuals are predominantly visual learners and would benefit from the use of pamphlets, charts, videos, and other visual teaching materials. Ideally, in the home healthcare setting these materials would be accompanied (or followed up by) a clinician/educator who can help address any questions that the patient might have. Learning information over the telephone, with little or no visual information or demonstration, may not provide an optimal learning environment for these patients. Other individuals are predominantly auditory learners. These learners like the lecture/discussion format of a classroom setting. They may need to verbally repeat new information given to them as they try to process it. This individual would potentially do well with teaching via telephone intervention. A third common learning style is that of the kinesthetic learner. These individuals need to feel in touch with the world around them. They do well when they can view a demonstration of new information or self-care techniques and then do it themselves. Telephone intervention might not be optimal for a home healthcare patient with a predominantly kinesthetic learning style.

Arndt found that learning style is not static, and individuals may actually modify or even change their learning style over time (Arndt & Underwood, 1990). It is important for teachers to be aware of their students' learning styles and try to devise learning strategies that will meet the needs of the learners in that group. In any group it is likely

that the learners in that group will fall into different learning styles. A teacher who tends to exclusively teach in only one strategy may well be missing opportunities to more effectively teach learners who have different strategies from his or her own. Arndt discussed strategies for learners who fall into one of four commonly identified learning strategies: divergent learners, assimilative learners, convergent learners and accommodative learners. Learners in each of these groups can certainly learn effectively in their own way, but their styles of learning may differ to the point where effectively teaching a group with learners of contrasting styles can be challenging. Health care providers (e.g., nurses, therapists, etc.) do not typically receive a basis in educational strategies in their professional programs. Chase agreed with this finding that home healthcare providers (e.g., nurses) often find themselves in key positions as patient educators. It has been pointed out that these clinicians have not always received adequate training in how to best serve in that role for their patients (Chase, 2001).

#### *Patient Education in the Home-Health Setting*

Teaching and learning in the home environment may be quite different from that which occurs in the more controlled classroom (or even clinic) setting (Duffy, 1998). The home setting is often unpredictable when compared to the classroom: lighting may be inadequate, the physical environment (temperature, etc.) may be less than ideal for learning, distractions from family members and others may be ever present, etc. In addition, when the teaching and learning involves an older individual who is medically compromised (i.e., arthritis and its accompanying pain) the challenges to learning may be even greater. Ideally, the needs of learners in any situation should be determined to aid in designing the educational program most appropriate for that individual (Duffy, 1998).

This assessment would include the individual's cultural, psychological, physical and cognitive backgrounds, in addition to any other factors that may be relevant. This type of individual assessment may not always be possible in the home healthcare environment, where the economics and logistics of healthcare delivery may dictate that patient education becomes "one size fits all". Rickheim et al conducted a randomized, study comparing the effects of group and individual patient education for patients with diabetes (Rickheim et al., 2002). The study revealed those patients in either individual or group education experienced similar improvements in learning and behavioral outcomes.

#### *Telephone Intervention and Arthritis Management*

The use of telephone intervention in the delivery of health care has been widely examined. The telephone works both ways: health care providers and educators can call the patient to offer advice and encouragement, remind them of upcoming appointments, etc. while patients and clients can call for information that may be general in nature or specific to their condition. Maisiak attempted to estimate the percentage of users who may undertake potentially beneficial health actions after contacting an arthritis phone help-line, to identify which actions these might be and to identify which types of help-line users might be most likely to take such actions (Maisiak, Koplon, & Heck, 1990). It was found that about half of the respondents believed that they were more in control of their arthritis because of using the phone service. This control was correlated with taking at least one positive health action. It is difficult to draw any strong conclusions due to the descriptive and uncontrolled design of this study. In a related descriptive study, Maisiak et al sought to identify individuals who would seek information about arthritis, to classify and estimate their needs for arthritis information, and to examine the relationship

between their characteristics and their informational requests (Maisiak, Koplon, & Heck, 1989). This descriptive study found that the largest percentage of callers to the information service were disproportionately female, white, well educated and symptomatic. Additionally, the main reason they called was for emotional support followed by requests for information and advice about managing their arthritis. The authors concluded that special efforts might need to be made to reach non-white and less educated individuals and to provide emotional support.

The use of telephone intervention in the delivery of health care is often related to reducing health care costs. Weinberger et al evaluated the cost-effectiveness of telephone intervention for patients with osteoarthritis (Weinberger, Tierney, Cowper, Katz, & Booher, 1993). Telephone contact was found to be a cost-effective means of communicating with patients. This study showed that the costs of administering a phone intervention were negligible (about \$14/year in 1987 costs). The study also showed that over the six month period of the study the patients not receiving the phone calls had poorer functional measurement scores and more pain at the end of the six months than at baseline. The patients who did receive phone calls had better functional measurement scores and less pain at the end of the study than at baseline. In other words the telephone intervention had a positive effect on functional status.

Numerous studies have examined the effectiveness of telephone intervention in comparison to personal intervention in the delivery of health care. Fenig et al compared telephone intervention to face to face interviewing in a community psychiatric survey (Fenig, Levav, Kohn, & Yelin, 1993). The relevance to the current study is Fenig's observations and analyses of telephone interventions. A potential advantage of using the

telephone is that the telephone enables access to otherwise hard to reach individuals (due to their work schedules, living in dangerous locales, being uncomfortable with face-to-face interviews, etc). A potential drawback to the use of telephone interventions is that bias may result from excluding individuals who may not have telephone service. Korner-Bitensky and colleagues, in a 1994 cross-sectional analytic study, attempted to determine the usefulness of a telephone administered health status questionnaire as an epidemiological survey instrument in high-risk groups, and to evaluate the value of a telephone interview for making judgements about individual patient management (Korner-Bitensky, Wood-Dauphinee, Siemiatycki, Shapiro, & Becker, 1994). It was found that many of the individuals interviewed by phone had questions or expressed uncertainties about their medications. Since lay interviewers did most of the interviews in this study, the authors felt that it might have been useful if a nurse or someone knowledgeable about medication use would have been available. This consideration is especially important since much of the older adult population is at risk for misusing medications. The study did not show a significant difference in rate of participation when lay interviewers conducted the interviews as compared to health professionals. Individuals with moderate to severe disability were found to less frequently report their level of disability over the telephone. The authors were concerned with the discord between home (i.e., face to face) and phone interview groups in reporting these severe disabilities. This indicates that exclusive use of phone monitoring might not be ideal for some patients. In other words, if there is reason to believe or suspect that a patient's condition may be more severe than he/she may be reporting on the phone, additional surveillance or home monitoring may be useful. The overall conclusion of the study was



that the telephone interview might be a useful and alternative approach to monitoring some patients.

Wasson et al examined the hypothesis that substituting clinician-initiated phone calls (phone care) for some clinic visits would reduce medical care utilization without adversely affecting patient health (Wasson et al., 1992). This randomized, two-year experimental study found that substituting phone care for some (selected) clinic visits significantly decreased utilization of medical services. Health status may be increased and mortality may be reduced by increased phone contact with very ill patients. In a similar study, Weinberger et al tested the hypothesis that telephone intervention that provided information to patients with OA and improved access to their health care provider would improve their functional status (Weinberger, Tierney, Booher, & Katz, 1989). The authors also compared alternative versions of the intervention that varied in cost and ease of administration. It was found that the group that received telephone intervention had less pain and functional disability and had a trend toward improved psychological status compared to the other groups (who had received face to face intervention). The participants in this study were predominantly African-American females from lower socioeconomic statuses and had an average of nine years of formal education. Weinberger proposed several explanations for these findings. One explanation was that the “phone-intervention only” groups actually had more interventions than the “clinic-visits” group did. Another possible explanation was that there was greater consistency in interviewers with the phone-only group as compared to the clinic-visit group (i.e., greater chance to develop supportive relationship with the interviewer in the phone group). The visits may have been more interrupted in the clinic than on the phone

interviews. Finally the personal contacts may have been interpreted as being more “threatening” or intimidating to the patients than were the telephone contacts. Maisiak, Austin and Heck examined health outcomes of two telephone interventions for patients with RA or OA (Maisiak et al., 1996). The purpose of the study was to extend the research on telephone contact to patients with RA, to evaluate two strategies of telephone contact (patient counseling vs. symptom monitoring), and to determine the effect of telephone contact on different health outcomes and on the frequency of physician visits. It was found that the overall health status of patients with RA or OA in the treatment counseling groups improved significantly compared to the control group (no phone intervention). The use of symptom monitoring techniques was not as effective as the treatment counseling techniques in decreasing number of physician visits. Rene’ et al examined whether telephone intervention improved functional status among patients in whom neither changes in their arthritis medications nor additional physical therapy were prescribed (Rene', Weinberger, Mazzuca, Brandt, & Katz, 1992). The findings support periodic phone interventions as being of significant benefit as an adjunctive treatment for knee osteoarthritis, especially for inner city patients.

Telephone intervention has also been compared to mail interventions in the delivery of health care. Castro et al evaluated phone and mail-mediated interventions on physical activity maintenance in (healthy) middle-aged and older adults (Castro et al., 2001). The group studied was predominantly white, well educated and healthy. It was found that in terms of exercise maintenance, participants in higher intensity groups who received only mail intervention tended to have higher maintenance rates than did corresponding participants who received both mail and phone interventions. Participants in lower

intensity groups maintained steady level of exercise regardless of type of contact (mail only vs. both mail and phone intervention). In the arthritis population, a mail-delivered arthritis self-management program has been shown to be effective in positively affecting patient outcomes and can decrease utilization of medical resources (Barlow, Pennington, & Bishop, 1997; Fries, Carey, & McShane, 1997).

The effects of telephone intervention on health outcomes have been investigated. Austin et al examined the effectiveness of two telephone intervention strategies for improving health outcomes of patients with systemic lupus erythematosus (SLE), considered a rheumatologic disease (Austin, Maisiak, Macrina, & Heck, 1996). The two phone intervention strategies used were telephone counseling and symptom monitoring. The main findings were that telephone counseling had a significantly stronger effect on social support and physical functioning than did just symptom monitoring. Both types of phone interventions improved scores on fatigue and fatigue self-efficacy; the only factor that was strongly associated with health outcomes was fatigue self-efficacy. The findings from this study of patients with SLE may be generalized to the arthritic population. There appears to be great similarity between the manner in which self-efficacy can affect patients' health outcomes with either condition. Lorig described the relationship of arthritis self-efficacy and its importance in affecting behavior and outcome (Lorig, Seleznick et al., 1989). In the SLE study and in Lorig's study of patients with arthritis, phone interventions were associated with significant improvements in fatigue self-efficacy, or the individual's confidence in being able to function despite their fatigue levels. According to Austin, "...findings suggest that telephone counseling may be effective because it improves the patient's confidence in the ability to control fatigue (or

arthritis) rather than because of improvements in communication or social support” (Austin et al., 1996). In addition, social support was moderately associated with health outcomes; the phone interventions had a positive but non-significant effect on levels of arthritis pain. Finally, Austin et al.’s findings support the theory that simply monitoring functional symptoms can improve the health status of patients with arthritis. There were some limitations to this study. It was not clear how frequently participants were called, how long the calls lasted, etc. There was not a true control group but this study was based in part on an earlier study by the same group in which there had been a control (i.e., phone vs. no phone) (Maisiak et al., 1996). The sample was predominantly white and well educated; the results may therefore be difficult to generalize to minority or lower SES groups.

A final observation is that, in general, telephone intervention has been shown to have the most significant impact on patients’ perceived functional status when the contact deals primarily with stress-related issues. Phone contact that is more specifically focused on specific health issues (e.g., scheduling changes, questions about medications, etc) has not been as effective in affecting perceived functional status (Weinberger, Hiner, & Tierney, 1986; Weinberger, Tierney, Booher, & Katz, 1991).

Summaries of relevant phone call intervention studies for patients with arthritis follow.

<i>Authors</i>	<i>Date</i>	<i>Phone call methodology</i>	<i>Findings</i>
Weinberger et al Weinberger et al Weinberger et al Rene' et al	1989 1991 1993 1992	<ul style="list-style-type: none"> <li>Used non-medical personnel as callers</li> <li>Phone calls reviewed with participant:               <ul style="list-style-type: none"> <li>-medications (side effects, etc)</li> <li>-joint pain</li> <li>-gastrointestinal symptoms</li> <li>-early warning signs of hypertension, heart disease, diabetes, chronic obstructive pulmonary disease (when appropriate)</li> </ul> </li> <li>Sample predominantly African-American, low levels of education &amp; low SES.</li> </ul>	In general, telephone interventions for patients with arthritis were found to report better health and less pain than patients who had not received the phone calls. Phone interventions were also found to be a cost-effective means of communicating with patients.
Maisiak et al	1996	<ul style="list-style-type: none"> <li>Used two phone strategies:               <ol style="list-style-type: none"> <li>1. symptom monitoring (SM)                   <ul style="list-style-type: none"> <li>-very structured</li> <li>-could not give additional advice</li> <li>-patient could not ask additional questions</li> </ul> </li> <li>2. treatment counseling (TC)                   <ul style="list-style-type: none"> <li>-more elaborate and multifaceted than SM</li> <li>-6 categories of patient behavior were targeted for potential change</li> <li>-used Reality Therapy as a model</li> </ul> </li> </ol> </li> <li>Sample predominantly white, well-educated</li> </ul>	The health status of both groups (SM and TC) improved compared to control, but improvement was significantly greater in TC group than SM group.
Mazzuca et al	1997	<ul style="list-style-type: none"> <li>Calls were unscripted (5-10 minutes long)</li> <li>Calls were made at 1 week and at 1 month</li> <li>Calls were structured to ensure that:               <ol style="list-style-type: none"> <li>1. patient compliance with self-care recommendations was assessed and reinforced; any patient misconceptions were clarified</li> <li>2. Continued patient participation in the study was encouraged</li> </ol> </li> <li>Sample predominantly Black; low SES; avg. education = 9.7 years</li> </ul>	<ul style="list-style-type: none"> <li>The short-term effects of decreased disability and perception of pain compared well to results from participants in the ASMP.</li> <li>Study did not examine arthritis self-efficacy</li> <li>Sample had low SES, and educational levels (described as "inner city")</li> </ul>

(table continued)

Thomas et al	2002	<ul style="list-style-type: none"> <li>• Monthly calls</li> <li>• Offered simple advice on knee pain</li> </ul>	Provided a control for the psychosocial contact inherent in delivery of exercise program.
Austin et al	1996	<ul style="list-style-type: none"> <li>• Worked with lupus patients</li> <li>• Used TC vs. SM phone intervention strategies:               <ol style="list-style-type: none"> <li>1. TC encouraged patients to ask questions, talk about their feelings and problems, etc.</li> <li>2. SM used strict question &amp; answer format; no patient counseling was done with SM group</li> </ol> </li> </ul>	<ul style="list-style-type: none"> <li>• TC had significantly stronger effect on social support and physical functioning than SM</li> <li>• <i>Both TC and SC interventions improved scores on fatigue and fatigue self-efficacy</i></li> <li>• The only factor that was strongly associated with health outcomes was fatigue self-efficacy</li> </ul>
Castro et al	2001	<ul style="list-style-type: none"> <li>• Study compared effects of telephone vs. mail intervention for maintenance of physical activity</li> <li>• Content of phone contact focused on strategies derived from Social Cognitive Theory; strategies designed to change behavior; strategies included:               <ol style="list-style-type: none"> <li>1. active problem solving of identified barriers to physical activity</li> <li>2. self-monitoring of progress</li> <li>3. discussion of motivation factors such as social support and self-rewards for increases in physical activity</li> </ol> </li> <li>• Callers adhered to a standardized protocol and phone script developed for the project</li> </ul>	Once telephone counseling has helped to successfully adopt physical activity, less intensive interventions are successful in helping older adults maintain their level of activity.
(table continued)			

Korner-Bitensky et al	1994	<ul style="list-style-type: none"> <li>• Phone calls were mainly used as interviews</li> <li>• Purposes of study were to assess usefulness of phone interview as an epidemiological instrument and to evaluate value of phone interview in making judgement about individual patient management.</li> </ul>	Overall conclusion was that the telephone interview might be a useful and alternative approach to monitoring some patients. It was suggested that lay people might not be able to answer all patients' questions about medications, etc.
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### *Summary*

In summary, the purpose of this study was to use telephone interventions on two clinical groups and two control groups to examine changes in self-efficacy in arthritis management, as well as ratings of depression and numeric self-ratings of pain and fatigue. Effective self-management of arthritis has been linked to reduced perception of pain, better functional status and an increased sense of control over the disease process. Programs to improve self-care techniques have focused on increasing patient knowledge and self-efficacy using the concepts of the Social Cognitive Theory. Research has often focused on developed programmatic efforts, which have been successful in higher SES, white and better educated individuals with arthritis. However, there is some precedent for developing these kinds of interventions with other populations and through other means. Research to date with the telephone methodology has not examined whether arthritis self-efficacy can be improved. The current study examined whether the telephone method is effective for patients from two different clinics, one of which represents an understudied population in the self-care literature and whether this method will increase self-efficacy and be associated with corresponding changes in pain perception.

## CHAPTER THREE

### METHODOLOGY

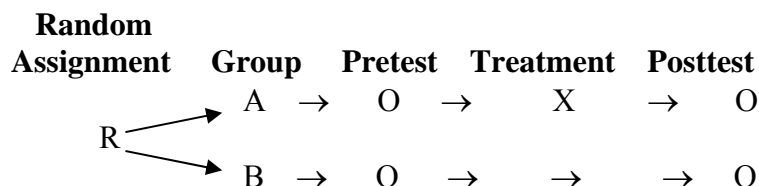
This chapter presents the study design, methodology, and procedures for data analysis. The content of the telephone intervention will be described. The instrumentation used in the study will also be discussed. The chapter is divided into the following sections: study design, sample description and selection criteria, instrumentation, data collection procedures, and data analysis procedures.

#### *Study design*

The basic design of this study was an experimental, pretest-posttest control group design. Participants were randomly assigned to one of two groups, each group was given the same pretest measurements, intervention was given to one group, and then posttest measurements were taken on each group. This design has been shown to be effective in controlling for common threats to internal validity: selection, statistical regression, pre-testing and maturation (McMillan & Schumacher, 1997). The design is diagrammed on the following page.



### Pretest-Posttest Control Group Design



The study was also a combined quantitative and qualitative design. The differing methods of data collection and analysis utilized in this study necessitated a combined study design. As described by Creswell, the study was a “more dominant-less dominant” design (Creswell, 1994). In this format, a dominant paradigm is used (the quantitative component) and a smaller component of the study becomes the alternative paradigm (the qualitative component). The nature of this study made a combined design the optimal means of data collection and analysis. The dominant portion of the study design was quantitative. The pre and post- test measurement and the random assignment to the intervention and control groups were reflective of the quantitative design. However, a significant portion of the data collection consisted of interviews (which were obviously qualitative). The information that was gathered during those interviews helped to clarify some of the quantitative data. It was believed that the results would be best understood if both quantitative and qualitative analyses were used.

#### *Sample*

A total of 92 volunteers aged 55 and older who had a primary diagnosis of either rheumatoid arthritis or osteoarthritis was recruited to participate in this study. These included patients from two different clinics: (1) Twenty-five patients from the Rheumatology Clinic held at Charity Hospital in New Orleans, and (2) Sixty-seven patients from the Rheumatology Clinic held in the Louisiana Health Sciences Center

network held at the Lion's Clinic Building, LSU Health Sciences Center in New Orleans. The four groups were designated as LSU-experimental (LSU-E), LSU-control (LSU-C), Charity-experimental (CH-E) and Charity-control (CH-C).

A total of 85 participants completed the study (Table 1). The attrition rate for this study was 7.6% (92.4% of the participants completed the study). The attrition rates for the four groups may be found in Table 2.

Table 1. *Breakdown of participants*

Group	n
LSU-E	31
CH-E	9
LSU-C	33
CH-C	12

Table 2. *Attrition rates for all groups*

Group	Began study	Completed study	Attrition rate
LSU-E	n = 33	n = 31	6.1 %
CH-E	n = 12	n = 9	25.0 %
LSU-C	n = 34	n = 33	3.0 %
CH-C	n = 13	n = 12	7.7 %
Total	n = 92	n = 85	7.6 %

One potential participant initially declined to participate, stating that she did not have the time that day. She later returned to the clinic and did participate in (and eventually complete) the study. This strong level of cooperation was probably due, at least in part, to the strong encouragement of the attending Rheumatologists for their patients to participate in the study. Of the seven participants who did not complete the study, one dropped out stating she no longer wanted to participate (she did not give a specific reason other than "I don't want to be bothered"). Two dropped out because they felt their grasp

of English made it difficult for them to continue, and the remaining four could not be reached by telephone after many attempts and had to be dropped.

The demographic information may be seen in Tables 3 and 4. In Table 3 the intervention and the control groups were combined. In Table 4 the sample demographics are examined as the four separate groups. The sample was primarily female, non-white and non-married. The large majority (80%) of the sample was unemployed, disabled or retired. The largest number of participants was high school graduates or less, and over half of the sample had an annual household income of less than \$15,000. Nearly half of all participants had been diagnosed with arthritis for ten years or longer. An alarming observation was that 70% of all participants had been diagnosed with hypertension.

Table 3. *Demographic description of participants who completed study.*

	Total participants (n = 85) Percentages
Gender - Female	80
Ethnicity - White	45.9
- Non-white	55.1
Marital status - Married	40
- Non-married	60
Employment status - Employed (full/part-time)	20
Unemployed, disabled or retired	80
Educational status – Less than 9 years	28.2
10 years – HS graduate	29.4
Attended college	24.7
College graduate	17.6
Annual household income- Less than \$15,000	54.1
\$15,000-\$30,000	20
\$30,000-\$45,000	12.9
More than \$45,000	12
Health insurance - Uninsured	16.5
- Insured	83.5
Arthritis type – Osteoarthritis	80
Rheumatoid arthritis	20
Arthritis history – Less than 1 year	7.1
1 – 5 years	14.1
5 – 10 years	29.4
More than 10 years	49.4
Presence of- - Cardiovascular disease	22.4
- Hypertension	70.6
- Diabetes	27.1
- Cancer (current/history)	15.3
- Fibromyalgia	28.2
- Lupus	2.4
-Other chronic diseases	50.6

Table 4. *Comparison of group demographics (in percentages).*

	LSU-E	LSU-C	CH-E	CH-C
Gender - Female	83.9	75.8	66.7	91.7
Ethnicity - White	61.3	57.6	11.1	0
- African-American	38.7	42.4	77.8	100
- Hispanic	0	0	11.1	0
Marital status - Married	41.9	54.5	11.1	16.7
- Non-married	58.1	45.5	88.9	83.3
Employment status - Employed (full/part-time)	16.1	18.2	44.4	16.7
Unemployed, disabled or retired	83.9	81.8	55.6	83.3
Educational status – Less than 9 years	25.8	24.2	33.3	41.7
10 years – HS graduate	25.8	33.3	11.1	41.7
Attended college	25.8	21.2	44.4	16.7
College graduate +	22.6	21.3	11.1	0
Annual household income- Less than \$15,000	38.7	42.4	88.9	100
\$15,000-\$30,000	25.8	24.2	11.1	0
\$30,000-\$45,000	22.6	12.1	0	0
More than \$45,000	12.9	21.2	0	0
Health insurance - Insured	96.8	100	22.2	50
- Uninsured	3.2	0	77.8	50
Arthritis type – Osteoarthritis	74.2	81.8	88.9	83.3
Rheumatoid arthritis	25.8	18.2	11.1	16.7
Arthritis history – Less than 1 year	0	12.1	11.1	8.3
1 – 5 years	13	9.1	44.4	8.3
5 – 10 years	29.0	33.3	22.2	25.0
More than 10 years	58.1	45.5	22.2	58.3
Presence of- - Cardiovascular disease	25.8	21.2	22.2	16.7
- Hypertension	64.5	63.6	100	83.3
- Diabetes	25.8	24.2	33.3	33.3
- Cancer (current/history)	12.9	18.2	22.2	8.3
- Fibromyalgia	25.8	33.3	22.2	25.0
- Lupus	6.5	0	0	0
- Other chronic diseases	48.4	51.5	55.6	50.0

The mean age of all participants was 64.7 (s.d. = 7.4), and was not statistically different across groups. Gender was not different across groups. Ethnicity, however, was significantly different between the LSU and the Charity groups ( $\chi^2 = 18.993$ ,  $df = 1$ ,  $p < .001$ ). The LSU sample was predominantly white; 38 of the 64 LSU participants were white (59.4%) while 26 of the LSU participants were non-white (40.6%). The Charity sample was predominantly non-white; 20 of the 21 participants (95.2%) were non-white while one participant was white (4.8%). Participants recruited at the LSU clinic were more likely to be married than were participants from the Charity clinic ( $\chi^2 = 8.404$ ,  $df = 3$ ,  $p = .038$ ). Annual household income was significantly less in the Charity sample than in the LSU sample ( $\chi^2 = 19.171$ ,  $df = 5$ ,  $p = .002$ ). Very few of the Charity participants had an annual household income of more than \$15,000, and none had an annual household income of more than \$30,000. In comparison, over one-third of the LSU participants had annual household incomes of more than \$30,000, and half of those had annual incomes of more than \$45,000. Almost all of the LSU participants had some form of health insurance; less than half of the Charity participants were insured. The type of arthritis and the length of the history of the disease were not statistically different between groups. Almost 70% of all participants had hypertension

Table 5 presents the self-description of functional status in the four groups. These four choices were presented to the participants during the initial meeting. Each participant was asked to select the description that they thought best applied to him or her.

Table 5. *Self-description of functional status (in percentages)*

Category	LSU-E	LSU-C	CH-E	CH-C
"I am not physically limited by my arthritis"	9.7	18.2	0	0
"I am somewhat physically limited by my arthritis"	45.2	45.5	66.7	50.0
"I am significantly physically limited by my arthritis"	22.6	18.2	22.2	16.7
"I am disabled due to my arthritis"	22.6	18.2	11.1	33.3

Table 6 presents self-assessment of general health status in the four groups. These choices were presented to the participants during the initial meeting. Each participant was asked to select the category that they thought most accurately described his or her current state of health.

Table 6. *Self-assessment of general health status (in percentages)*

Category	LSU-E	LSU-C	CH-E	CH-C
In general, would you say you health is: <i>Excellent</i>	6.5	3.0	11.1	0
<i>Very good</i>	25.8	21.2	0	0
<i>Good</i>	22.5	36.4	22.2	41.7
<i>Fair</i>	29.0	27.3	33.3	41.7
<i>Poor</i>	16.1	12.1	33.3	16.7

### *Selection Criteria*

To be eligible for participation in this study, participants were required to: 1) have a diagnosis of primary RA or OA, 2) be at least 55 years of age, and 3) be able to

communicate by telephone over a four month period. The attending physician confirmed each participant's diagnosis of arthritis. The patient may have had other medical problems as long as the problems did not interfere with their ability to participate in the study. In a related study, Lorig et al (1989) found that changes in behaviors and health outcomes were not significantly different for patients with RA and OA.

### *Sampling Method*

As each patient entered either the Charity or LSUHSC Rheumatology Clinics, the investigator reviewed his or her chart. The investigator did not have access to the patients scheduled for each clinic until the day of the clinic (i.e., there was no way to plan in advance for patients attending a clinic on any particular day). The chart was reviewed to determine if the patient met eligibility requirements for the study (age 55 or older, primary diagnosis of either rheumatoid arthritis or osteoarthritis). If the patient met the criteria, he or she was placed into either the control group or the intervention group by random technique (via use of a random numbers table). After the patient had completed their appointment with the physician, the investigator approached the patient and described the study to them. If the patient was interested in participating in the study, informed consent was carried out.

### *Instrumentation*

#### *Arthritis self-efficacy scale (ASE)*

Arthritis self-efficacy was the primary measured outcome in this study. The ASE, developed by Lorig and others (Lorig, Chastain et al. 1989) (Lorig, Seleznick et al., 1989), is a self-administered questionnaire consisting of 33 questions (see Appendix C) and can be completed in about 15 minutes. It consists of three major subsets: self-efficacy



to perform self-management behaviors (items 1-11), general self-efficacy (items 12-16), and self-efficacy to achieve outcomes (items 17-33). The three major subsets may be further divided into ten individual subsets, assessing the categories listed below. Each item was measured on a 1-10 Likert scale with anchors (1 = Not at all confident and 10 = Totally confident). Each area was analyzed separately with a higher score indicating higher self-efficacy.

1. Self-efficacy to exercise regularly (items 1–3).

Example: “*How confident are you that you can exercise without making your symptoms worse?*”

2. Self-efficacy to get information about disease (item 4).

Example: “*How confident are you that you can get information from community resources?*”

3. Self-efficacy to obtain help from community, family and friends (items 5–8).

Example: “*How confident are you that you can get family and friends to help you with things you need (such as household chores like shopping, cooking or transportation?)*”

4. Self-efficacy to communicate with physician (items 9-11).

Example: “*How confident are you that you can discuss openly with your doctor any personal problems that may be related to your illness?*”

5. Self-efficacy to manage the disease in general (items 12-16).

Example: “*How confident are you that you can reduce the emotional distress caused by your health condition so that it does not affect your everyday life?*”

6. Self-efficacy to do chores (items 17-19).

*Example: “How confident are you that you can get your errands done despite your health problems?”*

7. Self-efficacy to participate in social/recreational behaviors (items 20 – 21).

*Example: “How confident are you that you can continue to do the things you like to do with your family and friends (such as social visits and recreation)?”*

8. Self-efficacy to manage their symptoms (items 22-26).

*Example: “How confident are you that you can control any symptoms or health problems you have so that they do not interfere with the things you want to do?”*

9. Self-efficacy to manage shortness of breath (item 27).

*Example: “How confident are you that you can keep your shortness of breath from interfering with what you want to do?”*

10. Self-efficacy to control/manage depression (items 28-33).

*Example: “How confident are you that you can keep from getting discouraged when nothing you do seems to make any difference?”*

According to Lorig (Lorig, Chastain et al., 1989; Lorig, Seleznick et al., 1989), the original ASE has a Cronbach’s alpha of 0.93; the revised ASE has a Cronbach’s alpha of 0.89. The Cronbach’s alpha coefficient for the ASE used in this study was 0.96. Validity estimates of the ASE are as follows:  $r = 0.61$  for ASE correlation with home task performance and  $r = 0.35$  to  $0.73$  for ASE correlation with health status (Lorig, Chastain et al., 1989). Buescher found that higher self-efficacy was related to fewer pain behaviors in patients with RA ( $r = -0.32$  to  $-0.39$ ) (Buescher et al., 1991). Buescher also examined

the relationships between self-efficacy and symptoms of depression ( $r = -0.25$  to  $-0.44$ ). For patients with RA, the relationship between self-efficacy and health status was found to be  $r = 0.34$  to  $0.57$  (Brekke, Hjortdahl, & Kvien, 2001).

#### *Geriatric depression scale (GDS)*

The GDS was developed as a basic screening measure for depression in older adults. Yesavage and colleagues showed that the GDS is reliable, with a mean inter-correlation of items of 0.36 and a Cronbach alpha coefficient of 0.94, suggesting a high degree of internal consistency (Yesavage et al., 1983). Yesavage also found the GDS to be valid:  $F(2, 97) = 99.48$ ,  $p < 0.001$ . The GDS consists of 15 questions answered by yes or no. The answers are coded so that a “positive” answer indicates depression on that item. For clinical purposes, a score of greater than five is suggestive of depression and indicates the need for follow-up evaluation. A score of greater than ten is almost always suggestive of depression. The GDS may be seen in Appendix D; the answers in bold indicate a positive score for depression. The GDS used in this study was based on an earlier version developed by Brink et al (Brink et al., 1982).

#### *Perceived pain and fatigue ratings*

Perceived pain and perceived fatigue were measured on a numeric rating scale (NRS). Mawdlsey, Moran and Conniff showed that the NRS could be used reliably with elderly patients who suffered from musculoskeletal pain and had no cognitive disorders (Mawdsley, Moran, & Conniff, 2002). The intraclass correlation coefficient for all subjects in the study was 0.76 ( $p < .0001$ ). The standard errors of measurement were 0.66. The participants were asked during the initial session to rate both their pain and their fatigue on a 0 to 10 scale, with “0” representing no pain (or fatigue) and “10”

representing pain (or fatigue) as bad as it can be. The investigator read the scale and the instructions to the participant as the scale and description were placed in front of them; they were asked to circle the appropriate number themselves. During each subsequent phone call, the participants in the intervention group were asked to rate their pain in the same method. During the final data collection call each participant in the study was asked to rate their pain and their fatigue over the phone.

### *Goal Assessment*

Each participant was asked the following question: “What is your primary goal for participating in this study?” Data from this question were analyzed both quantitatively and qualitatively.

### *Procedures for Conducting the Study*

The study was conducted at the Rheumatology Clinics at Charity Hospital and at the LSUHSC Lion’s Clinic Building. In each clinic, volunteers were assigned to a control or an intervention group by random technique. A random numbers table was used for this purpose. This method was performed in the same way at each clinic (Charity and LSU). The four groups were classified as CH-C, CH-E, LSU-C and LSU-E. Upon selection each participant first received and completed an informed consent form. They next completed a demographic questionnaire providing information such as gender, race, educational level, annual household income and the number of years since the diagnosis of their arthritis. Following this, each participant completed the Arthritis Self-Efficacy Scale (ASE). The ASE includes assessments of self-management behaviors, self-efficacy, pain perception, and various physiological and psychological status outcomes. The ASE was administered orally to each participant by the investigator. The participant and the

investigator sat next to each other at a table. A copy of the ASE was placed in front of the participant and the investigator read each item aloud as the participant read it at the same time. Each item was read to the participant in the form of a question. The participant would select a response (number from 1 to 10) and the investigator would then circle the response on the paper. After completion of the ASE, the investigator orally administered the 15-item Geriatric Depression scale (GDS) to each participant in a manner similar to that used with the ASE. Each participant also noted their respective levels of perceived pain and fatigue on both a 10-cm. visual analog scales (VAS) and on a 1-10 numeric rating scale. The VAS was not collected on the post-test since the post-test telephone format was used; it was not practical to collect another VAS using the telephone interview method. Finally, each participant was asked the following question during the initial meeting: “What would be a goal you would hope to accomplish (re: your arthritis) in the next 6 weeks?” This question helped to lay the groundwork for part of the follow-up phone calls. Each of these instruments may be found in Appendices E and F, respectively.

The CH-E and LSU-E participants received weekly follow-up phone calls for the first four weeks and then one final phone call in the sixth week. This six-week period was selected to reflect the typical six weeks needed to complete the ASMP. The phone calls were structured as described in the next section. The CH-C and LSU-C groups did not receive phone intervention during the 6-week period. During the final week of participation each participant completed the ASE again. The investigator administered the final ASE measurement of each participant over the telephone.

### *Telephone Call Intervention*

The participants in the intervention groups were called weekly for the first four weeks and then received one final call in the sixth week. This format was designed to closely match the format of traditional ASMP, which is usually taught on consecutive weeks for a six-week period (Lorig et al., 1996). The content of the phone calls drew from the material in the ASMP Workshop Leader's Manual (Lorig, 2001) and from the phone intervention strategies used in previous studies (Austin et al., 1996; Castro et al., 2001; Mazzuca et al., 1997). The focus of each phone call differed from one week to the next, but each call was structured so that adherence with self-care recommendations was assessed and reinforced, that any misconceptions were clarified, and that continued participation in the study was encouraged. The outline of each of the weekly phone calls is listed below. Specific objectives were developed for each phone call. The script for each of the calls may be found in Appendix H. During the initial session the investigator asked each participant for a preferred time/day of the week to be called (this included evenings and weekends). The investigator made every attempt to accommodate the participants' schedules with the telephone calls. If a participant was not at home, the investigator left messages whenever possible (either on an answering machine or with another household member who may have answered the phone).

#### Week 1 phone call (Call 1):

1. Greeting (subjective assessment of status; report of symptoms)
2. *Focus*: discuss exercise/activity level for the past week
3. Discuss progress toward their primary stated goal (emphasize importance of positive self-talk); establish action plan.

4. Answer any other questions participants may have

Week 2 phone call (call 2):

1. Greeting (as above)
2. Briefly discuss exercise (as above)
3. *Focus*: discuss participant's pain level in the past week, and focus on pain management techniques.
4. Discuss progress toward their primary stated goal (emphasize importance of positive self-talk); review action plan.
5. Answer any other questions participants may have

Week 3 phone call (Call 3):

1. Greeting (as above)
2. Briefly discuss exercise (as above)
3. Briefly discuss pain level/management (as above)
4. *Focus*: discuss barriers to medical care and to overall health behaviors
5. Discuss progress toward their primary stated goal (emphasize importance of positive self-talk); review action plan.
6. Answer any other questions participants may have

Week 4 phone call (Call 4):

1. Greeting (as above)
2. Briefly discuss exercise (as above)
3. Briefly discuss pain level/management (as above)
4. Briefly discuss barriers to care (as above)

5. *Focus*: identify any new behaviors that may have arisen (healthy and/or unhealthy new behaviors)
6. Discuss progress toward their primary stated goal (emphasize importance of positive self-talk); review action plan.
7. Answer other questions participants may have

Week 6 phone call (Call 5):

1. Greeting (as above)
2. Briefly review involvement in the program (ask for overall comments regarding participation in the program).
3. Administer the ASE
4. Administer the GDS
5. Ask the participant for their current pain rating (1-10 scale)
6. Ask the participant for their current fatigue rating (1-10 scale).
7. Ask for final comments/questions and thank participant for being in the study

The overall strategy of the phone calls was to build upon and reinforce the discussion that had taken place in the previous week's call. By the final call (Week 6) no new content was added to the call. As noted, the primary goal of the final call was to administer the final ASE, GDS, pain and fatigue rating instruments. It was anticipated that the calls might get progressively longer from the first through the fifth calls. The first call took about 5 minutes; the final call averaged about 15-20 minutes. The caller took notes on the participant's responses during the calls.

Most of the qualitative data was collected during the weekly interviews with the intervention groups. The final phone calls that participants in all groups received were



designed primarily to administer the final measurement tools: the ASE, the GDS, and the pain and fatigue numeric analog scales. Since these calls typically required about 15-20 minutes just for the administration of the instruments, additional conversation was usually limited. This was not a significant issue with participants in the intervention groups, since the investigator had already had four phone conversations with them, providing opportunity for qualitative data collection. However the final call was the only opportunity for the investigator to collect significant qualitative (interview) data from the participants in the control groups.

The investigator wrote down field notes during each phone call. Whenever possible, actual participant quotes were recorded. After each phone call the investigator reviewed the field notes and supplemented notes with additional detail and contextual information. The majority of the qualitative data draws from these field notes and descriptions rather than participant votes.

#### *Comparison of SCT, ASMP and Telephone Intervention*

The ASMP was largely based on Social Cognitive Theory, and the telephone interventions used in the current study were designed to be consistent in format with the ASMP. As may be seen in Table 7, the comparisons of the ASMP and telephone interventions to the four basic components of SCT are described.

Table 7 - *Comparisons of integration of SCT into ASMP and Telephone Intervention Methodology*

Social Cognitive Theory (SCT)	Arthritis Self-Management Program (ASMP)	Telephone Intervention Methodology
	<i>Demonstrated by:</i>	<i>Demonstrated by:</i>
Performance Accomplishments	<p><b>Session Two:</b> Practice pain distraction and muscle relaxation techniques</p> <p><b>Session Five:</b> Apply problem-solving principles to his/her life</p> <p><b>Session Six:</b> State self-management accomplishments</p>	<p><b>Phone Call #2 *:</b> Discuss progress made on action plan</p> <p><b>Phone Call #5:</b> Summarize progress toward goal, &amp; changes in depression, pain and fatigue</p>
Vicarious Experiences	<p><b>Session Three:</b> Call “Buddy” during week &amp; report on progress</p>	
Verbal Persuasion	<p><b>Session One:</b> Provide information on importance of physical fitness for arthritis; make contract</p> <p><b>Session Five:</b> Discuss pain management techniques</p>	<p><b>Phone Call #1:</b> Discuss importance of physical fitness to self-management of arthritis</p> <p><b>Phone Call #2:</b> Discuss strategies for dealing with pain</p> <p><b>Phone Call #4:</b> Discuss strategies for dealing with fatigue</p>
Emotional Arousal	<p><b>Session One:</b> Use information to dispel perceived myths and anxiety</p> <p><b>Session Four:</b> Demonstrate strategies for changing negative self-talk to positive self-talk, and discuss strategies for dealing with depression</p> <p><b>Session Five:</b> Demonstrate use of “I” messages to communicate better with others (and decrease anxiety)</p>	<p><b>Phone Call #1:</b> Use information to dispel perceived myths and anxiety</p> <p><b>Phone Call #3:</b> Discuss specific communication strategies for dealing with doctors; discuss use of “I” messages to communicate better with others (and decrease anxiety)</p>

\* = Repeated with each subsequent phone call.

#### *Qualitative Design – Interview Method*

The qualitative data were collected via telephone interviews. According to Creswell (1994) the interview data collection method has several advantages and disadvantages.

The main advantages are that the investigator can control the line of questioning and the method can be used when the participants cannot be directly observed. The primary disadvantages are that not all participants are equally responsive, articulate and receptive to the interview process; the investigator's presence (even over the telephone) may bias the participant's responses, and a telephone interview does not place the participant in a natural setting (like a field observation might do).

#### *Quantitative Data Analysis Procedures*

A 2x2 repeated measure ANOVA was the primary means of statistical analysis in this study. Differences in ASE scores between the control and intervention groups were examined, as well as differences in ASE scores between the participants in the two clinical settings. The between group factors were site (LSU vs. Charity) and treatment (Control vs. Intervention). Scores for the GDS, pain and fatigue numeric rating scales were computed and analyzed in a similar manner.

#### *Qualitative Data Analysis Procedures*

The investigator took notes during the phone calls to the participants. In some cases exact quotes were used; in other cases the investigator paraphrased the participant's responses. At the end of a participant's involvement in the study, the investigator examined the initial goals and action plan that the participant and the investigator had agreed upon. The investigator then made a determination of whether the participant had met his/her goal. This determination was made primarily by the investigator comparing the original action plan goal with the participant's activity level as described by the participant during the phone call(s). The participants were also asked (usually during the final phone call) if they believed they had reached their goal. Participants were asked to

be as specific as possible in describing their activity level; this information was used to determine whether the participant had met his or her goal. The investigator had five weeks of interview data for the participants in the intervention group. Analysis of that data was more than adequate to determine if the goal had been reached. Participants in the control group were only contacted once, for the final phone call in week six. At that time the investigator would ask the participant to describe his or her progress and activity level. That information would be analyzed in comparison to the initial goal to determine whether or not the goal had been met. In the course of the interviews the participant would describe their progress in detail, and the investigator would record that information. Analysis would confirm whether or not the goal had been reached. The next step in analyzing the qualitative data was to examine the interview material for major themes that might emerge. The investigator reviewed the transcripts and field notes from all of the participants. The qualitative data was typed into the word processor and was reviewed for common themes. The major themes emerged and were coded with different font colors. The themes were then grouped together for further analysis. This method of coding, chunking and analysis has been described by qualitative researchers (Glesne, 1999). The major themes were then divided into subcategories that were relevant to the topic. Glesne and others (Creswell, 1998; Lincoln & Guba, 1985) describe several verification procedures that are often used to strengthen the validity of qualitative data.

### *Summary*

An experimental pretest-posttest experimental design was used in this mixed quantitative/qualitative study. Older adults who met selection criteria were randomly assigned to control or intervention groups. All participants received pretest assessments

on arthritis self-efficacy, depression, pain and fatigue. All participants received a packet of information related to arthritis self-management, established an action plan for self-management and set goals for that plan. Participants in the intervention group were called four times over a five week period; the calls followed a script and were designed to provide information (based on the informational packet) and meet any special needs the participant might have related to their arthritis self-management. All participants were called in the sixth week and pre-test measurements were reassessed. The quantitative and qualitative data were analyzed.

## CHAPTER FOUR

### RESULTS

The overall quantitative results reveal that there was a significant change in Arthritis Self Efficacy scores over time for all participants, but the change was not unique to the intervention group. The quantitative and qualitative results are described in this chapter.

A repeated measures analysis of variance (ANOVA) was performed on four dependent variables: arthritis self-efficacy (ASE scores), depression (GDS scores), pain, and fatigue with the independent variable being intervention. The between group factors were site and treatment group. Repeated measures ANOVA was run using SPSS (Statistical Package for Social Sciences version 11.0, Graduate Pack for Windows) software for the analyses. Results of evaluation of assumptions of normality, homogeneity of variance-covariance matrices, linearity, and multicollinearity were satisfactory.

#### *Arthritis Self-Efficacy (ASE)*

According to Wilks' Lambda criterion, the dependent variable of arthritis self-efficacy was significantly affected by time of measurement indicating that scores on the ASE significantly improved from pretest to post-test for the entire group:  $F(1,81) = 6.822$ ,

$p = .011$ . The F-values are listed in Table 8. The between groups factors of site and group were not significant.

Table 8. *Repeated measures ANOVA – ASE*

Effect	F	Hypothesis df	Error df	Significance
Time	6.822	1	81	.011
Time*Site	.012	1	81	<i>ns</i>
Time*Group	2.652	1	81	<i>ns</i>
Time*Site*Group	.154	1	81	<i>ns</i>

\*Note: **Time** = pretest → posttest; **Site** = LSU vs. Charity; **Group** = Intervention vs. Control; All ANOVA tables reflect Wilks' Lambda values

The mean ASE scores increased from pre-test to post-test in each of the four groups; the mean values by group are listed in Table 9. The 33-item ASE instrument can be divided into three major sub-categories scales and eleven smaller sub-categories scales, as was described in Chapter Three. A repeated measures ANOVA was performed on each of the sub-categories, comparing scores in relation to group (intervention vs. control) as well as site (LSU vs. Charity). Analyses resulted in similar findings of overall increases, but no between group effects. As these additional analyses did not result in new information, the specifics are not reported.

Table 9. *Mean values of pre and post-test ASE scores.*

Group	ASE Pre-test Mean (s.d.)	ASE Post-test Mean (s.d.)
LSU-E	242.8 (54)	249.8 (60.4)
LSU-C	231.0 (61.9)	251.8 (54.4)
CH-E	262.0 (55.4)	265.9 (54.9)
CH-C	212.2 (66.6)	238.5 (72.5)
Total	235.9 (59.6)	250.7 (58.8)

### *Geriatric Depression Scale*

According to Wilks' Lambda test, the effects of time, site, and group did not significantly affect the Geriatric Depression Scale (GDS) scores (Table 10). Although the means decreased from pretest to posttest, these changes were not significant for the sample in total or by group or site. The mean GDS scores may be seen in Table 11.

Table 10. *Repeated measures ANOVA – GDS*

Effect	F	Hypothesis df	Error df	Significance
Time	2.329	1	79	<i>ns</i>
Time*Site	.893	1	79	<i>ns</i>
Time*Group	1.165	1	79	<i>ns</i>
Time*Site*Group	.094	1	79	<i>ns</i>

\*Note: **Time** = pretest → posttest; **Site** = LSU vs. Charity; **Group** = Intervention vs. Control; All ANOVA tables reflect Wilks' Lambda values

Table 11. *Mean values of pre and post-test GDS scores.*

Group	GDS Pre-test Mean (s.d.)	GDS Post-test Mean (s.d.)
LSU-E	4.5 (3.7)	3.4 (3.8)
LSU-C	4.1 (4.2)	3.5 (3.7)
CH-E	4.7 (3.0)	4.0 (3.5)
CH-C	5.5 (4.2)	5.7 (4.3)
Total	4.5 (3.9)	3.8 (3.8)

The mean pretest GDS scores for the CH-C group were the only pretest scores that were greater than five (and the mean posttest scores for the CH-C group were the only posttest scores greater than five). According to the scoring criteria for the GDS test, scores greater than five indicate the need for further testing for the possibility of clinical depression (Yesavage et al., 1983). This finding suggests that the mean pretest GDS scores for the participants in the Charity control group indicated that those participants might be in need for further screening for the possibility of clinical depression.



### *Pain Numeric Rating Scale*

According to Wilks' Lambda criterion, the pain numeric rating scale scores were significantly affected by time (pre-test vs. post-test scores) indicating that scores on the pain scale significantly improved (decreased) from pretest to posttest for the entire group:  $F(1,81) = 9.721$ ,  $p = .003$ . There was no effect for treatment or site. These results may be viewed in Table 12. The mean pain scale scores decreased in each of the four groups (Table 13) and were not significantly different from one another

Table 12. *Repeated measures ANOVA – Numeric Pain Rating*

Effect	F	Hypothesis df	Error df	Significance
Time	9.721	1	81	.003
Time*Site	0.421	1	81	<i>ns</i>
Time*Group	1.802	1	81	<i>ns</i>
Time*Site*Group	0.459	1	81	<i>ns</i>

\*Note: **Time** = pretest → posttest; **Site** = LSU vs. Charity; **Group** = Intervention vs. Control; All ANOVA tables reflect Wilks' Lambda values

Table 13. *Mean pain ratings over time*

Group	Pre-test pain rating Mean (S.D.)	Post-test pain rating Mean (S.D.)
LSU-E (n = 31)	6.52 (2.9)	4.87 (3.1)
LSU-C (n = 33)	6.09 (2.9)	4.94 (2.9)
CH-E (n = 9)	8.22 (1.6)	6.56 (3.0)
CH-C (n = 12)	7.33 (2.2)	7.17 (2.7)
Total	6.65 (2.8)	5.40 (3.0)

### *Fatigue Numeric Rating Scale*

According to Wilks' Lambda criterion, the fatigue numeric rating scale scores were significantly affected by the interaction of time, group and site:

$F(1,81) = 4.126, p = .046$ . These results may be viewed in Table 14.

Table 14. *Repeated measures ANOVA – Numeric Fatigue Rating*

Effect	F	Hypothesis df	Error df	Significance
Time	1.717	1	81	<i>ns</i>
Time*Site	.031	1	81	<i>ns</i>
Time*Group	.062	1	81	<i>ns</i>
Time*Site*Group	4.126	1	81	.046

\*Note: **Time** = pretest → posttest; **Site** = LSU vs. Charity; **Group** = Intervention vs. Control; All ANOVA tables reflect Wilks' Lambda values

The interaction may be interpreted as the fatigue scores changed differently as a result of participants being in a certain group and at a certain clinical site. The mean fatigue scores decreased over time for the LSU-E and CH-C groups and increased over time for the LSU-C and CH-E groups (Table 15). The total sample mean changes over time for all dependent variables are summarized in Table 16.

Table 15. *Mean fatigue ratings over time*

Group	Pre-test fatigue rating Mean (S.D.)	Post-test fatigue rating Mean (S.D.)
LSU-E (n = 31)	6.06 (3.2)	4.84 (2.7)
LSU-C (n = 33)	5.42 (2.9)	5.70 (2.9)
CH-E (n = 9)	5.67 (3.2)	6.00 (3.5)
CH-C (n = 12)	6.83 (3.3)	5.25 (3.7)
Total	5.88 (3.1)	5.35 (3.0)

Table 16. *Total sample mean changes over time for all dependent variables (n = 85)*

Dependent variable	Pre-test rating Mean (S.D.)	Post-test rating Mean (S.D.)
ASE	235.9 (59.6)	250.7 (58.8)
GDS	4.5 (3.9)	3.8 (3.8)
Pain	6.65 (2.8)	5.40 (3.0)
Fatigue	5.88 (3.1)	5.35 (3.0)

*Goal Attainment*

During the initial meeting with each participant, action plan goals were established. The investigator asked each participant what he or she would like to accomplish from participating in the study. Attainment of the goal was re-assessed during the final phone call with each participant. As described in Chapter Three, the investigator reviewed five weeks of interview data for participants in the intervention group to determine whether participant goals had been attained. Participant descriptions of progress were continually assessed during the telephone interventions; these descriptions were recorded by the investigator and analyzed. Participants in the control group had one opportunity to reflect on the past six weeks and describe their progression (or lack thereof); their descriptions were recorded and analyzed in the same manner as the data collected from the participants in the intervention group.

The types of goals selected by the participants (and their success rates in attaining them) are described in Tables 17-21.

Table 17. *Selected goals and rates of achievement for all participants*

<b>All participants (n = 85)</b>		
<i>Goal:</i>	<i>Met goal</i>	<i>Failed to meet goal</i>
1. Walk better (n = 57)	45 (78.9%)	12 (21.1%)
2. Increase exercise level (n = 17)	8 (47%)	9 (53%)
3. Better use of arms (n = 5)	4 (80%)	1 (20%)
4. Increase household activity (n = 2)	0	2 (100%)
5. Move better/decrease pain (n = 1)	1 (100%)	0
6. Work in garden more (n = 1)	1 (100%)	0
7. Do more housework (n = 1)	1 (100%)	0
8. More time at sewing machine (n = 1)	0	1 (100%)
Total (n = 85)	60 (70.6%)	25 (29.4%)

Table 18. *Selected goals and rates of achievement for LSU-E*

<b>LSU-E (n = 31)</b>		
<i>Goal:</i>	<i>Met goal</i>	<i>Failed to meet goal</i>
1. Walk better (n = 21)	18 (85.7%)	3 (14.3%)
2. Increase exercise level (n = 8)	5 (62.5%)	3 (37.5%)
3. Better use of arms (n = 1)	1 (100%)	0
4. Work in garden more (n = 1)	1 (100%)	0
Total	25 (80.6%)	6 (19.4%)

Table 19. *Selected goals and rates of achievement for CH-E*

<b>CH-E (n = 9)</b>		
<i>Goal:</i>	<i>Met goal</i>	<i>Failed to meet goal</i>
1. Walk better (n = 5)	4 (80%)	1 (20%)
2. Better use of arms (n = 2)	2 (100%)	0
3. Do more housework (n = 1)	1 (100%)	0
4. More time sewing (n = 1)	0	1 (100%)
Total	7 (77.8%)	2 (22.2%)

Table 20. *Selected goals and rates of achievement for LSU-C*

<b>LSU-C (n = 33)</b>		
<i>Goal:</i>	<i>Met goal</i>	<i>Failed to meet goal</i>
1. Walk better (n = 20)	16 (80%)	4 (20%)
2. Increase exercise level (n = 8)	3 (37.5%)	5 (62.5%)
3. Better use of arms (n = 2)	1 (50%)	1 (50%)
4. Increase household activity (n = 2)	0	2 (100%)
5. Move better/decrease pain (n = 1)	1 (100%)	0
Total	21 (60%)	14 (40%)

Table 21. *Selected goals and rates of achievement for CH-C*

<b>CH-C (n = 12)</b>		
<i>Goal:</i>	<i>Met goal</i>	<i>Failed to meet goal</i>
1. Walk better (n = 11)	7 (63.6%)	4 (36.4%)
2. Increase exercise level (n = 1)	0	1 (100%)
Total	7 (58.3%)	5 (41.7%)

A majority of participants (67%) in the study selected “walking better” as their primary goal. This was the case in each of the four groups; walking better was the primary goal for the LSU-E group (66.7%), the CH-E group (55.6%), the LSU-C group (60.6%) and the CH-C group (91.7%). Walking better was a term that encompassed a range of goals for the participants. For example, a number of the participants began the study with a relatively low functional level. These individuals may have been limited by their arthritis to being able to walk one block (or even less) before having to stop due to their pain. Their primary goal was simply to increase their ability to walk a little further before having to stop. Other participants were already at a relatively high functional level, sometimes already walking many blocks (or even several miles) on a regular basis. When asked for an outcome goal for participating in the study, these individuals stated a desire to be able to walk further and/or faster. In both of these cases (and others between the two described extremes), the participants’ goals fell into a common goal category of “want to

walk better”. Thus, while a large majority of study participants apparently shared a common goal for participating in the study; their actual functional status and goals may have varied widely. Increasing level of exercise activity was the next most common goal for participants in three of the four groups: LSU-E (25.8%), LSU-C (24.2%) and CH-C (8.3%). This was another descriptive label that encompassed a relatively wide range of functional abilities and goals. Some participants were, by their own description, quite sedentary at the beginning of their participation. They wanted to be able to initiate a very low-level exercise/activity program. Other participants were already at a relatively high level of physical activity (e.g., playing golf on a regular basis, involved in yoga or low impact aerobics classes, etc.). They were interested in further increasing their respective activity level in a manner that would not aggravate their arthritic condition. Other goals selected by participants (total in study) included better use of upper extremities in functional activities (5.9%) and increasing level of household activities/housework (5.9%). The differences in goal attainment between groups was not found to be significant:  $\chi^2 (1,81) = 3.224, p = .096$ .

### *Qualitative Themes*

The investigator took notes during the phone calls to the participants. In some cases exact quotes were used; in other cases the investigator paraphrased the participant’s responses. At the end of a participant’s involvement in the study, the investigator examined the initial goals and action plan that the participant and the investigator had agreed upon. The investigator then made a determination of whether the participant had met his/her goal. The next step in analyzing the qualitative data was to examine the

interview material for major themes that might emerge. Five major themes were identified (Table 22).

Table 22. *Major themes that emerged during coding and analysis of qualitative data.*

<b>1.</b> Ways in which the study was useful to participants.
<b>2.</b> Adhering to the plan or making changes to it.
<b>3.</b> Evidence of enhanced participant understanding of their condition.
<b>4.</b> Specific problems encountered by participants - events that occurred during the study.
<b>5.</b> Observations related directly to the phone intervention.
<b>5.A.</b> Problems of the investigator with the phone calls.
<b>5.B.</b> Logistical problems/situations related to the phone calls.
<b>5.C.</b> Auditory observations of the investigator during the phone calls (e.g., background noises, distractions to the participant, etc.)
<b>5.D.</b> Other unusual events related to the phone calls.
<b>5.E.</b> Perceived or stated dependency (or developing dependency) of the participant on the phone calls.

The investigator reviewed the transcripts and field notes from all of the participants. The qualitative data was typed into the word processor and was reviewed for common themes. Five major themes emerged and were coded with different font colors. The themes were then grouped together for further analysis. This method of coding, chunking and analysis has been described by qualitative researchers (Glesne, 1999). The major themes were then divided into subcategories that were relevant to the topic. Glesne and others (Creswell, 1998; Lincoln & Guba, 1985) describe several verification procedures that are often used to strengthen the validity of qualitative data. The investigator attempted to clarify researcher bias (reflection of the investigator's subjectivity and how the subjectivity is used and monitored during the research) (Glesne, 1999), as well as content analysis in the qualitative review of the data.

Five major themes (and corresponding sub-categories) emerged during coding and analysis of the interview material. Three of the major themes identified represent

potential benefits from participating in the telephone intervention program. These included identification of ways in which the program could benefit the participants, descriptions of how participants would adhere to their respective action plans, and evidence of participants gaining better understanding of their condition from taking part in the program. Interview data analysis also revealed challenges that emerged as major themes: the development of medical or other problems that may have affected participant involvement in the program, and problems that were often attributed to the nature of a telephone intervention program (e.g., missed phone calls, noisy phone lines, etc.). None of the names used in the following descriptions are the participants' real names.

*Qualitative Theme One – Ways in which Study was Useful to Participants*

One of the first major themes that emerged during analysis of the interview data was ways in which the participants reported the study had been useful to them. Their descriptions of how their participation benefited them included examples such as helping their self-esteem, and meeting a long desired (but unfulfilled) goal of establishing and practicing better health activities. Another apparent benefit of participation was the facilitation of access to medical care. As described below, there were several examples of the investigator teaching strategies to participants to assist them in gaining quicker access to their physicians, either over the phone for consultation or changing appointment dates so as to be seen sooner by the physician than had been scheduled. This help was manifested in different forms as illustrated by some of the following examples.

Jim, a 64-year-old African American part-time restaurant inspector, was an example of someone that was so highly motivated and determined that he pushed himself too hard. He had taken his initial action plan and by the first week had already pushed himself past



his ultimate goal (in terms of times and distance walked). The price that he paid for this was that by the time of the first phone conversation his arthritis pain had significantly increased (due to overuse). The chief value of the calls in this case was to educate Jim in terms of setting limits for him and the potential negative impact of doing too much. Once he saw the value in this and agreed to reduce his activity to a more appropriate level (i.e., follow his action plan) he did very well. He was able to increase his walking level according to the plan and do so without an increase in his discomfort.

Jim was also an example of increased understanding by a participant. He had, on his own, significantly increased his level of activity well beyond that outlined in his action plan. This is not unusual; patients often believe that if a little exercise (or medication) is good for a condition, then a lot would be more helpful. If Jim had been in the control group (he was not) and had received the initial action plan but no follow-up phone calls, it is possible that he may have rapidly increased his walking level to the point of pain or even injury.

Jim repeatedly expressed a desire to get into a more structured fitness/wellness program at the conclusion of this study. He had been managing his arthritis for more than ten years, and stated that he was excited about bringing fitness into his life and did not want it to end with the study. Prior to the study, he had not thought much about fitness (and had not exercised regularly before) and had a strong desire to continue.

At the last (sixth week) call, Kathy (a 60-year-old African American disabled domestic worker who had been diagnosed with RA more than ten years earlier) sounded positive about her participation in the program. She gave the program full credit for getting her started on an exercise program. Kathy had never exercised regularly before

participating in this program and vowed to continue to do so. She was sorry to see the phone calls end. At the beginning of the program, Kathy had a Nordic skier (a piece of exercise equipment that simulates cross-country skiing) that had never been put together. During the first call she mentioned that she had gotten someone to assemble it and she had started exercising with it. She indicated that she was excited about this and her enthusiasm continued for the duration of the program. Kathy kept a pad and pen beside the Nordic skier to record her progress. After several weeks, she reported that she felt great and spoke about how impressed her family and friends were with her.

Sarah was a 64-year-old white retired secretary who was physically very active. She was participating in several different types of exercise: tennis, yoga, body sculpting, etc. Sarah also had some good questions about how her exercise was potentially affecting her osteoarthritis. She indicated that she was enthusiastic about her progress. By week two she reported that she was doing even better. Sarah stated that she was so active and was doing so many different kinds of exercise that she barely had time for them all. She mentioned that the teacher of her body sculpture class had told her to use more weight for certain exercises and she began having increased shoulder pain as a result. The investigator advised her to be careful and to decrease the amount of weight she was using. Sarah also stated that she was being “a cheerleader” and a role model for the other family members who need help in establishing a conditioning program. She was encouraged about her participation in the program. By the next week she noted that things were still better. Using the material from the packet of information, she was now teaching her yoga classmates about the importance of avoiding pain with their exercises. By the end of the program she had exceeded her goals and was not having any discomfort

or pain. She stated that this program had been very helpful to her and to others around her. Sarah exercised regularly before volunteering to participate in the study, and consequently the intervention did not result in initiating her exercise program. However there did appear to be benefits of involvement: she was able to take a more global view of how exercise can affect her and her health, and how some activities may exacerbate her condition. She was able to share this information with others.

The preceding examples were illustrations of how participants believed that their involvement was helpful in initiating and maintaining levels of fitness activities. The following cases are examples of how participation facilitated access to medical care

#### *Facilitating Access to Medical Care*

The program also appeared to be helpful in facilitating access to medical care and in helping participants to understand their role in the self-management of their condition. This is consistent with objectives stated in the ASMP. Following are several examples of this.

Carlos, a 59-year-old Hispanic part-time cook with less than nine years of formal education and a very low annual household income, was experiencing a significant exacerbation of his arthritis symptoms and was not scheduled to return to the Charity Rheumatology Clinic for more than a month. The investigator was able to facilitate Carlos in getting a much earlier appointment, and showed him how to work through the Charity appointment system to do the same for himself in the future. This was an example of using verbal persuasion to help Carlos gain self-efficacy and to help him to be more knowledgeable in self-managing his condition. The telephone network at Charity Hospital can be a very confusing maze, and guidance in successfully reaching the

appropriate number may help a patient (e.g., Carlos) be more confident and willing to seek out appropriate care in the future. Once Carlos had successfully intervened in the scheduling and management of his care, it was hoped that the self-accomplishment would further enhance his self-efficacy.

During the final phone call with Linda, a 56-year-old African American disabled clerical worker, it became clear that she was very likely depressed (as evidenced by her score on the GDS scale). This possibility was discussed with Linda, and she stated that she suspected that she was depressed but she had not wanted to bring it up with her physician. Linda had an appointment scheduled with him the following week and she was strongly encouraged to discuss her possible depression with him. She stated that she would do so. Linda had been diagnosed with her rheumatoid arthritis within the past two years.

Participation in the study was helpful to some participants in gaining assistance in contacting or obtaining medical care. For some patients with arthritis and have other medical problems, facilitated access to medical care may be a valuable component of their self-management.

#### *Relief of Social Isolation*

Part of the ASMP benefits is that the program allows people to be with those who understand their condition. Evidence that the phone calls mimic this can be found in the following example.

Jan is a 56-year-old disabled Wal-Mart worker with an annual household income of between \$15,000 and \$30,000. During the week-one phone call, Jan sounded depressed and anxious. Her pain had increased since her initial visit. Jan did recall that her

insurance would allow her to have access to a fitness center for a low price. This option was discussed and the alternative suggestion of substituting a stationary bike for a walking program seemed to be a good idea to her (however, she did not further explore any of these options during her participation in the study). She sounded relieved and grateful for the call and the suggestion. Also during the first phone call, Jan stated that “I am having a lot of trouble moving around. I’m not sleeping well and my pain in my legs and toes is worse.” During the week- four phone conversation, Jan stated that “I have been really down and depressed this past week...No one believes that I am sick. My kids are 20 and 22; they don’t understand and believe me. They won’t let me drive anymore...I just go in my room and don’t deal with it.” During week four Jan talked at length about how depressed she was and how no one around her (family, etc.) believed that she was really sick or gave her any type of encouragement. She wanted to walk the seven blocks to Wal-Mart just to get out but was afraid to do so. By week five Jan stated that she was “very, very depressed.” She did try to walk the seven blocks to Wal-Mart the previous week but had to stop due to pain and fatigue. She eventually had to have someone come and get her. Since then she had not left her room. Jan felt like a “total failure.” Barriers to her care and related problems were discussed, along with the relationships between depression and fatigue. She stated that her physician did know about her depression and was working with her in terms of medications, etc.

During the week-four phone conversation, Jan mentioned that she was becoming dependent on the phone calls as they were her only source of encouragement. This tendency was discussed and it was suggested that she needed to try and develop positive self-encouragement and support, and to try not to rely on the external support that was

not evident in her life. She stated that she had ordered a Walkman CD player and she would begin to play her relaxation CD's when it arrived. She was hopeful that would help. By the end of the study Jan had met her modest goal of improving her ability to walk around her house for short periods and to begin to overcome her nearly constant fear of falling.

As illustrated by the qualitative data, the telephone intervention program benefited some participants in a manner not easily reflected in quantitative analysis. In addition to helping some participants engage in self-care activities, the telephone interventions were in some cases successful in facilitating access to needed health care.

#### *Qualitative Theme Two - Adhering to the Plan/Attempts Toward Mastery*

A second major theme that emerged was the participants' desire to adhere to their program; this might also be described as their attempts toward mastery. Some of the participants expressed their adherence as a way to deal or cope with their arthritis or other factors in their lives. Other participants simply dedicated themselves to whatever their task was. Some participants worked so hard at following their plans and reaching their goals that it became counterproductive (i.e., they made themselves worse). The following example may help to clarify this theme.

At the final call, Patty (a 61-year-old white retired computer accountant) indicated that she was doing very well in spite of a tropical storm that was literally bearing down on her. She was doing a very good job of coping with and managing her condition and sounded optimistic about her future. During the first phone call Patty felt that she was already doing all of the exercises in her action plan and wanted more to do. During the second call she expressed that "I really believe that pain control is a state of mind, and

over the years I have had a lot of practice in dealing with it.” Patty had been diagnosed with fibromyalgia, and the symptoms from that had caused her to modify her exercise level on any given day according to her pain levels. Program modifications were discussed during the phone calls. She had an extreme exacerbation of her fibromyalgia during the course of the study, making her pain nearly unbearable. Even during her worst pain, Patty remained very pleasant on the phone and expressed her determination to resume taking care of herself (i.e., exercising) as soon as her condition would allow her to do so. Patty had been managing her osteoarthritis for more than ten years.

Adherence is a goal that usually accompanies initiation of fitness activities. Qualitative analysis indicates that the telephone interventions were, at least in some cases, helpful in promoting adherence to fitness activities. Future research examining long-term follow-up is indicated.

*Qualitative Theme Three - Evidence of Enhanced Participant Understanding of their Condition*

Often patients initially lacked even a basic understanding of their disease; in some cases they are unable to even name the type of arthritis that they have been diagnosed with. This lack of understanding was observed even in patients who had been dealing with their arthritis for many years. The third major theme that emerged during the coding of the interview material was evidence of enhanced participant understanding. The design of the study did not include a pre-test/post-test design that would allow measurement of participant understanding. This design was consistent with the Arthritis Self-Management Program (ASMP) upon which the telephone intervention format used in this study was based. Specific knowledge measures were not included in the ASMP; therefore the

ASMP did not have a manner in which to assess the learning that may occur during participation in the program. However participants' indicated during the interviews that they had used the informational packets given them and had increased their understanding of their condition. Following is an example of this (see also the earlier description of Jim on pages 94-95).

Dan was a 61-year-old African American part-time patient program coordinator who had attended graduate school, had an annual household income of less than \$15,000 and had a five to ten year history of osteoarthritis. He indicated that he appreciated the calls: "I know you want to help and you want to see if self-care works." He indicated that he had read the handouts and was working toward his goals. By the second call he was familiar with the relaxation techniques and was using them to successfully manage stress and pain.

Several participants expressed unrealistic expectations and/or misunderstandings of what they might be able to accomplish; the phone calls gave the investigator an opportunity to clarify the misunderstandings. Following is an example of this theme.

During the first call, Jack (a 74-year-old white retired oil company clerk who had attended graduate school) was able to accurately recall what type of arthritis he had. He then asked the investigator: "When do you think I'll be able to get rid of this pain entirely?" The investigator discussed with Jack that this was probably not a realistic goal and then discussed the role of self-care in pain management. Jack had a one to two year history of rheumatoid arthritis.

It was thought that the telephone interventions might be helpful in increased understanding of the participants' arthritic conditions. While the study design did not



allow for measurable analysis of possible learning effects, the qualitative data described some evidence of increased understanding. Future research measuring the effects of telephone intervention on patient understanding of the condition is indicated.

*Qualitative Theme Four - Specific Problems Encountered by the Participants*

A fourth major theme that was identified was that the participants typically had other life events arise during the course of their involvement in the study. These events are likely not to be unique to the intervention group, but are significant as they often seemed to have significant impact on the participants' involvement in and potential benefit from the study. Further, these results underscore the challenges that older adults face when managing arthritis. A major sub-category that quickly emerged during the phone calls was that many participants were developing new illnesses (or were at least experiencing exacerbations in symptoms of existing problems) that were interfering with their action plan programs. Depression emerged as an important factor; in many cases the participant would state that no one believed or understood the pain/problems he or she was having; this lack of support seemed to exacerbate the feelings of depression. The participants in the study sample were all older adults, most of who had health problems in addition to their arthritis. Many of the participants also had low annual incomes and educational levels. These problems may not have been significant enough to preclude their participation in the study, but may have affected their level of adherence to their respective action plans and their sense of mastery over arthritis. It was assumed that the control group had the same level of comorbidity as the intervention group. Participants described or experienced these problems as follows:

Margaret, a 78-year-old, white retired dressmaker stated that “I have been in bed and been very sick with the flu for the past week, but I have been trying to get out of bed and exercise”. This quote occurred during week two; until that time she had been ahead of schedule in her action plan program. By the third week she stated “I have been so sick and have been lying around so much...I feel very feeble...my right hip and spine hurt so much.” By week four Margaret indicated that she was extremely depressed. She had a close friend pass away that week and had also experienced some financial problems. These events, combined with her being sick much of the time, had greatly limited her physical activity. Her depression had also greatly interfered with her sleep cycle. Fatigue was discussed and she was referred to the handout on fatigue. The potential use of distraction techniques for her pain was discussed. Margaret did not fully understand them but the techniques were further explained. She decided that she preferred to rely on her pain medications and muscle relaxers instead.

Margaret interrupted several of the calls to her; the calls had to be continued at a later time. The final phone call (using the final data collection instruments) took three separate phone calls to complete. Margaret seemed to be tired and exasperated with the calls by the end of her involvement.

Sam was a 66-year-old white male who was still working part-time as a janitor. Sam had less than nine years of formal education and an annual household income of less than \$15,000. He was quite depressed and had significant medical problems (mainly cardiac and respiratory problems) that made life very difficult for him. Sam had to have a pacemaker inserted during the course of the study and continued to work as a janitor (he had to keep working for financial reasons). Sam had numerous challenges as he

attempted to meet his goal or stay on the program that was established with and for him. Through it all he remained very appreciative of the program and the weekly calls. He frequently became short of breath during the phone calls to the point where the calls sometimes had to be cut short.

Several significant developments arose over the course of the study for Rose, a 55-year-old African-American disabled adult care sitter who had less than nine years of formal education. She called the investigator at home several times during the study to describe symptoms that may be associated with a developing serious medical condition (rapid weight loss, sweating at night, unable to eat, possible blood in her urine and stool). The investigator encouraged her to seek immediate medical care and then was able to help facilitate her in getting that care. In spite of her problems, Rose attempted to adhere to her action plan contract. During the last phone call she was very depressed and upset and was in a great deal of pain. The investigator encouraged her to see the rheumatologist as soon as possible and she agreed to do so. It is quite likely that her state of mind during the final phone call may have affected her final ASE and GDS scores.

Nancy, a 62-year-old African American retired cashier, was having severe knee pain at the beginning of the study and she reported that the pain continued to increase throughout the duration of her participation in the study. She became increasingly depressed about it and was beginning to take pain medication that she had been given for an earlier episode of the knee pain. However Nancy was becoming afraid that the new medications would be contraindicated by some new medical conditions. The investigator made several calls for her to the medical staff at Charity, and was eventually able to get

the participant on the phone with her physician at Charity. The doctor recommended that she change her medication immediately.

Many of the participants reported significant life events (often physical, emotional or medical challenges) that arose during the course of their participation. Some of the participants were able to function without any apparent effects of these events, while others had their ability to participate in the program impacted to varying degrees.

*Qualitative Theme Five – Observations Directly Related to the Phone Methodology*

The fifth major theme that emerged was that of observations related directly to the phone intervention. Other than the initial intake interviews, virtually all of the data collection was done over the telephone. Approximately 250 phone calls were completed during the study, with perhaps twice that many being attempted (some participants were not home, etc.). The phone calls themselves emerged as a theme during the coding and analysis process. Some of the subcategories were background noise and logistical problems, observations on communication, and a tendency for some participants to develop dependency on the phone calls. The following examples help to illustrate this theme.

Jason was somewhat unusual for this study. He was a fully employed contractor (58-year-old African-American) who was a college graduate, and had an annual household income of more than \$75,000. Virtually all of the phone conversations occurred via his cell phone while he was at work (his preference). During one conversation, Jason was under a house; he was working on a broken sewer line and was surrounded by raw sewerage. He insisted on finishing the call and remained very pleasant and cooperative.

The conversations with Marla, a 78 year-old African-American retired cook, were

often somewhat challenging. She had less than nine years of formal education, an annual household income of less than \$15,000 and a long history of osteoarthritis. There was always loud and constant background noise and distractions. Usually one person answered the phone and it was two or three people later before Marla actually came to the phone. When she did come to the phone she was usually also dealing with constant comments and conversations from the others present at her house and the television was usually so loud that she could barely be heard. The conversations (and the data collection, especially over the phone) were made difficult by the impression that Marla had a difficult time following and understanding what was the purpose of the phone call. Through the entire program she always remained very pleasant and cooperative, but the investigator was not sure Marla ever knew who he was or what was trying to be accomplished over the phone.

The types of problems described in this section are inherent challenges to any program utilizing a telephone methodology. How effectively the individuals both receiving and making the phone calls in this type of intervention deal with these problems may play a significant role in the eventual success of the program.

### *Summary of Results*

The quantitative results of this study do not indicate that the intervention or site had significant effects on any of the dependent variables measured: ASE, GDS, and perceptions of pain or fatigue. Time did have a significant effect on ASE scores for all groups; i.e., participants in both the control and intervention groups had higher levels of confidence (self-efficacy) in managing their arthritis at the end of the study than they did at the beginning.

The qualitative results described an intervention that appeared to be quite important and helpful to many of the participants in the intervention group. Many of these individuals live in a manner that often presents special challenges and barriers to obtaining even basic medical care, let alone individual guidance in the management of chronic conditions such as arthritis. These individuals would not be likely to attend classes or arthritis management sessions offered outside of their homes. Telephone intervention was useful to these individuals in several ways, including facilitating their general medical care and appearing to help enhance their understanding of their condition.

## CHAPTER FIVE

### DISCUSSION

The results of this study indicate that telephone intervention can serve a population (older adults with arthritis) by offering them information and skills they can use in the self-management of their condition. The sample that participated in this study might not otherwise be served as well by traditional manners (i.e., attending classes educational courses designed to promote self-management behaviors). These individuals, many of whom have little formal education or who may be described as belonging to a lower socioeconomic status, were able to participate in the convenience of their homes at virtually no cost to them. Additionally, a telephone intervention program similar to the one used in this study may be implemented at a relatively minimal cost compared to a more formal and structured intervention program might cost. The qualitative data accumulated in this study, as evidenced by the interview transcripts and comments, reveal that the participants discussed the value of the program and wanted to participate in a program of this nature. The low attrition and low refusal rates seen in this study are further evidence of the apparent need for and desire to be a part of this type of healthcare intervention.

## *Summary of Research Questions*

### *Question One*

Was there a difference by group in the effects of telephone intervention on self-efficacy (as measured by ASE scores)? The study findings revealed a significant increase in arthritis self-efficacy across all groups over time, but the change was not unique to the intervention group. There was a trend toward reaching goals in a population that may otherwise not have been served.

The study design was classified as an experimental design, utilizing random assignment of participants to control and intervention groups. The independent variable was the telephone intervention. Every participant in the study received the same packet of information during the initial meeting, and each participant was involved in establishing goals and developing an action plan designed to help meet that goal. The primary difference between the intervention and the control groups was that the intervention groups then received four phone calls before the final data collection call in week six, while the control group participants received only the final call.

Discussion with several members of the control groups during the final phone call indicated that these individuals had been using the information given to them and the action plan established during the initial meeting. This may have been a factor in the lack of significant differences between the control and intervention groups, especially on the post-ASE scores. Some of the participants in the control group may have been sufficiently self-motivated to use the material presented to them, along with their plan of action, and derive similar levels of benefit as the intervention group (who were being called weekly) did. From both practical and clinical standpoints, this behavior was very



desirable; patients can be given information and assistance in setting goals and developing an action plan, and use it to pursue self-management behaviors without the need for a lot of external reinforcement or guidance (i.e., the phone calls). This interpretation suggests that minimal intervention might be sufficient to raise arthritis self-efficacy.

An additional group would have allowed the comparisons among three conditions: 1) a no treatment group that was simply pre-tested and post-tested on the outcome measures, 2) a second group that received the educational materials and developed goals and action plans, and 3) a third group that received the educational materials, set goals and developed action plans and received the weekly phone calls. Participants in this third additional group would have undergone the initial data intake as did the other groups: demographic data, ASE and GDS scores, and self-ratings of pain and fatigue levels. However, these participants would not have been given the informational packets and would not have developed action plans. They would have been contacted during week six. The modified design may have helped to differentiate the relative effects of the educational materials, the action plan/goals setting, and the phone intervention on the outcome measures of arthritis self-efficacy, depression, pain and fatigue.

This rationale has been supported by other research. Burckhardt et al, in a randomized, controlled trial examining the effects of education and physical training on patients with fibromyalgia, described similar concerns (Burckhardt, Mannerkorpi, Hedenberg, & Bjelle, 1994). In that study, one group was a control while the two other groups received different levels of intervention. Groups two and three both received initial education, but the third group also received guidance in physical training. This design is similar to the

current study, in which both groups received an educational component with the intervention group also receiving weekly guidance in their action plan. In Burckhardt's study, the group that received both education and physical training achieved positive results that were similar (in self-efficacy and other factors) to the group that received education only. Burckhardt hypothesized that the education plus physical training group may not have taken as much responsibility or self-initiative as did the education only group; they may have relied on the guidance from the physical training sessions as a sort of crutch. There may be some similarities in the current study. Participants in the control group may have sensed the need to take more responsibility for initiating and continuing their action plan, knowing that they would not be receiving the weekly calls of information and encouragement that the intervention group participants would be receiving.

The telephone intervention design of the study may have contributed to another potential explanation for the lack of significant group effect. The ASMP, the model upon which the telephone intervention was based, was shown to have positive effects on patient outcome. It has not been clearly shown which specific aspects of the ASMP were most responsible for the positive outcomes. However, it is likely that the social nature of the ASMP (the group classroom setting) may have contributed to the positive outcomes. This may be especially true in the increases in arthritis self-efficacy. Performance accomplishments, verbal persuasion and vicarious experiences are all elements of the SCT that can contribute to increased self-efficacy, and these elements are all more likely to be present in the group setting. In other words, it may be difficult to replicate the social nature of the ASMP over the telephone.

The sample utilized in this study was different in composition from most of the samples previous ASMP/ASE research had been based upon. Most of the samples used in previous research tended to be more highly educated, belonged to a higher SES and were more predominantly white than the sample used in the current study. It has been surmised that many of the participants in the current study either would not or could not have attended (at least on a regular basis) a program like the ASMP.

### *Question Two*

Did the telephone intervention have an effect on the depression ratings for the participants in the different groups? There were no significant changes in depression scores from pretest to posttest. Many of the participants had pretest GDS scores that were near or above the level indicating a significant level of suspicion for the presence of clinical depression. It was unrealistic to expect that a series of telephone calls could have a significant impact on as complex of a condition such as depression. However, screening for depression is an important part of managing chronic conditions like arthritis, both in terms of patient self-management and clinician intervention. Several of the participants were counseled during the telephone calls that seeking help for their depression could potentially be in their self-interest.

### *Question Three*

Did the telephone interventions have any significant effects on the participants' perceptions of pain? There was a significant decrease in pain ratings across time for all participants, but the changes were not unique to the intervention group. The above discussion arguing the need for a third group is relevant to this finding as well.

*Question Four*

Did the telephone interventions have any significant effects on the participants' perceptions of fatigue? The perception of fatigue changed differently as a result of participants being in a certain group and at a certain clinical site. This is relevant from a functional standpoint; fatigue is a common and often debilitating side effect of arthritis. During the telephone conversations, many of the participants repeatedly voiced complaints of fatigue. The information packets given to all participants included several pages devoted to potential causes of and tips for managing fatigue. It is possible that the participants in the control group benefited from this written information as much as the participants in the intervention group did.

*Question Five*

The final research question addressed the effects of telephone intervention on participants' attempts to reach various functional/activity goals in the self-management of their arthritis. More participants in the intervention group were able to achieve the desired goals than were the participants in the control group, but the difference was not statistically different. The goals that participants set for themselves were virtually all functional. Any intervention might help participants reach their goals (and thereby potentially improve their functional status). It should be noted that many of the participants needed some guidance in helping to establish participation goals. The last question on the initial demographic data/interview sheet was "What is your primary goal for participating in this study"? Participants who were still a little confused about the overall purpose of the study were not sure what to say when asked this question. When this occurred the investigator proceeded with the intake in an attempt to clarify things for

the participant. The role of arthritis self-efficacy was explained to each participant, as well as the nature of their involvement in the study. Finally the development of the action plan was discussed with each participant. At this point the goal question was again asked of each participant. Nearly all of them could now define a goal in more concrete terms (i.e., related to their action plans). For some of the participants the initial goal question was too abstract for them to answer unless it was tied to a behavior such as the action plan. It can be argued that this process of working through goal-setting and tying it in to an action plan served as a form of intervention for the control groups.

A majority of participants in each group selected “walking better” as their primary goal. This finding may be an indicator of the basic level at which arthritis affects the older adult population. Older adults tend to greatly value their independence. Arthritis commonly affects the knees, hips and spines, making walking difficult, painful, and at times unmanageable. Impaired walking can limit the functional independence of older adults. This combination of factors might help to explain why such a large number of participants (67% of the total sample) identified walking as a major problem and one that they would most like to address by their participation in the program. The types of walking goals varied greatly among participants according to their respective levels of involvement. Some participants who were already functioning at high levels and walking significant distances were interested in enhancing their distances (e.g., improving from their current one mile to two miles or more). Other participants were more severely involved; a typical goal for them might be to simply walk up one flight of stairs without having to stop secondary to pain or fatigue. In either situation participants had identified walking limitations as a barrier to the quality of life (and potentially a level of

independence) that they would like to be leading. They looked at involvement in this program as an opportunity to set a structured walking program with weekly goals that they could follow and possibly exceed. A high percentage of participants in both the intervention (84.6%) and control groups (74.2%) were able to reach or exceed their goals for walking better. Since each group was given a structured walking program with weekly goals at the beginning of the study, it is not possible to compare their accomplishments to a true control group (a group that would not have received a structured program).

The second most frequent goal selected by participants was to increase their exercise level. Several of the participants mentioned during the study that they had never engaged in any type of regular exercise program and looked at participation in the study as an opportunity to do so. Others had exercised at one time but believed that their arthritis would no longer allow them to do so safely. The information in their handout packets discussed the fact that exercise is possible and is even desirable for patients with arthritis. The investigator regularly reinforced this message to participants in the intervention groups.

The only other goal that was selected by more than five percent of the participants was the desire to gain better functional use of their upper extremities. This typically involved participants whose arthritis had affected their shoulders and/or hands, making many functional activities painful. Several participants did select goals that were specifically related to functional activities that they felt limited in (e.g., being able to work longer in the garden or at the sewing machine with less pain). However, as noted, the large majority of participants focused their efforts on more general goals (i.e., being

able to get around better as opposed to focusing on more detailed or specific activities). It is possible that if the question had been stated differently more of the participants may have stated their goals in more specific functional terms. This is an idea to be explored in future research.

### Qualitative Analysis

The five major themes that emerged during the qualitative analysis were identified in Chapter Four. The relevance of these themes is discussed in the following section.

#### *Usefulness of the Study*

The first major qualitative theme that emerged was various ways in which the participants believed that their involvement in the study was helpful to them. A number of the participants reported that the individual management program designed for them helped them to initiate and maintain some form of fitness/exercise program for the first time in their lives. This outcome is valuable. Telephone intervention seems to be helpful in encouraging older adults to participate in programs and have positive experiences. These positive experiences, in turn, might then help to overcome negative misperceptions about exercise that may exist. This scenario would be a practical illustration of the personal accomplishment aspect of the Social Cognitive Theory (Bandura, 1986a). As was pointed out earlier, the older adult may have to overcome a barrier such as depression to even engage in an exercise program, a program that might prove to build for future positive behaviors.

A related theme that several participants mentioned during the interviews was that the telephone interventions gave them confidence and reassured them that it was appropriate

for older adults to exercise, even if they had not done so before. This is a message that is not always reinforced in our culture, which tends to be youth oriented. Modern media reflects this and may be a potential barrier to exercise. Blair and colleagues proposed that media and advertising campaigns may increase older adults' apprehension levels about exercising by portraying exercise as something that must be highly strenuous to be health-promoting (Blair, Kohl, Gordon, & Paffenbarger, 1992). The informational packets and subsequent telephone interventions emphasized the importance of engaging in enough fitness activity to be helpful but not to the extent of being potentially harmful. A well-structured telephone intervention can be helpful in encouraging older adults that fitness activities need not be limited to the youth in our culture.

The unconditional support and positive reinforcement provided to participants during the telephone interventions also emerged as a theme during the interviews. Lack of positive support or even disapproval from physicians, family members and close friends may also serve as deterrents to older adults considering a fitness program. O'Brien-Cousins and Burgess examined the role of the physician in this area and concluded that most people do not get detailed advice or information from their physician regarding starting an exercise program (O'Brien-Cousins & Burgess, 1992). In fact, the standard "See your physician before starting an exercise program..." disclaimer may serve as a deterrent to those wishing to start an exercise program because it potentially creates a dependency in some individuals wishing to begin to exercise. Telephone intervention might be an appropriate manner of providing positive reinforcement and encouragement.

Several of the participants in this study were already engaged in regular fitness programs, and the telephone interventions may have served as a source of continued



encouragement to them. Certainly there are older adults who do think about exercising late in life and weigh the risks and benefits in making their decision (O'Brien-Cousins, 1998). O'Brien-Cousins described older adults who had chosen to exercise as individuals who knew the benefits of exercise. Some of these individuals even expressed disappointment about their cohorts who had chosen not to exercise (some of these same feelings were expressed during interviews in the current study). The older adults in O'Brien-Cousins study who did not exercise did not talk about ways in which they might benefit from exercise. These individuals did, however, talk quite a bit about their reasons for not exercising. Dishman and Steinhardt concluded that attitudes, opinions, and beliefs can be changed (Dishman & Steinhardt, 1990). This was interpreted as meaning that most individuals do have the potential to be open to and respond to health and exercise initiatives, and that this potential can be developed. This would seem to be a potentially positive application of a telephone intervention program.

Finally, several of the participants commented on how much they enjoyed receiving the phone calls; it seemed apparent that they may not have been receiving much social support from other sources. Social support is a construct describing the relationship between the social environment and optimal health (Kaplan, Atkins, & Reinsch, 1984). Social support has been found to be important in several ways: it is important to the maintenance of good health (Pilisuk & Minkler, 1985); it reduces psychological distress (Holohan & Moos, 1981); and it has been shown to reduce mortality in elderly populations (Blazer, 1982). O'Brien-Cousins stated that "for older adults to live actively, some degree of social endorsement or incentive may be an essential prerequisite". This may be important in overcoming the lack of support (or even disapproval) that spouses,

children, friends and physicians may express to older adults who are interested in becoming more physically active.

### *Facilitating Medical Care*

A practical and important theme that emerged during the interviews was the opportunity for the investigator to facilitate medical care (or access to medical care) of the participants. One of the more common variations on this theme involved questions about appropriate medication dosage. Participants had questions about their current prescriptions, or questions about how they might adjust their medications (especially pain medications) in response to exacerbations they were experiencing. The investigator was not qualified to advise participants on medication dosage, but in each case was able to inform the participant of the most efficient manner to contact the appropriate person. This advice often involved giving the participant a direct clinic or office phone number that would enable them to contact their physician. Finding the correct number without assistance, especially in the bewildering Charity Hospital system, might have been much more difficult and resulted in potentially harmful delays in changing medication dosage.

The telephone interventions were also helpful in assisting participants in their efforts to reschedule medical appointments. Several participants, during the course of the interviews, indicated that their symptoms or other medical conditions had significantly worsened, and their next scheduled appointment may have been months away. The investigator was able to facilitate the participants in re-scheduling their appointments for more acceptable dates, often within a day or two. The participants may have been able to reschedule these appointments without this assistance, but (again, especially in the Charity system) it is often very difficult to contact the appropriate person or office to

make such a change.

The investigator was also able to help participants communicate with their physician who may have gotten their message but had been unable to contact the participant (due to logistics, volume of messages, etc.). The investigator was able to speak directly with the physician, explain what the participant's concern was, and hand the physician the participant's number so that the communication could occur almost immediately. In all of these cases the investigator served as an unofficial ombudsman for the participant. Although this was not necessarily an anticipated outcome or result of the study, it seemed to be greatly appreciated by the participants affected. Patients in today's healthcare system often feel intimidated and overwhelmed by the system. They may not know who to call and do not feel that they can be their own advocates in issues of healthcare. This may even be truer of older patients who have chronic conditions and may be depressed. It should be noted that when the investigator was able to find a way to facilitate care (i.e., locate the direct phone number, etc) the participant was instructed in how to do this themselves so that in the future they would be more knowledgeable in facilitating their own care.

#### *Adherence to Action Plan/Attempting Mastery*

Participants' desire to adhere to their program was another theme that emerged. Adherence was an important factor; it was hoped that fitness behavior practiced during the study might transform into long-term lifestyle changes that might assist in self-management of the participants' arthritis. The relationship between self-efficacy and adherence has been examined. Although he did not specifically examine arthritis self-efficacy, McAuley et al performed a series of studies that examined various aspects of the

effects of exercise efficacy on short and long term adherence to exercise (McAuley, 1992, 1993; McAuley et al., 1993). To summarize the three studies, self-efficacy was shown to be the main factor in helping an individual initiate an exercise program and in helping the individual continue with the program after the formal supervision had ended. During the intermittent period (in the middle of a long exercise program) efficacy was not as important as the habitual changes that had taken place. In other words, if the participant continued their fitness behavior long enough it would become habitual and the arthritis self-efficacy would not play as much of a role.

As may be seen in Table 7, there was a trend for the participants' arthritis self-efficacy scores (ASE) to increase over the duration of the study. While this trend was not unique to the intervention group, it was hoped that long-term follow-up might reveal that many of the participants would be adherent to their fitness behavior. The short term qualitative data revealed that many of the participants expressed a strong desire to "stick with" their new fitness programs in spite of potential barriers (e.g., poor weather, home and work responsibilities, new health problems, etc.).

#### *Evidence of Enhanced Participant Understanding of their Condition*

The design of this study did not include a pre-test/post-test design that would allow measurement of participant understanding. This design was done in part due to the attempted comparisons between the telephone interventions conducted in this study and the Arthritis Self-Management Program (ASMP) described in Chapter Two. The ASMP did not utilize testing of knowledge base but rather assessed outcome measurements as a basis of evaluating the effectiveness of the ASMP in helping individuals in their self-management of their arthritis. However, qualitative interview data did give the

investigator some insight as to whether participants had used the informational packets and had increased their understanding of their condition. Several of the participants indicated (without prompting from the investigator) that they had read the instructional information provided to them. They had questions and comments about the material that demonstrated their level of understanding of the material in the packets and their desire to learn more. In several instances it became apparent that participants had read through the information but were confused by some of it. The investigator was usually able to discuss the information with those participants until they indicated that they were comfortable with and understood the material. In some cases where this was becoming difficult the participants put another family member on the phone with the investigator, who then attempted explained the information to that person's level of understanding. Even though these clarifications were usually successful, several shortcomings of the telephone intervention were brought to mind.

1. In a typical clinical situation (in person), any teaching or patient education for older adult patients is usually done (whenever possible) with another family member present. This may help to reinforce the instruction that has taken place. Once the patient/client gets home, the family member can assist them in reviewing what had been told to them in the clinic.
2. While several of the participants did admit to being confused and sought help from family members in helping them to interpret the information, the investigator must assume that there were other participants who did not grasp or retain the instructional information but did not ask for clarification. This could certainly affect the level of success attained with the intervention and might be reflected in the final assessment

results. Without a pre-test/post-test assessment tool for content understanding, no definitive conclusions can be drawn.

It was thought that the individual teaching attention provided for each participant might provide a benefit over the group environment. However, Rickheim found that patient learning does not vary significantly individual versus group learning formats in the home health environment (Rickheim et al., 2002).

### *Depression*

Another qualitative theme that emerged from reviewing the interview material was that participants encountered specific problems during the course of their participation in the study. As was pointed out in Chapter Four, depression quickly emerged as a major problem with many of the participants. This result was not surprising. According to a 2000 report by the National Academy on an Aging Society, older adults with arthritis were more likely to be dissatisfied with their life, dissatisfied with their health or physical condition, and dissatisfied with their financial condition than were their cohorts who did not have arthritis (Society, 2000).

However, the prevalence of depression in the general older adult population has been the source of debate. Roberts and colleagues categorically stated that healthy older people are no more likely to be depressed than others are (Roberts, Kaplan, Shema, & Strawbridge, 1997). Other researchers have argued that many older people do show signs of depression but that their signs are relatively minor. These individuals may blend into older adult stereotypes and may not qualify then for a medical diagnosis of depression (Blazer, Hughes, & George, 1987; George, 1993).

Exercise has been shown to be significantly related to fewer depressive symptoms in the elderly population (Allison & Keller, 1997; King, Taylor, & Haskell, 1993; Ross & Hayes, 1988). This relationship is thought to exist because exercise increases the body's natural opiates (endorphins) leading to a feeling of well-being and regulates norepinephrine release (a hormone that may lead to decreased depression) (Cronan & Howley, 1984; Siever & Davis, 1985). The key was getting the depressed individuals to engage in their exercise program. Davis-Berman provided evidence that depression may minimize physical self-efficacy in aging women and make them less likely to exercise (Davis-Berman, 1989). Several of the participants in this study indicated that the depression itself appeared to be a barrier to the involvement in an exercise program that could potentially help the depression. The impression that arose from the interviews was that for many of the participants, depression was as much or more of a problem for them than was their arthritis or other physical problems. It may be difficult to separate the "chicken or the egg" phenomenon that often affects individuals with chronic pain conditions. Are they depressed because of their condition or is their condition worse because of their depression? Both aspects may be difficult to effectively address. Chronic conditions like osteoarthritis (or fibromyalgia, another condition that affected over 28% of all participants) may not be "visible" to others. Others may view the affected individual as someone whom is constantly complaining about a condition that cannot be as bad as it is being portrayed. Pain is an extremely subjective concept. If someone tells us that they hurt, we can choose to believe them or not. An individual who is in virtually constant pain may find that complaining about that pain may begin to elicit responses ranging from diminished support to outright ridicule from those around them. Several of

the participants indicated that no one believed that they were sick; they felt misunderstood and often very isolated as they tried to cope with their chronic conditions. It might be argued that the telephone interventions may provide an outlet for these individuals.

### *Other Problems Encountered by Participants*

During the course of the interviews, participants related various problems that may have affected the course and outcome of their participation in the study. These problems may have developed during the study (e.g., some participants had a cold, flu or some other transient but significant medical condition) or may have been ongoing. Several participants were full-time caretakers for sick and elderly spouses or other family members. Their involvement and responsibility in providing this care often necessitated the need for them to make their self-care a lower priority. The discussion of these problems is not noteworthy in the sense that it may have affected the results between the control and intervention groups. It is most likely that in this randomly assigned sample, participants in both the control and intervention groups would have experienced problems in terms of frequency and severity to similar degrees. What is relevant is that many older adults have problems (or at least life situations) that may have significant impact on their ability to self-manage their medical condition (e.g., arthritis). These circumstances can potentially have a negative effect on the usefulness and ultimate success of a telephone intervention program. Someone who is spending virtually every waking moment caring for an ill spouse may be unlikely to have the time or energy to engage in fitness or other self-care activities. However, it may be argued that such scenarios further indicate the need for expanded telephone intervention in health care. The previously mentioned



individual who may have very little time to engage in home self-care activities may be even less likely to leave the home for a physician visit or even take the time to initiate a call to a physician for advice or information. Telephone intervention, to some extent, can take a form of intervention to the patient rather than relying upon them to initiate their own care.

#### *Observations Directly Related to the Phone Interventions*

The telephone calls themselves emerged as a theme during the coding and analysis process. As previously stated in Chapter Four, about 250 phone calls were completed during the study, with perhaps twice that many being attempted (participant not reached for various reasons). The observations that were made and situations that arose were not unique or unusual for the telephone intervention program used in this study. Some of the problems encountered during this study were probably unavoidable by nature of utilizing a telephone intervention design. Several calls were unable to be completed after being initiated. The participant would begin the call and then have something develop on “their end of the line” that would necessitate the need for terminating the call before its completion. While this was not unexpected, it did point out a potential drawback to utilizing a telephone intervention program. Several participants became frustrated and even exasperated during calls with them. Their feelings surfaced soon after the call began, and seemed to be related to their fatigue or other feelings of discomfort (according to them). The calls would be stopped at that point; the investigator would try and arrange for a convenient time with the participant to conclude the call. This happened several times during the final (data collection) call. The calls needed to be finished over a one to two week period rather than the desired one continuous session. Again, this was not

likely to affect differences in results between the control and intervention groups but rather points out potential problems with data collection as well as clinical intervention utilizing the telephone call format. Logistical problems might also affect the success of future telephone intervention programs using healthcare professionals. Repeated episodes of unsuccessfully communicating with patients or clients might result in a health care professional determining that telephone intervention might not be the most efficient use of time in trying to communicate with their patients/clients.

### *Learning Styles and Telephone Intervention*

It has been shown that learning styles vary among learners, and their needs are often best served when the teaching methods can adapt to those learning styles (Arndt & Underwood, 1990; Chase, 2001). The form of teaching that was utilized in this study was one that did not attempt to adapt to the individual learning styles of the participants. The same teaching style was used consistently throughout the study. The investigator discussed the information in the packets with each participant during the initial meeting. This style would tend to be most efficient with learners who employ an assimilative style of learning; i.e., learners who are able to reason by induction, and are good at systemic planning (Arndt & Underwood, 1990). However participants may have had different learning styles (e.g., divergent, convergent or accommodative learning styles) that may not have been met as well by the teaching style utilized in the study. The nature of the study dictated that a consistent teaching method be used for all participants. However, in practice it might be useful to analyze patients to determine which teaching style could best meet their needs. Most health care providers/patient educators do not have the training or background to perform this type of educational analysis (Arndt & Underwood,

1990; Chase, 2001).

The style of teaching utilized in telephone intervention is an area that has not been well explored. The review of literature for this study revealed that essentially all of the studies utilized a format similar to the one employed in this study. Exploring this topic might be an area of interest for future research. As has been discussed, most health care providers/patient educators have little training in assessing their own teaching styles or the learning styles of their patients. A program designed to assist clinicians in developing this type of expertise could be useful. Additionally, it is not clear how various teaching styles might be implemented in a telephone intervention format. Further research in this area is indicated.

The telephone intervention format was designed to be similar to the course structure of the ASMP, and both the ASMP and the telephone intervention format in the current study have a basis in SCT. A comparison between SCT, the ASMP and the telephone intervention was described in Table 7 (page 79). SCT has four major components that are thought to be responsible for enhancing self-efficacy: performance accomplishments, vicarious experiences, verbal persuasion and emotional arousal. The ASMP is structured so that all four SCT components are addressed by one or more of the weekly class sessions, in addition to tasks that ASMP participants are responsible for completing on their own. The telephone intervention format addressed three of the four SCT components that enhance self-efficacy. The only component not addressed by the telephone intervention format was to try and increase self-efficacy through the use of vicarious experiences. Individuals are more likely to benefit vicariously through the experiences of others when they have a chance to interact with them. The telephone

intervention format, by its nature, does not lend itself to interactions that could result in vicarious experiences. This lack of social interaction with fellow arthritis patients is a potential disadvantage for participants receiving telephone interventions when compared to those enrolled in the ASMP. Individuals whose major means of enhancing their self-efficacy is through vicarious experiences might be better served by participating in a self-management program that would allow for that interaction to occur. A possible solution would be to have patients with arthritis make the telephone calls to their fellow patients; the sharing of experiences may contribute to enhancement of self-efficacy through vicarious experiences.

### *Limitations*

The sample size may not have been sufficiently large to detect a small effect, especially between groups. According to Aron and Aron, for medium effect size 33 participants would be needed ( $d = .50$ ); for a small effect size 196 participants would be needed (Aron & Aron, 1999).

The lack of a true control group may also be considered to be a limitation of this study. As discussed earlier, the control group study still received an information packet, an action plan, and set goals for participating in the study. Administering only pre-test and post-test measurements, with no other intervention, might give more clarification to the effects of the telephone intervention and the information derived from the packets, as well as having a plan to follow.

### *Areas of Future Research*

Areas of future research may include further refinement of current study design. An additional control group, that receives no intervention, might result in a significant linear

difference in phone intervention effects between the three groups. Additional changes in study design might include carrying out the intervention for a longer period of time and changing the phone intervention to focus on other areas consistent with the Social Cognitive Theory.

### *Conclusions*

In a sample of older adults with arthritis, telephone intervention was related to perceptions on increased understanding of the condition as well as participants' belief that the intervention may help participants improve their fitness and self-management behaviors. Additionally, telephone intervention is a low cost alternative that may offer enhanced communication with and support from health care providers for patients who might otherwise not receive that level of care. Many older adults in the United States, especially those of lower socioeconomic status and/or low levels of formal education, do not have regular access to health care in the management of their arthritis. Telephone intervention may be a low cost and valuable alternative for these individuals.

The investigator believes that the telephone intervention used in the current study was of some benefit to people who would otherwise not have participated; this population would typically be underserved. The format of the intervention can be changed to improve its effectiveness, but based on the investigator's experiences and collecting the study data the investigator believes that the mechanism works and that this type of intervention could be a difference in the lives of those who participate.

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## APPENDIX A

### LOUISIANA STATE UNIVERSITY HEALTH SCIENCES CENTER IN NEW ORLEANS INFORMED CONSENT FORM

**1. Study Title:** The Effects of Patient Education on Arthritis Self-Efficacy in Senior Arthritis Patients in Different Clinical Settings.

**2. Performance Sites:** (1) Rheumatology Clinic, Room 222 Central, Medical Center of Louisiana (Charity Hospital); (2) Rheumatology Clinic, 7<sup>th</sup> Floor Lions' Clinic Building, LSUHSC.

**3. Names and Telephone Number of Investigators:**

Principal Investigator: David Pariser M.Ed., PT

Phone: (504) 568-4288; 24-hour phone number (504) 486-3509

Co-Investigators: Luis Espinoza, MD

Phone:

Richard Speaker, Ph.D.

Phone:

Ann O'Hanlon, Ph.D.

Phone:

**4. Purpose of the Study:**

The purpose of this research study is to examine the effects of telephone intervention on arthritis self-efficacy in older patients with arthritis. Arthritis self-efficacy is a term that describes how much confidence someone has in their ability to manage and cope with their arthritis. This confidence can be improved by the amount of information and education a patient receives about arthritis. The patient can receive this information from their health care provider (for example their doctor, physical therapist or nurse) in various ways. The most common way that a patient receives information about their arthritis is



during a clinic appointment. However, patients often have long periods of time between clinic appointments, and calling them on the phone may be a way to give them even more information about how to manage their arthritis. We are trying to determine if calling patients and giving them information and encouragement may be an effective way to increase their confidence in managing their disease.

### **5. Description of the Study:**

Approximately 120 adults will take part in this study. To be part of this study you must be at least 55 years old, you must have a diagnosis of either rheumatoid arthritis or osteoarthritis, and it must be possible to reach you by phone for the next 2 months. If you receive physical or occupational therapy treatment either in your home or in a physical or occupational therapy department during the next 2 months you cannot participate in this study.

The surveys you complete will be given to you by a physical therapist with 20 years of experience in working with patients who have arthritis. After you complete the surveys the same therapist may also call you to see how you are doing.

Once you have read and signed the informed consent form, you will be asked to complete 2 surveys today, which will take a total of about 20 minutes. There are a total of about 40 questions on the surveys. These surveys will include questions about how much confidence you have in your ability to perform functional activities (such as shopping, cleaning, running errands and exercising). There will also be some questions related to your feelings about your arthritis (does it make you sad, etc). We will ask you for a phone number where you may be reached. You may be called several times over the next 8 weeks. These phone calls will last about 5 minutes and will consist of me asking you questions about how you are doing with your arthritis and providing you self-care advice and encouragement. I will make every attempt to call you at your convenience. At the end of the 8 week period you will be asked to complete the same 2 surveys you will complete today so that we can determine if there have been changes in your confidence and functional levels of activity. If you have a return appointment scheduled for this clinic in 8 weeks the survey will be given to you in person. If you do not have a return appointment scheduled around that time you will receive the survey in the mail and will be asked to return them in a pre-addressed and pre-stamped envelope included with the surveys.

Participation in this study will not affect the regular care you receive in this or any clinic. There will be no change in your regularly scheduled clinic appointments. Your prescriptions will not be affected, and you may continue to communicate with your doctor in any way that you choose. In other words, you will receive the same treatment for your arthritis that you normally would whether you have chosen to participate in the study or not. The only difference is that you may receive several phone calls over the next 8 weeks.

### **6. Benefits to Subjects:**

No direct benefit to individual patients is expected. As a whole the study may help address whether a telephone-based patient education program helps the patient develop more confidence in dealing with and managing their arthritis.

**7. Risks to Subjects:**

There are no anticipated risks to you while participating in the study.

**8. Alternatives to Participation in the Study:**

You can choose not to participate in the study. If you choose not to participate in the study you will continue to receive the same treatment for your arthritis that you normally would receive.

**9. Subject Removal:**

You will be removed from the study if you cannot be reached by telephone during the next 2 months or if you receive physical therapy treatment for your arthritis (other than advice given to you over the phone by the therapist) in the next 2 months.

**10. Subject's Right to Refuse to Participate or Withdraw:**

Participation is voluntary. Refusal to participate in the study will involve no penalty or loss of benefits to which you are otherwise entitled. You may discontinue participation at any time without penalty or loss of benefits to which you are otherwise entitled. You may refuse to participate or withdraw from the study at any time without jeopardizing, in any way, your medical treatment at this institution in the present or future. Should significant findings develop during the course of the research, which may be related to your willingness to continue participation, that information will be provided to you.

**11. Subject's Right to Privacy:**

The results of the study may be published. The privacy of subjects will be protected and their names will not be used in any manner. The study is being conducted in the LSUHSC Department of Physical Therapy.

**12. Release of Information:**

The records will be available to the LSU Health Sciences Center, Institutional Review Board; the Department of Education, Curriculum and Instruction at the University of New Orleans; and the Department of Human Performance & Health Promotion, University of New Orleans. While every effort will be made to maintain your privacy, absolute confidentiality cannot be guaranteed. Records will be kept private to the extent allowed by law.

**13. Financial Information:**

- a. Subjects will not be charged or paid to participate in the study.
- b. Subjects must meet all costs due to unforeseen complications.

**14. Signatures:**

The study has been discussed with me and all my questions have been answered. I understand that additional questions regarding the study should be directed to the investigator listed on page one of the consent form. I understand that if I have questions about subject rights or other concerns, I can contact the Chancellor of LSU Health Sciences Center at (504) 568-4801. I agree with the terms above and acknowledge that I have been given a copy of the consent form. I understand that I have not waived any of my legal rights by signing this form.

---

 Signature of the Subject

---

 Date

---

 Signature of the Witness

---

 Date

The subject has indicated to me that the subject is unable to read. I certify that I have read this consent form to the subject and explained that by completing the signature line above, the subject has agreed to participate.

---

Signature of the Reader

---

Date

---

Signature of the Person Administering Consent

---

Date

---

Signature of the Principal Investigator

---

Date

## APPENDIX B

Research group: \_\_\_\_\_

ID#: \_\_\_\_\_

Date: \_\_\_\_\_

***Demographic information*****1. Name:** \_\_\_\_\_**2. Address:** \_\_\_\_\_  
\_\_\_\_\_**3. Gender:**☐ 1. Male☐ 2. Female**4. Age:** \_\_\_\_\_**5. Height** \_\_\_\_\_ **Weight:** \_\_\_\_\_**6. What is your ethnic group?**☐ 1. African-American☐ 2. White☐ 3. Hispanic☐ 4. Asian☐ 5. Other**7. What is your marital status?**☐ 1. Married☐ 2. Widowed☐ 3. Separated/divorced☐ 4. Never married**8. What is your occupational status?**☐ 1. Employed full-time (Current occupation \_\_\_\_\_)☐ 2. Employed part-time (Current occupation \_\_\_\_\_)☐ 3. Retired (Former occupation \_\_\_\_\_)☐ 4. Disabled (Former occupation \_\_\_\_\_)

Research group: \_\_\_\_\_  
ID#: \_\_\_\_\_

**9. How many years of formal education have you had?**

- ☐ 1. < 9 years
- ☐ 2. 10-12 years
- ☐ 3. High school graduate
- ☐ 4. Attended college
- ☐ 5. College graduate
- ☐ 6. Attended graduate school
- ☐ 7. Graduate degree

**10. What is your annual household income?**

- ☐ 1. < \$15,000
- ☐ 2. \$15,000 - \$30,000
- ☐ 3. \$30,000 - \$45,000
- ☐ 4. \$45,000 - \$60,000
- ☐ 5. \$60,000 - \$75,000
- ☐ 6. > \$75,000
- ☐ 7. Refused to answer

**11. What kind of health insurance do you have?**

- ☐ 1. Uninsured
- ☐ 2. Medicare
- ☐ 3. Medicaid
- ☐ 4. Medicare/Medicaid
- ☐ 5. Commercial insurance

**12. Who is your rheumatologist?**

- ☐ 1. Dr. Espinoza
- ☐ 2. Dr. Scopelitas
- ☐ 3. Dr. Wilson
- ☐ 4. Dr. McGrath

**13. What is your primary medical diagnosis?**

- ☐ 1. Osteoarthritis
- ☐ 2. Rheumatoid arthritis

**14. How long have you had your arthritis?**

- ☐ 1. < 1 year
- ☐ 2. 1-2 years
- ☐ 3. 2-5 years
- ☐ 4. 5-10 years
- ☐ 5. > 10 years

Research group: \_\_\_\_\_  
 ID#: \_\_\_\_\_

**15. What other medical problems do you have?**

- ☐ 1. Cardiovascular disease
- ☐ 2. High blood pressure
- ☐ 3. Diabetes
- ☐ 4. Cancer (or history of cancer)
- ☐ 5. Fibromyalgia
- ☐ 6. Lupus
- ☐ 7. Other

**16. How would you describe your functional status?**

- ☐ 1. I am not physically limited by my arthritis.
- ☐ 2. I am somewhat physically limited by my arthritis.
- ☐ 3. I am significantly physically limited by my arthritis.
- ☐ 4. I am disabled due to my arthritis.

**17. In general, would you say your health is:**

- ☐ 1. Excellent
- ☐ 2. Very good
- ☐ 3. Good
- ☐ 4. Fair
- ☐ 5. Poor

**18. What would be the best time/day to call you?**

	Mon	Tues	Wed	Thurs	Fri	Sat	Sun
8-10 am							
10 am-12							
12-2 pm							
2 pm-4 pm							
4 pm-6 pm							
6 pm-8 pm							
8 pm-10 pm							

**19. What phone number(s) should I use to reach you?**

**20. What is your primary goal for participating in this study?**

## APPENDIX C

*Arthritis Self-Efficacy Scale*

## Self-Efficacy to Perform Self-Management Behaviors

We would like to know **how confident** you are in doing certain activities. For each of the following questions, please circle the number that corresponds to your confidence that you can do the tasks regularly at the present time.

How confident are you that you can...

1. Do gentle exercises for muscle strength and flexibility three to four times per week (range of motion, using weights, etc.)?

Not at all											Totally
Confident	1	2	3	4	5	6	7	8	9	10	confident

2. Do an aerobic exercise such as walking, swimming, or bicycling three to four times each week?

Not at all											Totally
Confident	1	2	3	4	5	6	7	8	9	10	confident

3. Exercise without making your symptoms worse?

Not at all											Totally
Confident	1	2	3	4	5	6	7	8	9	10	confident

4. Get information about your disease from community resources?

Not at all											Totally
Confident	1	2	3	4	5	6	7	8	9	10	confident

5. Get family and friends to help you with the things you need (such as household chores like shopping, cooking, or transport)?

Not at all											Totally
Confident	1	2	3	4	5	6	7	8	9	10	confident

6. Get emotional support from friends and family (such as listening or talking over your problems)?

Not at all											Totally
Confident	1	2	3	4	5	6	7	8	9	10	confident

7. Get emotional support from resources other than friends or family, if needed?

Not at all											Totally
Confident	1	2	3	4	5	6	7	8	9	10	confident

8. Get help from your daily tasks (such as housecleaning, yard work, meals, or personal hygiene) from resources other than friends or family, if needed?

Not at all											Totally
Confident	1	2	3	4	5	6	7	8	9	10	confident

9. Ask you doctor things about your illness that concern you?

Not at all											Totally
Confident	1	2	3	4	5	6	7	8	9	10	confident



10. Discuss openly with your doctor any personal problems that may be related to your illness?

Not at all											Totally
Confident	1	2	3	4	5	6	7	8	9	10	confident

11. Work out differences with your doctor when they arise?

Not at all											Totally
Confident	1	2	3	4	5	6	7	8	9	10	confident

12. Having an illness often means doing different tasks and activities to manage your condition. How confident are you that you can do all the things necessary to manage your condition on a regular basis?

Not at all											Totally
Confident	1	2	3	4	5	6	7	8	9	10	confident

13. Judge when the changes in your illness mean you should visit a doctor?

Not at all											Totally
Confident	1	2	3	4	5	6	7	8	9	10	confident

14. Do the different tasks and activities needed to manage your health condition so as to reduce your need to see a doctor?

Not at all											Totally
Confident	1	2	3	4	5	6	7	8	9	10	confident

15. Reduce the emotional distress caused by your health condition so that it does not affect your everyday life?

Not at all											Totally
Confident	1	2	3	4	5	6	7	8	9	10	confident

16. Do things other than just taking medication to reduce how much your illness affects your everyday life?

Not at all											Totally
Confident	1	2	3	4	5	6	7	8	9	10	confident

17. Complete your household chores, such as vacuuming and yard work, despite your health problems?

Not at all											Totally
Confident	1	2	3	4	5	6	7	8	9	10	confident

18. Get your errands done despite your health problems?

Not at all											Totally
Confident	1	2	3	4	5	6	7	8	9	10	confident

19. Get you shopping done despite your health problems?

Not at all											Totally
Confident	1	2	3	4	5	6	7	8	9	10	confident

20. Continue to do your hobbies and recreation?

Not at all											Totally
Confident	1	2	3	4	5	6	7	8	9	10	confident

21. Continue to do the things you like to do with friends and family (such as social visits and recreation)?

Not at all											Totally
Confident	1	2	3	4	5	6	7	8	9	10	confident

22. Reduce your physical discomfort or pain?

Not at all											Totally
Confident	1	2	3	4	5	6	7	8	9	10	confident

23. Keep the fatigue caused by your disease from interfering with the things you want to do?

Not at all											Totally
Confident	1	2	3	4	5	6	7	8	9	10	confident

24. Keep the physical discomfort or pain of your disease from interfering with the things you want to do?

Not at all											Totally
Confident	1	2	3	4	5	6	7	8	9	10	confident

25. Keep any other symptoms or health problems you have from interfering with the things you want to do?

Not at all											Totally
Confident	1	2	3	4	5	6	7	8	9	10	confident

26. Control any symptoms or health problems you have so that they don't interfere with the things you want to do?

Not at all											Totally
Confident	1	2	3	4	5	6	7	8	9	10	confident

27. Keep your shortness of breath from interfering with what you want to do?

Not at all											Totally
Confident	1	2	3	4	5	6	7	8	9	10	confident

28. Keep from getting discouraged when nothing you do seems to make any difference?

Not at all											Totally
Confident	1	2	3	4	5	6	7	8	9	10	confident

29. Keep from feeling sad or down in the dumps?

Not at all											Totally
Confident	1	2	3	4	5	6	7	8	9	10	confident

30. Keep yourself from feeling lonely?

Not at all											Totally
Confident	1	2	3	4	5	6	7	8	9	10	confident

31. Do something to make yourself feel better when you are feeling lonely?

Not at all											Totally
Confident	1	2	3	4	5	6	7	8	9	10	confident

32. Do something to make yourself feel better when you are feeling discouraged?

Not at all											Totally
Confident	1	2	3	4	5	6	7	8	9	10	confident

33. Do something to make yourself feel better when you feel sad or down in the dumps?

Not at all											Totally
Confident	1	2	3	4	5	6	7	8	9	10	confident

## APPENDIX D

Name: \_\_\_\_\_

ID#: \_\_\_\_\_

***Mood Scale***

Choose the best answer for how you have felt over the past week:

1. Are you basically satisfied with you life? YES / NO
2. Have you dropped many of your activities and interests? YES / NO
3. Do you feel that your life is empty? YES / NO
4. Do you often get bored? YES / NO
5. Are you in good spirits most of the time? YES / NO
6. Are you afraid that something bad is going to happen to you? YES / NO
7. Do you feel happy most of the time? YES / NO
8. Do you often feel helpless? YES / NO
9. Do you prefer to stay at home, rather than going out and doing new things? YES/NO
10. Do you feel you have more problems with memory than most? YES / NO
11. Do you think it is wonderful to be alive now? YES / NO
12. Do you feel pretty worthless the way you are now? YES / NO
13. Do you feel full of energy? YES / NO
14. Do you feel that your situation is hopeless? YES / NO
15. Do you think that most people are better off than you are? YES / NO

## APPENDIX E

Name\_\_\_\_\_

ID number\_\_\_\_\_

Date\_\_\_\_\_

***Pain Visual Analog Scale***

We are interested in learning whether or not you are affected by pain because of your arthritis.

Please mark an “x” on the line below to describe your pain in the past two weeks.

No pain

Pain as bad  
As can be

\_\_\_\_\_

***Numeric Rating Scale***

“Please describe for me the pain you are currently having from your arthritis on a scale from 0 to 10, with 0 representing no pain and 10 representing the worst possible pain”.

0      1      2      3      4      5      6      7      8      9      10

## APPENDIX F

Name \_\_\_\_\_  
 ID number \_\_\_\_\_  
 Date \_\_\_\_\_

***Fatigue Visual Analog Scale***

We are interested in learning whether or not you are affected by fatigue because of your illness. Please mark an “X” on the line below to describe your fatigue in the past two weeks:

No  
Fatigue

Extreme  
Fatigue

\_\_\_\_\_

***Numeric Rating Scale***

“Please describe for me the fatigue you are currently having from your arthritis on a scale from 0 to 10, with 0 representing no fatigue and 10 representing extreme fatigue”.

0      1      2      3      4      5      6      7      8      9      10

## APPENDIX G

**Handout #1*****Types of arthritis***

“You are probably aware of the fact that there are several different types of arthritis, the two most common types being Rheumatoid Arthritis (RA) and Osteoarthritis (OA). Your primary type of arthritis is \_\_\_\_\_. Below is a chart that briefly describes the differences between these different types of arthritis.

<b>Pathology</b>	<b>Rheumatoid Arthritis</b>	<b>Osteoarthritis</b>	<b>Fibromyalgia</b>
What happens	<i>Inflammation of synovial membrane, bone destruction, damage to ligaments, tendons, cartilage, joint capsule.</i>	<i>Cartilage degeneration; bone regeneration (growth) may result in bone spurs.</i>	<i>Unknown. Accompanied by sleep disturbance and prolonged muscle contraction.</i>
Joints affected	<i>Symmetrical: wrists, knees, knuckles (both sides).</i>	<i>Hands, spine, knees, hips. May be one-sided.</i>	<i>Joints not affected. Certain tender points. Muscles, ligaments, tendons may be affected.</i>
Features and symptoms	<i>Swelling, redness, warmth, pain, tenderness, nodules, fatigue, stiffness, muscle aches, fever.</i>	<i>Localized pain, stiffness; bony knobs of end joints of fingers; usually not much swelling.</i>	<i>Overall aching, morning stiffness, fatigue. Sleep disturbance.</i>
Long-term prognosis	<i>Less aggressive with time; deformity can often be prevented.</i>  <i>(continued)</i>	<i>Less pain for some, more pain and disability for others; few severely disabled.</i>	<i>Usually improves slowly over time. Pain and fatigue may be disabling in some, most are not disabled.</i>



Age at onset	<i>Adults in 20s to 50s, children approaching adolescence.</i>	<i>Age 45 to 90; most of us have some features with increasing age.</i>	<i>Age 30s to 50s</i>
Sex	<i>75% female.</i>	<i>Males and females equally.</i>	<i>More frequently female.</i>
Heredity	<i>Familial tendency.</i>	<i>The form with knobby fingers can be familial.</i>	<i>Unknown at this time.</i>

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## Handout #2

### *Disease chronicity and self-management*

“As you know, arthritis is a chronic disease. Although there is not a known cure for arthritis, there are a variety of known treatments to control it (relieve discomfort and reduce disability). **Self-help** means being willing to learn about these treatments and assume responsibility for using them in the daily care of your arthritis.”

“Self-care for your arthritis means being responsible for it; this includes things like:

- Keeping informed about your arthritis: ask questions!
- Take part in your treatment: tell me and the rest of your health care team about preferences and goals.
- Inform the health care team about problems and changes you make in your daily program.
- Set goals and work toward them.”

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## Handout #3

### *Importance of exercise*

“Exercise is the single most important thing you can do to help your arthritis. Just because you have arthritis is no reason why you should not be fit and enjoy exercise. There are three main parts of a fitness program:

- Warm-up: for muscle strength and flexibility, and to get you ready for aerobic exercise
- Endurance (aerobic) exercise: for cardiovascular fitness, endurance and weight control
- Cool-down: for body relaxation and to avoid sore muscles

“There are many potential benefits of exercise; these might include things like:

- Increasing your muscle strength
- Improving your flexibility
- Enhancing the performance (endurance) of your heart and lungs.
- Helping you to sleep better.
- Helping you to better deal with stress in your life.
- Helping you to lose weight and/or maintain proper body weight.
- Reducing your fatigue and giving you more energy...you feel better when you exercise!!

Please remember:

- Your exercise should not be painful!!
- You should not hurt more after your exercise than you did before your exercise!!

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## Handout #4

### ***Pain***

“Pain is obviously a very real and very important part of your arthritis. Lets talk about some things that might be making your pain worse and some things you can do (in addition to your medication) to help relieve your pain.”

There is a concept called a ***pain cycle*** that might be a part of your arthritis. Understanding this pain cycle might be useful to you as you manage your arthritis and attempt to control your level of pain. The pain cycle means that pain can be affected by a variety of factors, including things like:

- Stress
- Negative thoughts
- Depression
- Fear anxiety

These factors can combine or act separately, but each can play a significant role in your pain. They can work together to form a cycle that be very difficult to break out of. In addition, the more you hurt, the less likely you are to exercise or even to move very much. The result of this inactivity is that you may become even more stiff, which then may lead to your pain increasing even more, etc....you can see that we now have ***another*** negative cycle!

Other than medication, what are some techniques you can use to help control your pain?

**Distraction:** This is a technique that involves your thinking about something else whenever you find that pain is interfering with your functional activities. For example, if your knees hurt while you are climbing the stairs, you may focus on what you are going to do when you get to the top of the stairs rather than how much your knees hurt with each step you are taking. Can you think of any examples of how you might use distraction in the management of your pain?

***Muscle relaxation:*** *There may be times when you find yourself getting especially tense and having muscle spasms that may be interfering with your functional activities. A technique that might be helpful is muscle relaxation. Try to become aware of your breathing and slow it down. For example, try to take 5 seconds or so to inhale and another 5 or 6 seconds to gently exhale. As you are doing this first gently tighten the muscles that are already tight and painful, then let them (let the muscles relax) go as you are exhaling. You might even visual the tight, painful muscles as a bright red color that gradually becomes light pink and then turns to a nice, light shade of blue. Can you think of any examples of how you might use muscle relaxation in the management of your pain?*

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## Handout #5

### Communication

“What are the problems you have working with your doctors/health care professionals?”

“When you talk to your doctor, these tips might be helpful:

- Write down the key points about your health and medication since your last visit, so you can spend the time on more important points and questions.
- Write down a short list of concerns you want to address during your doctor visit
- Medication/refills: hand the doctor a list of names and dosages of medication refills you need, or bring the containers so your doctor doesn't have to look them up in your chart

### *The use of “I” messages*

“The stress you feel as you manage your arthritis is often shared with those around you, and that stress can sometimes interfere with your communication with others. Part of the problem is that the conversation can sometimes result in either you or the person with whom you are speaking feeling defensive. A technique that might be useful in these situations is the “I” message. In this technique you talk about *your* feelings and how the situation is affecting *you*, rather than projecting the problem (and perceived blame) onto the *other* person.

Following is an example of how this might work:

“You” message: “*You are walking too fast; you know my knees hurt and I can't keep up with this pace.*”

“I” message: “I am sorry that I can't keep up with you right now but my knees are really hurting today and I just can't walk that fast.”

- “Do you see how this technique might be useful in some situations? Can you think of some examples where you might be able to make use of this technique?”

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## Handout #6

### *Fatigue*

*“You are probably well aware of how fatigue can be a big factor in your arthritis management. Arthritis drains the body of energy in many ways, and this can interfere with your attempts at increasing or even maintaining your functional levels. There are several causes of fatigue that are often associated with arthritis; let’s talk about some of these.*

- **The arthritis itself:** Your body is less efficient because it takes energy to cope with the physical effects of the arthritis. Your body is trying very hard to heal itself and this takes energy.
- **Inactivity:** Your arthritis may have caused you to become less active, which in turn has probably led to your becoming more deconditioned. As a result your body is less efficient and requires more energy to meet even the most basic demands placed on it. Your heart is a muscle that needs activity for it to be efficient and deliver the oxygen your body systems need to stay active and alert.
- *Recommendation: try to stay with the action plan and goals that we have been talking about.*
- **Poor nutrition:** Your nutritional intake may be lacking; you may be eating the wrong foods for or you may not be eating enough of the “right” foods (i.e., a well-balanced diet).
- *Recommendation: your doctor can recommend an appropriate diet or refer you to a nutritionist for a consultation.*
- **Insufficient rest:** You may be not getting enough sleep, and/or the quality of the sleep you are getting may not be sufficient.
- *Recommendation: ideally you should be getting at least 7-8 hours of sleep/night. If you are not we can talk about some tips that might be helpful. In addition make sure that your doctor knows about this; he/she may have additional suggestions.*
- **Stress/tension:** Stress and tension can cause us to feel fatigued even if we are not dealing with a physical challenge like arthritis.
- *Recommendation: the relaxation techniques we have been talking about might be helpful in coping with your stress. Also, might some of this stress be avoidable?*
- **Depression:** Fatigue is known to be a major symptom of depression.
- *Recommendation: true depression is a medical diagnosis that can be made by your doctor. If you have reason to believe that you are depressed, please communicate this with your doctor.*

- **Medication side effects:** Certain medications may lead to fatigue as a side effect. Additionally certain medications may interact with others to result in the same problem.
- *Recommendation: please make sure that your doctor has a complete and current list of all of your medications (including dosages). Your pharmacist is also a good source of information if you think that medications may be playing a part in your fatigue.*

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## APPENDIX H

### **Week 1 - Call #1**

The focus of the 1<sup>st</sup> phone call is on discussing the exercise/activity level for the past week, as well as on reviewing and reinforcing the action plan that had been established during the initial meeting. In addition, the basic information about what type of arthritis the patient has will be reviewed (this was discussed in the initial meeting). Finally the role of self-care in the management of arthritis will be reviewed (topic was introduced during the initial meeting).

Objectives for Call #1:

- A. By the end of the telephone call the participant will be able to state their role in the care of their arthritis.
- B. By the end of the telephone call the participant will be able to define what type of arthritis they have.
- C. By the end of the telephone call the participant will be able to state the benefits of physical fitness for arthritis.
- D. By the end of the telephone call the participant will be able to discuss their action plan contract and their arthritis-related behavior in the coming week (emphasize importance of self-talk).

#### *1. Greeting*

“Hi, Mr./Ms.\_\_\_\_\_. This is Dave Pariser calling from the LSU Physical Therapy department. How are you doing today?”

- Please tell me about how your arthritis symptoms have been in the past week (since the last time we talked). Have your symptoms changed much one way or the other?  
[ ] Better [ ] Worse [ ] No real change
- If there has been a change, please tell me what you mean.”

#### *2. Arthritis information – refer to Handout #1*

“Remember last week we talked about the fact that arthritis is a chronic disease, and that there are different types of arthritis. We spent some time talking about the specific type of arthritis that you have.”

- Do you remember what type of arthritis that you have?  
[ ] Yes [ ] No [ ] Not sure
- (If yes) Please tell me what type that was and how it affects you
- If no or not sure....review

**Refer to Handout #2**

“Do you also recall that we talked about how even though there is no cure for arthritis, there are ways of managing the pain and other problems that accompany it; do you recall that we talked about the concept of *self-care*”? ☐ Yes ☐ No

- Please briefly tell me what self-care means (*review if they are unsure*)

**3. Focus – exercise****Refer to Handout #3**

“Let’s talk about your exercise/activity level in the past week. Can you please tell me about what you have been doing?”

- You may recall that last week we talked about how important exercise is in managing your arthritis; do you remember that? ☐ Yes ☐ No
- *If yes: ask participant to briefly review the benefits of exercise in arthritis mgmt*
- *If no: review the concept with them.*
- When we last spoke we talked about what your activity level was at that time...has it changed during the past week? ☐ Yes ☐ No
- Have you been able to exercise during the past week? ☐ Yes ☐ No
- Why/why not?”

**4. Progress/Action plan Refer to “contract”**

- Lets look at the contract you filled out when we met (you have a copy in your folder and I have a copy in front of me). Do you remember that when we met last week we had talked about a plan that would help you to reach the goal(s) you had set for yourself?

☐ Yes ☐ No

- Tell me about what you have done in the past week toward reaching that goal?
- We had talked about how you might develop some steps toward reaching the goal. Have you been able to do some of the things we talked about in developing those steps? ☐ Yes ☐ No
- *You can do this*, Mr./Ms.\_\_\_\_\_, especially the way we talked about it. You can start on the steps we talked about, and when you put those steps together you *will* make progress toward the goal.”

**5. Answer any other questions**

Do you have any questions or concerns that we haven’t talked about during this phone call? I’d be more than happy to try and answer them.”

**6. Closure**

“I would like to call you again in about a week to keep track of how you are doing.

- Can you please tell me what time/day is the most convenient for you to be reached?
- Is the number I used today the same number I should use next week?
- ☐ Yes ☐ No
- Thank you again very much for participating in this project, Mr./Ms.\_\_\_\_\_. I look forward to talking to you again next week when I call you at \_\_\_\_\_ on \_\_\_\_\_.”

## **Week 2 - Call #2**

The focus of the 2<sup>nd</sup> phone call is on discussing the past week's pain level, as well as the pain management techniques that were discussed in the initial meeting. The information discussed during the 1<sup>st</sup> phone call will also be reviewed.

Objectives for Call #2:

- A. By the end of the telephone call the participant will be able to state that they should not hurt more after finishing their exercise than before they started.
- B. By the end of the telephone call the participant will be able to describe the relationship between stress, pain and negative thoughts, as well as feelings of depression, fear, anxiety, etc.
- C. By the end of the telephone call the participant will be able to describe distraction and muscle relaxation techniques and will discuss how they can use the techniques in their self-management.
- D. By the end of the telephone call the participant will be able to discuss their action plan contract and their arthritis-related behavior in the coming week (emphasize importance of self-talk).

### *1. Greeting*

"Hi, Mr./Ms. \_\_\_\_\_. This is Dave Pariser calling from the LSU Physical Therapy department. How are you doing today?"

- Please tell me about how your arthritis symptoms have been in the past week (since the last time we talked). Have your symptoms changed much one way or the other? ☐ Better ☐ Worse ☐ No real change
- If there has been a change, please tell me what you mean."

### *2. Exercise*

"Let's talk about your exercise/activity level in the past week. Can you please tell me about what you have been doing?"

- When we last spoke we talked about what your activity level was at that time...has it changed during the past week? ☐ Yes ☐ No
- Have you been able to exercise during the past week? ☐ Yes ☐ No
- Why/why not?"

### *3. Focus – pain*      ***Refer to Handout #4***

"You may recall that during our initial meeting we talked about how pain can be affected by things like stress, pain, anxiety, etc. Do you remember that conversation? ☐ Yes ☐ No

- *If yes: ask them to briefly describe that relationship.*
- *If no: review the concept with them.*

"You may recall that we talked about the relationship of pain to your exercise; i.e., when is pain acceptable as it relates to your exercise program. Do you remember our talking about that? ☐ Yes ☐ No

- *If yes: ask them to describe the relationship of pain to exercise (they should not hurt more after the exercise than they did before they started).*
- *If no: review the concept with them.*

“Let’s talk about your pain level, Mr./Ms.\_\_\_\_. The first time we talked you told me that your pain was a “\_\_” on a scale of 1 to 10.”

- What level would you describe your pain at now?  
0 1 2 3 4 5 6 7 8 9 10
- Has it changed much in the past week (better or worse) or has it stayed pretty steady? [ ☐ ] Better [ ☐ ] Worse [ ☐ ] No change
- Are your medications helping your pain? [ ☐ ] Yes [ ☐ ] No

“You may also recall that we talked about some tools that you can use to help manage your pain: things like distraction and muscle relaxation techniques. Do you remember that discussion”? [ ☐ ] Yes [ ☐ ] No [ ☐ ] Not sure

- *If yes: ask them to give some examples of how they have used the techniques for managing their pain*
- *If no or not sure: review the techniques and their applications.*

#### 4. *Progress/Action plan*      ***Refer to “contract”***

- Lets look at the contract you filled out when we met (you have a copy in your folder and I have a copy in front of me). Do you remember that we had talked about a plan that would help you to reach the goal(s) you had set for yourself?  
[ ☐ ] Yes [ ☐ ] No
- Tell me about what you have done in the past week toward reaching that goal?
- We had talked about how you might develop some steps toward reaching the goal. Have you been able to do some of the things we talked about in developing those steps? [ ☐ ] Yes [ ☐ ] No
- *You can do this, Mr./Ms.\_\_\_\_, especially the way we talked about it. You can start on the steps we talked about, and when you put those steps together you will make progress toward the goal.”*

#### 5. *Answer any other questions*

Do you have any questions or concerns that we haven’t talked about during this phone call? I’d be more than happy to try and answer them.”

#### 6. *Closure*

“I would like to call you again in about a week to keep track of how you are doing. Can you please tell me what time/day is the most convenient for you to be reached? Is the number I used today the same number I should use next week? Thank you again very much for participating in this project, Mr./Ms.\_\_\_\_. I look forward to talking to you again next week when I call you at \_\_\_\_\_ on \_\_\_\_\_”

### Week 3 - Call #3

The focus of the 3<sup>rd</sup> phone call is on discussing barriers to medical care and to overall good health behaviors. This will include establishing/maintaining a good relationship with their doctor and other health-care team members as well as discussing any other relevant barriers (e.g., transportation problems, etc). The information discussed during the first two phone calls will also be briefly reviewed.

Objectives for Call #3:

- A. By the end of the telephone call the participant will be able to discuss three (3) strategies for establishing a good relationship with their doctors.
- B. By the end of the telephone call the participant will be able to demonstrate the use of “I” messages.
- C. By the end of the telephone call the participant will be able to discuss their action plan contract and their arthritis-related behavior in the coming week (emphasize importance of self-talk).

#### *1. Greeting*

“Hi, Mr./Ms.\_\_\_\_\_. This is Dave Pariser calling from the LSU Physical Therapy department. How are you doing today?

- Please tell me about how your arthritis symptoms have been in the past week (since the last time we talked). Have your symptoms changed much one way or the other?  
[ ] Better [ ] Worse [ ] No real change
- If there has been a change, please tell me what you mean.”

#### *2. Exercise*

“Let’s talk about your exercise/activity level in the past week. Can you please tell me about what you have been doing?

- a. When we last spoke we talked about what your activity level was at that time...has it changed during the past week? [ ] Yes [ ] No
- b. Have you been able to exercise during the past week? [ ] Yes [ ] No
- c. Why/why not?”

#### *3. Pain*

“Let’s talk about your pain level, Mr./Ms.\_\_\_\_. Last week when we talked you told me that your pain was a “\_\_\_” on a scale of 1 to 10.

- What level would you describe your pain at now?  
0 1 2 3 4 5 6 7 8 9 10
- Has it changed much in the past week (better or worse) or has it stayed pretty steady? [ ] Better [ ] Worse [ ] No change
- Are your medications helping your pain? [ ] Yes [ ] No
- Have you been able to use any of the distraction or relaxation techniques to help manage your pain? [ ] Yes [ ] No

***Refer to Handout #5***

**4. Focus - barriers**

“Let’s talk about some of the problems you may be running in to.

- Do you feel that there are obstacles to your receiving your medical care...things like transportation, lack of support at home or work, etc?  
☐ Yes    ☐ No

If yes, what are the obstacles?

- Have you tried to deal with these problems?    ☐ Yes    ☐ No  
     If yes, how?
- Do you believe that these obstacles are more of an inconvenience or are they a real problem in terms of your overall health?  
☐ Inconvenience    ☐ Real problem    ☐ Not sure

“You may recall that during our first meeting together we talked about some tips that might be helpful in getting the most out of your visits with your doctor...things like writing down your questions ahead of time, writing down any recent/significant changes in your health status that you wanted to discuss, your current list of medications and their dosages (especially if you need refills, etc). Do you recall that discussion?    ☐ Yes    ☐ No    ☐ Not sure

- *If yes: have them describe how they might use these techniques with their doctor.*
- *If no or not sure: review the concepts with them.*

**5. “I” messages**

“You may recall that when we first met we very briefly discussed verbalizing your feelings through the use of “I” messages; you have a handout included in the folder you received. Do you remember what “I” messages are and how they are used?    ☐ Yes    ☐ No    ☐ Not sure

- *If yes: ask them to describe the “I” message and how they might use it in their own situation to enhance communication and verbalization of feelings.*
- *If no or not sure: discuss the topic as described in the handout.*

6. *Progress/Action plan* ***Refer to “contract”***

- a. Lets look at the contract you filled out when we met (you have a copy in your folder and I have a copy in front of me). Do you remember that when we met we had talked about a plan that would help you to reach the goal(s) you had set for yourself?  
☐ Yes    ☐ No
- b. Tell me about what you have done in the past week toward reaching that goal?
- c. We had talked about how you might develop some steps toward reaching the goal. Have you been able to do some of the things we talked about in developing those steps? ☐ Yes    ☐ No
- d. *You can do this*, Mr./Ms.\_\_\_\_\_, especially the way we talked about it. You can start on the steps we talked about, and when you put those steps together you *will* make progress toward the goal.”

7. *Answer any other questions*

Do you have any questions or concerns that we haven’t talked about during this phone call? I’d be more than happy to try and answer them.”

8. *Closure*

“I would like to call you again in about a week to keep track of how you are doing. Can you please tell me what time/day is the most convenient for you to be reached? Is the number I used today the same number I should use next week? Thank you again very much for participating in this project, Mr./Ms.\_\_\_\_\_. I look forward to talking to you again next week when I call you at \_\_\_\_\_ on \_\_\_\_\_”

### **Week 4 - Call #4**

The focus of the 4<sup>th</sup> phone call is to help the participant deal with fatigue. This will include identifying potential causes of fatigue as well as interventions. The information discussed during the first three phone calls will be briefly reviewed.

Objectives for Call #4:

- A. By the end of the telephone call the participant will be able to identify at least four different potential causes of fatigue.
- B. By the end of the telephone call the participant will be able to list at least four ways of dealing with fatigue.
- C. By the end of the telephone call the participant will be able to discuss their action plan contract and their arthritis-related behavior in the coming week (emphasize importance of self-talk).

#### *1. Greeting*

“Hi, Mr./Ms. \_\_\_\_\_. This is Dave Pariser calling from the LSU Physical Therapy department. How are you doing today?”

- Please tell me about how your arthritis symptoms have been in the past week (since the last time we talked). Have your symptoms changed much one way or the other?  
[ ] Better [ ] Worse [ ] No real change
- If there has been a change, please tell me what you mean.”

#### *2. Exercise*

“Let’s talk about your exercise/activity level in the past week. Can you please tell me about what you have been doing?”

- a. When we last spoke we talked about what your activity level was at that time...has it changed during the past week? [ ] Yes [ ] No
- b. Have you been able to exercise during the past week? [ ] Yes [ ] No
- c. Why/why not?”

#### *3. Pain*

“Let’s talk about your pain level, Mr./Ms. \_\_\_\_\_. Last week when we talked you told me that your pain was a “\_\_” on a scale of 1 to 10.

- What level would you describe your pain at now?  
0 1 2 3 4 5 6 7 8 9 10
- Has it changed much in the past week (better or worse) or has it stayed pretty steady? [ ] Better [ ] Worse [ ] No change
- Are your medications helping your pain? [ ] Yes [ ] No
- Have you been able to use any of the distraction or relaxation techniques to help manage your pain? [ ] Yes [ ] No



#### 4. *Barriers (if appropriate)*

“Let’s talk about some of the problems you may be running in to. ...have you made any progress in dealing with them? [ ☐ ] Yes [ ☐ ] No

- Comments:

#### ***Refer to handout #6***

#### 5. *Focus – fatigue*

“You may recall that during our first meeting we talked about fatigue and how it can affect your arthritis self-management (you have a handout on this topic in your folder). We talked about some of the causes of fatigue (*refer to handout*)...things like the disease itself, inactivity, poor nutrition, not enough rest, stress/tension, depression, and possible side effects of some medications. Do you remember our discussion about fatigue? [ ☐ ] Yes [ ☐ ] No [ ☐ ] Not sure

- *If yes: ask which causes of fatigue are relevant and how those causes might be managed/dealt with*
- *If no/not sure: Review the handout in greater detail, specifically address any cause(s) of fatigue that are relevant to that participant (i.e., ways in which they can self-manage the causes of the fatigue).*

#### 6. *Progress/Action plan*

#### ***Refer to “contract”***

- Lets look at the contract you filled out when we met (you have a copy in your folder and I have a copy in front of me). Do you remember that when we met we had talked about a plan that would help you to reach the goal(s) you had set for yourself?  
[ ☐ ] Yes [ ☐ ] No
- Tell me about what you have done in the past week toward reaching that goal?
- We had talked about how you might develop some steps toward reaching the goal. Have you been able to do some of the things we talked about in developing those steps? [ ☐ ] Yes [ ☐ ] No
- You can do this, Mr./Ms.\_\_\_\_\_, especially the way we talked about it. You can start on the steps we talked about, and when you put those steps together you will make progress toward the goal.”*

#### 7. *Answer any other questions*

Do you have any questions or concerns that we haven’t talked about during this phone call? I’d be more than happy to try and answer them.”

8. *Closure*

“I would like to call you again in about a week to keep track of how you are doing. Can you please tell me what time/day is the most convenient for you to be reached? Is the number I used today the same number I should use next week? Thank you again very much for participating in this project, Mr./Ms. \_\_\_\_\_. I look forward to talking to you again next week when I call you at \_\_\_\_\_ on \_\_\_\_\_”

**Week 6 – Call #5**

The focus of the 5<sup>th</sup> phone call is to briefly review any questions/problems the participant would like to address, then have them complete the following instruments over the phone:

1. Arthritis Self-Efficacy scale
2. Geriatric Depression scale
3. Pain Numeric Rating scale
4. Fatigue Numeric Rating scale

## APPENDIX I

UNIVERSITY OF NEW ORLEANS  
COMMITTEE ON THE USE OF HUMAN SUBJECTS

**Form Number:** 4FEB03 (please refer to this number in all future correspondence concerning this protocol)

**Principal Investigator:** Ann O'Hanlon **Title:** Associate Professor

**Department:** HP / HP **College:** Science

**Name of Faculty Supervisor:** \_\_\_\_\_ (if PI is a student)

**Project Title:** The effects of patient education on arthritis self-efficacy in senior arthritis patients in different clinical settings.

**Date Reviewed:** January 13, 2003

**Dates of Proposed Project Period:** From 1/03 to 1/04\*

\*approval is for one year from approval date only and may be renewed yearly.

**Note:** Consent forms and related materials are to be kept by the PI for a period of three years following the completion of the study.

☐ Full Committee Approval

☒ Expedited Approval

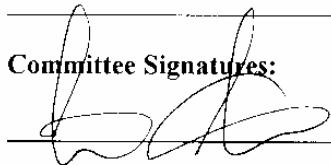
☐ Continuation

☐ Rejected

☐ The protocol will be approved following receipt of satisfactory response(s) to the following question(s) within 15 days:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Committee Signatures:**



Matthew S. Stanford, Ph.D. (Chair)

\_\_\_\_\_  
Scott Bauer, Ph.D.

\_\_\_\_\_  
Gary Granata, Ph.D.

\_\_\_\_\_  
Betty Lo, M.D.

\_\_\_\_\_  
Hae-Seong Park, Ph.D.

\_\_\_\_\_  
Jane Prudhomme

\_\_\_\_\_  
Jayaraman Rao, M.D. (NBDL protocols only)

\_\_\_\_\_  
Richard B. Speaker, Ph.D.

\_\_\_\_\_  
\_\_\_\_\_

## APPENDIX J

David A. Pariser, PT, M.Ed.  
LSUHSC Department of Physical Therapy  
1900 Gravier Street  
New Orleans, LA 70112  
Phone 504-568-4288; Fax 504-568-6552

November 13, 2003

Kate Lorig RN, DrPH  
Professor  
Stanford Pt. Education Research Center  
1000 Welch Road, Suite 204  
Palo Alto, CA 94304

Dear Dr. Lorig:

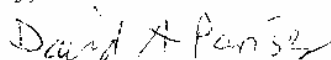
This letter will confirm our recent e-mail communication. I am completing a doctoral dissertation at the University of New Orleans entitled "The Effects of a Telephone Intervention on Arthritis Self-Efficacy, Depression, Pain and Fatigue in Older Adults with Arthritis." I would like your permission to reprint in my dissertation excerpts from The following:

Arthritis Self-Help Course Leader's Manual and Reference Materials. by Dr. Kate Lorig, Stanford University. 1995 ©

The excerpts to be reproduced are several pages from the manual, attached for your review in an earlier e-mail.

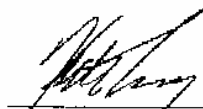
The requested permission extends to any future revisions and editions of my dissertation, including non-exclusive world rights in all languages, and to the prospective publication of my dissertation by UMI Company. These rights will in no way restrict publication of the material in any other form by you or others authorized by you. Your signing of this letter will also confirm that you own (or Stanford University owns) the copyright to the above-described material. If these arrangements meet with your approval, please sign this letter and return it to me by fax (504-568-6552). Thank you very much.

Sincerely,



David A. Pariser

PERMISSION GRANTED FOR THE USE REQUESTED ABOVE:

  
\_\_\_\_\_  
Kate Lorig

Nov 13, 2003  
Date

## VITA

Dave Pariser was born in Uniontown, Pennsylvania and received his B.S. in Physical Therapy from West Virginia University in 1983. Dave received his M.Ed. in Physical Education from the University of New Orleans in 1988. He is an Associate Professor in the Department of Physical Therapy, Louisiana State University Health Sciences Center in New Orleans, and has been on the faculty since 1988. Dave and his wife Gina have twin daughters, Ada and Kayla.