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THE EFFECTIVENESS OF AN ARTHRITIS SELF-MANAGEMENT
PROGRAM ON A POPULATION OF PERSONS WITH SCLERODERMA

By

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ABSTRACT

The purpose of this research study was to evaluate the effectiveness of the Arthritis Self-Management Program (ASMP), developed by Dr. K. Lorig, on a population of persons with scleroderma. This particular condition is a type of arthritis (also known as progressive systemic sclerosis) involving a disorder of the small blood vessels and connective tissues. It is characterized by the induration and thickening of the skin and by inflammatory, fibrotic, ischemic, and degenerative changes in the tissues throughout the body. Eighteen people, most of which were female, in the Vancouver Lower Mainland with the diagnosis of scleroderma volunteered for this study. Quantitative and qualitative methodological orientations were used to collect and analyze the data. A quasi-experimental, pretest-posttest nonequivalent comparison group design was used. Self-administered, standardized questionnaires were distributed to a sample of subjects to collect the quantitative data, and a standardized open-ended interview questionnaire was used to collect the qualitative data. The quantitative questionnaire comprised research instruments including The Visual Analogue Pain Scale, Health Assessment Questionnaire, Centre for Epidemiological Studies of Depression Scale, Cantril Quality of Life Scale, Arthritis Self-Efficacy

Scale, and Health Locus of Control Scale. The quantitative findings indicated that no statistically significant improvements in health status were found. However, clinically significant improvement trends in health status were found. The qualitative findings generally indicated that the experimental subjects enjoyed the ASMP, found it to increase their perceived level of coping with the management of scleroderma, and found the ASMP to be a positive learning experience. With the exception of the ASMP being limited in its specific application to people with scleroderma, it proved to be a feasible patient education course for these people.

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CHAPTER ONE

BACKGROUND AND PROBLEM AREA OF THESIS

Introduction

Patient education in the field of arthritis treatment has been evolving in recent years, however, its early development met some difficulties. The purpose of this chapter is to introduce the background and problem area of this thesis as it relates to the evolution and development of patient education in arthritis self-care research. To accomplish this purpose, I shall, first, define and describe the problem area, including the prevalence of the problem, the type of arthritis studied, known as scleroderma, and two other types of arthritis which have received considerable research attention in the field of patient education. Primarily, rheumatoid arthritis and osteoarthritis have received most the attention in the research field of treatment and patient education, which is one reason for selecting a more uncommon type of arthritis, scleroderma, as the focus of this thesis research. This discussion includes an overview of the economic, physical, psychological and social adjustment costs of arthritis. Second, societal awareness of and response to the problem area are examined in the light of some early psychosocial factors and patient education. Third, determining the focus of

patient education is discussed. Fourth, I examine what this problem area has to do with social work and the importance of social workers' professional contribution to the field. Finally, I shall end by presenting a brief outline of the thesis chapters to follow.

With an aging population, a rapidly growing health problem today is arthritis. Arthritis refers to over one hundred diseases which affect the joints and/or the surrounding tissues such as the bones, muscles and tendons. Although arthritis can affect people at any age, it is the single greatest cause of disability in the elderly and affects more than thirty-six million Americans (Lorig et al., 1987). Sixty to ninety percent of all persons over the age of sixty have or will contract arthritis (Lorig et al., 1984). One in seven people is subject to this chronic disease which strikes and stays with its victims for life (Doyle and Brunk, 1986).

Arthritis produces a range of physical problems from discomfort and annoyance to severe pain and disability. It contributes more to morbidity than to mortality, however, growing evidence suggests that rheumatoid arthritis (RA) as well as systemic lupus erythematosus contribute to premature mortality (Lorig et al., 1987). With few exceptions, arthritis cannot be prevented or

cured by either medical or behavioral interventions. Like other chronic diseases, arthritis must be managed over a long period of time. The goals of management are to minimize pain, disability, deformity and the social and psychological dysfunction which often accompany long term, painful illnesses.

Scleroderma

A type of arthritis that is of particular interest to this thesis is called scleroderma. It is also known as progressive systemic sclerosis and is a disorder of the small blood vessels and connective tissues. It is characterized by induration and thickening of the skin and by inflammatory, fibrotic, ischemic, and degenerative changes in the tissues throughout the body. These changes are most obvious in the skin, but since the disease is systemic, changes also occur in the central nervous system, muscles, joints, alimentary tract, lungs, heart, and kidneys. This disease affects women more frequently than men with a ratio of three to one. Initial symptoms of scleroderma usually appear between the third and fifth decade of life. Prognosis varies from death within a few years to an average life span (Melvin et al., 1984; Petersen et al., 1985).

In addition to being disabling and possibly life

threatening, scleroderma can cause severe facial and upper extremity disfigurement that complicates the psychological and social adjustment process for patients. Because of virtually no research on this adjustment process for scleroderma patients, this complex disease is difficult to manage, perhaps more so than other forms of arthritis (as we shall examine). "The difficulty of managing this complex disease is compounded by the lack of an organized team approach to patient care and the false belief that nothing can be done for patients with systemic sclerosis" (Melvin et al., 1984).

According to Melvin et al. (1984), comprehensive care for people with scleroderma includes:

1. Providing counselling to help the patient explore and work through the psychologic, familial, social, and vocational ramifications of an uncommon disease with visible deformities.
2. Educating the patient about symptoms and about those treatments that are effective and those that are not.
3. Employing specific medications and modalities (eg., biofeedback) to control symptoms, relieve pain, and improve function.
4. Providing the patient with an effective

program for maintaining joint mobility and chest excursion.

5. Counselling the patient about nutrition and dental care.

6. Instructing the patient about adaptive methods of compensating for functional loss.

The Course of Scleroderma

The course of scleroderma can vary considerably. For example, in some people with this disease, symptoms are confined for years to the hands, while in others, skin sclerosis may progress to total body involvement within the first year (diffuse scleroderma). Disease involvement is usually symmetric and occurs in the hands first. The symptoms, then, might progress proximally to include the arms, neck, face, trunk, and lower extremities. Systemic, or internal organ involvement can occur before there is any skin involvement or at any time during the course of the disease. Periods of stability or apparent remission can also occur at any time and may last from a few months to many years. "During these periods, symptoms can subside and the skin may soften and become more pliable; however, established fibrotic or atrophic changes in the tissues or joints usually do not reverse" (Melvin et al., 1984).

As it is the case for other types of arthritis, it is recommended that members of health care teams be involved early in scleroderma patients' care before mobility and function are lost. Early involvement allows the team members to use patients' normal or nearly normal measurements as a baseline for treatment to maintain mobility. In addition to the physical problems that develop, early involvement of health care teams can help patients cope with and overcome the psychosocial dysfunction which accompanies scleroderma.

Psychosocial Issues for Persons with Scleroderma

The psychological and social needs of people with scleroderma are similar to those of patients with other disabling chronic diseases (as we shall discuss later), but additional factors complicate the difficulty of adjusting and coping with life. First, disfigurement and deformity are often more severe and occur more rapidly than other types of arthritis. The psychological impact of this type of disfigurement is probably more closely related to that incurred by people who have been severely burned and that incurred by people affected by other rheumatic diseases. For many people with scleroderma, their entire skin becomes scar tissue in that they become untouchable, their movement is restricted and their

ability for expression is distorted.

Unlike other types of rheumatic disorders, scleroderma is a disease that is virtually unheard of outside the medical profession. Somewhat similar to other types of rheumatism, though, such as osteoarthritis and rheumatoid arthritis, scleroderma patients, their families and friends usually have no knowledge or understanding of the disease or the significance of its chronic nature. It is often extremely difficult for the people with scleroderma to explain the nature of their arthritis to family, friends or employers. This lack of public knowledge and understanding creates a formidable environment for the patient that compounds the difficulty of coping with the condition.

Scleroderma is a severe, painful and debilitating disease which creates considerable emotional stress in a person's life. The concepts and techniques used in general stress management and patient education programs can potentially be very beneficial in helping individuals with scleroderma cope with the stress that the disease causes, and can reduce the effect that this stress has on their systemic symptoms.

To maintain mobility and prevent deformity, scleroderma patients, like others with chronic disease conditions, must actively and diligently carry out home

exercises. They must take some control over their treatment into their own hands and become active participants in their own care. Melvin et al. (1984) argue that scleroderma patients' psychological attitudes towards the disease, treatment and themselves are often key to a successful home program that maintains mobility and function. "Patients who are depressed or having difficulty coping are likely to withdraw, become inactive, and be unable to participate in their own treatment. If this occurs during a period of exacerbation, contractures could develop in a matter of days" (Melvin et al., 1984).

The psychosocial needs of individuals with scleroderma cannot be met with routine medical follow-up or rehabilitation visits. Some therapists would argue that they can benefit most from evaluation and counselling by health professionals skilled in psychotherapeutic intervention. Although other researchers would not disagree with this approach, they would add that it could be enhanced by some instruction in the use of self-management techniques (Melvin et al., 1984). The type and amount of counselling and self-instruction or patient education needed might depend on the severity and extent of the scleroderma, its speed of progression, the patients lifestyle, ability to work,

personal relationships and family support. For some people, weekly counselling or group therapy is preferred. As is the case for other rheumatic patients, some scleroderma patients may need continuing therapy, whereas others may need support only during periods of crisis.

Rheumatoid Arthritis and Osteoarthritis

Most of the literature on patient education and arthritis pertains to rheumatoid arthritis (RA) and osteoarthritis (OA). Since most of the literature refers to RA and OA, these types of arthritis will be defined. Rheumatoid arthritis involves the synovial membrane lining in the joint becoming inflamed. Cells in the membrane divide and grow and inflammatory cells enter into the joint. Joints become swollen and feel puffy or boggy to touch. Over several years, RA can cause damage to the joint. Rheumatoid arthritis is much like a virus which involves fatigue, aching in the muscles, and stiffness particularly in the morning, except that this condition might persist for months or years. Like scleroderma, rheumatoid arthritis is systemic in that it may attack other body tissues including the whites of the eyes, the nerves, small arteries and the lungs (Anderson et al., 1985). Rheumatoid arthritis affects more women than men. Although this condition usually appears in

middle life, in the forties or fifties, it can appear at any age (Lorig and Fries, 1986).

Osteoarthritis, also known as a degenerative joint disease, is a kind of arthritis that affects everyone. It is practically universal, increasing with age. Fortunately, OA is usually a much less severe arthritis. Osteoarthritis mainly involves the cartilage between joints. Over many years, the cartilage may become frayed or may even wear away entirely. When this happens, bone surfaces grate against each other and cause discomfort (Lorig and Fries, 1986).

Economic, Physical, Psychological, and Social Adjustment

Costs of Arthritis

After defining the above three types of arthritis, it becomes self evident that they can be associated with enormous economic, physical, psychological and social adjustment costs not only to the individual, but to society in general. Rheumatoid arthritis alone affects over four million Americans and is responsible for costs of several billion dollars each year in disability, loss of income and loss of function (Strauss et al., 1986). Although scleroderma is not as prevalent as RA, it is similarly responsible for emotional and psychological costs to the individual such as depression, anxiety,

irritability, social withdrawal, dependent and/or compliant personality traits.

Psychological Responses to Rheumatic Diseases

Banwell and Ziebell (1985) have documented various features of rheumatic disease that evoke psychological responses. First, as a result of the disease or treatment, the subject may have a change in physical experience which further fosters a disrupted body image and a barrier to satisfying social interaction. Second, pain resulting from arthritis exerts a powerful influence upon the personality and emotions. It dulls the environment, interrupts well established patterns of behaviour and interferes with intellectual and emotional functioning. These authors note that "pain is the most disconcerting problem encountered by the patient with a rheumatic disease." Other investigators have also documented the importance of pain as being the most salient patient concern followed by other concerns of physical or psychological disability (Kazis et al., 1983), functional disability (Bradley, 1985), fear, depression and deformity (Lorig et al., 1984). Bradley (1985) notes that subjects' self-reported pain intensity is associated significantly with their functional disability. Positive correlations have also been found

between self-reported pain and depression (Moldofsky and Chester, 1970).

A third discouraging concomitant of the rheumatic diseases is weakness, fatigue and loss of energy. Fourth, along with fatigue and pain comes a loss of functional ability and other physiological impairment. This impairment and loss of functional ability has some important implications for how the person with arthritis identifies him or herself.

Many adults are socially defined primarily by the name of their occupation; for example, cooks, teachers, truck drivers, painters or surgeons. Loss of the ability to carry out these tasks and functions in these roles may cause loss of social identity and diminished self-esteem, even though function in another role would be quite possible (Banwell and Ziebell, 1985).

Loss of function causes dependence in others which means seeking and asking others for help. Fifth, persons with arthritis must bear the financial costs of chronic illness.

Personal adjustment to arthritis may even be problematic when the disease activity decreases. If the patient shows little or no psychological improvement when

the disease activity decreases, we cannot assume that medical management has been successful. Nor can we assume that modern medical management will result in a concomitant improvement in the patient's acceptance of his/her disease. Joint symptoms may improve but the subject may continue to have psychological and social problems. The patient may continue to exhibit his/her initial anxiety, hostility, and inability to accept his/her disease. This reaction constitutes a continuing problem to this person and to others who enter his/her life orbit.

Some additional psychological responses to rheumatic diseases have been observed by Banwell and Ziebell (1985). First, they state that anxiety develops when symptoms appear. Second, denial manifests when the subject ignores the symptoms or insists they have no meaning. Third, anger develops when the individual perceives the injustice of the illness, dependency, pain, and an interruption of life patterns. Fourth, depression is seen as the most common psychological diagnosis in which this condition results in a loss of energy and motivation.

Psychosocial Responses to Rheumatic Diseases

The combination of the above psychological features

of the rheumatic diseases can potentially influence the subjects' family and social environment. Two independent studies have found that about sixty percent of RA patients experience at least one major psychosocial change related to family functioning such as increased arguments with marital partners, sexual problems or changes in the health of family members (Liang et al., 1984; Yelin et al., 1979). Social and marital stress as a result of RA has been evident in some divorce studies (Cobb et al., 1959; Medsger and Robinson, 1972). One finding is that a significant higher level of divorce existed in people who developed RA compared to normal controls. And another finding suggested that the prevalence of divorce in people with RA was primarily a reflection of a lower rate of remarriage. In addition to the decline in family functioning, a study with a population of 180 persons with RA determined that disease, social, and work factors were all found to contribute to the development of work disability. Social and work related factors combined have a far larger effect on work disability than all disease factors. "Among work factors, control over the pace and activities of work and self-employment status had the greatest effect on continued employment, suggesting that time control issues are crucial to the maintenance of one's

job after onset of this illness." With reference to all social and work factors, those measuring autonomy within work rather than demographic background or the physical characteristics of work have the strongest effect. The study suggested that work disability is not strongly associated with the physical requirements of the job among persons with rheumatoid arthritis. The authors suggest that the probability of work disability could be reduced by creation and the development of more flexible roles and pace in work settings. Employers and other labour-management personnel need to be educated by arthritis health professionals in this direction (Yelin et al., 1980).

Family functioning and social adjustment difficulties suggest a need for psychosocial analysis of the patient's needs. Such an analysis would include a social history or assessment of family functioning, an occupational assessment and so forth. The biomedical model assumes a biological pathology underlies the rationale for treatment. It emphasizes treating an illness or disease with a corresponding biomedical solution rather than interacting with the person. By placing less emphasis on the psychological and social issues facing by a patient, the medical model encourages the presumption that negative reactions are a product of

dysfunctional patient character. We have seen that arthritic patients do not necessarily develop dysfunctional characters or pathological personality disorders, however, McFarlane and Brooks (1987) make a case for psychological factors actually having the potential to predict more variance in disability than does disease activity. Psychological factors, such as anxiety, denial, anger and depression were associated with dilemmas caused by having a chronic illness, difficulty in accepting the physician's reassurances and clinical depression. In osteoarthritis, psychological variables have been found to be strong indicators of individual differences in functional impairment and pain (Summers et al., 1988). These findings suggest that the prognosis for future functional ability may be formulated when patients attitudes and psychological states are carefully assessed.

Psychological and social assessments are pertinent to understanding patients with chronically painful joints who often become hostile or appear to feel angry and bitter. Multiple causes are suspected of contributing to these feelings, including becoming defensive against depression and projecting anger upon significant others. Some people with arthritis react to their dependency feelings and the sense of being burdened unfairly with an

unpleasant and painful disease. Their anger can also be directed to the health care provider for not being able to alleviate their symptoms. Injustice is often expressed to the world in general by statements like, "Why me? I have done nothing to deserve this." If not expressed openly, their anger may manifest as passive-aggressive, manipulative behaviour; a manner in which anger can be expressed in a socially acceptable way such as always talking on the phone, watching television, forgetting treatment sessions and/or forgetting to take medications (Potts and Brandt, 1983). Like anger, denial is a defense mechanism that serves to buffer against threatening information; defense against a reality that could overwhelm a patient. Continued denial might be detrimental if the patient cannot psychologically accept the need for treatment. "While some patients may deny that they have arthritis, others can accept the diagnosis on an intellectual basis, but deny its potential seriousness or its chronicity" (Potts and Brandt, 1983).

Bargaining is a behaviour that might appear when denial has diminished and the patient can accept part, if not all, of the situation. For example, a patient might state that "I believe I can cope with my arthritis if only I am able to work until I am sixty-five years old."

(Potts and Brandt, 1983). The social worker in this case must question whether the patient's bargain is realistic. If yes, it can be used as a goal, however, if not, he/she must ask the patient questions to obtain a realistic picture.

Another common emotional response is depression. Zigmond and Snaith (1983) found that hospitalized patients undergoing a flare of RA exhibit a greater degree of depression and especially anxiety than that which occurs in healthy people using the Hospital Anxiety and Depression (HAD) Scale. Depression has been associated with RA by other investigators (Moos and Solomon, 1964; Polley et al., 1970; Lang et al., 1984) who found an association between personality and physical disease and depression. Rheumatoid arthritis patients' responses to objective standardized psychometric tests consistently indicate levels of depression (Anderson et al., 1985; Anderson et al., 1986). Findings of depression have also been documented by Liang et al. (1984), Zaphiropoulos (1974), and Gardiner (1980). Some investigators have suggested that self-reports of depression represent a reaction to the experience of any chronic, disabling illness to the degree that no differences can be found between RA patients and those individuals with other chronic diseases (Bradley, 1985).

In their study, Potts and Brandt (1983) noted that of the thirty to sixty RA patients who were depressed, an association was attributed to decreased independence in performance of daily activities. The investigators stated that this outcome was a normal reaction to loss of function, self-esteem, employment, mobility, or anticipated loss of social contacts and marital dissolution.

Potts and Brandt (1983) make a distinction in sequential emotional responses between patients with terminal illness and those with arthritis. They note that terminally ill patients proceed through denial, anger, bargaining, depression and acceptance of their illness, however, arthritis patients, who exhibit these sequential emotional responses, are different because arthritis is marked by flares and remissions. Fluidity between the stages of emotional responses is more marked in individuals with arthritis than most terminally ill people.

In addition to pain, affective changes and functional disability, patients must adjust to the psychosocial changes that can result from chronic diseases. For example, Earle et al. (1979) found RA patients expressed lower self-esteem, less work satisfaction, and a greater sense of meaninglessness than did

healthy control persons. Others reported dysfunction in social interaction and communication. Other mechanisms by which psychosocial dysfunction may follow illness include a disturbing subjective meaning of the illness and its manifestations for the patient, impairment of the patient's capacity to cope with need and goals, impairment of the ability to meet the demands of sexual, social and economic roles, and disruption of normal sleep and wakefulness patterns. Any disease or disability which threatens or destroys these personal values is bound to have a profound psychosocial effect on the patient and may precipitate one or more psychiatric disorders concurrently or sequentially.

Nicassio et al. (1985) in their use of the Arthritis Helplessness Index (AHI), which measures the extent to which individuals believe they can control their arthritis symptoms, found that helplessness was associated with high levels of pain, anxiety, depression, low self-esteem, and functional disability. Helplessness was also found to be associated with perceptions of negative changes in disability status.

Personal helplessness and passive resignation are postulated by Nicassio et al. (1985) to be the result of the patient's limited tolerance of the unpredictable nature of remission and exacerbation in RA. They suggest

that patients who learn to tolerate the unpredictable nature of RA may be able to achieve better control of their disease (Kirwan, 1988). Achieving greater control over their arthritis involves the patient in a learning process which requires their acceptance of the unpredictable nature of arthritis; that is, its continual remission and exacerbation.

When dealing with the uncertainty and unpredictability of arthritis, patients are unable to predict how the disease will progress, how soon the treatment effect will be noticeable, and which joints will be painful. All of these concerns complicates emotional adjustment.

Psychosocial problems can be tied to the person's general quality of life or life satisfaction. LaBorde and Powers (1980) found that persons with osteoarthritis had significantly lower life satisfaction scores than persons undergoing chronic haemodialysis. They attributed this finding to chronic pain, decreased mobility and preoccupation with the disease.

Family Functioning

A neglected area of psychosocial analysis is the examination of how patient-family communication and interactions are affected by arthritis. It is natural to

expect other family members to react to the disease. Medical personnel do not always encounter all family members and are thus often unaware of their concerns. Conflicts and misunderstandings can develop which can lead to a lack of family support and noncompliance in medical treatment regimens. When good communication does not exist between family members, problems and feelings often go unrecognized and unresolved. The result might be expressed in terms of the patient's resentment, anger, and depression (Banwell and Ziebell, 1985). Another common feeling is when patients verbalize guilt because they are unable to fulfil their customary roles as family members. Under these circumstances some patients perceive themselves as a burden to the family. Failure to communicate adequately with family members and poor social adjustment are other psychosocial problems responsible for inadequate family functioning. Because of a lack of understanding among the patient as well as other family members, improvements in family functioning might require intervention with both parties.

Family members may deny the illness because it seems too threatening and may react with anger toward the patient. Furthermore, guilt may arise because of the anger. Family members might require education regarding common emotional reactions of patients. They may need to

know that anger can be normal for some arthritis patients. As a result, family members may not feel as hurt as they would otherwise if the patient directs anger at them. To enhance family well-being and to prevent family discord, intervening with family members regarding their own emotional reactions to the patient and the disease may be as important as intervening with the patient.

Lack of family support may be a reason for noncompliance in following treatment regimens. Ferguson and Bole (1979) recognize this issue as needing strategies for improving compliance. It must start by convincing the patient that a given recommendation is necessary and is expected to be helpful in terms of either symptomatic relief or prevention of the disease. "In cases where a lack of family support is directly interfering with compliance, direct intervention through education or counselling may improve compliance" (Ferguson and Bole, 1979).

Patients concerned with their impact on their family structure worry about becoming a burden to their family by virtue of the amount of physical and psychic energy which must be expended on their care. Depending on its severity, arthritis can interfere with the physical and financial maintenance of the home and may

limit spare time available to spend with spouses or play time activities with the children. People with arthritis may have a need to discuss their health problems with other members of the family or social network, but frequently they do not wish to impose on others by what might be regarded as "complaining." Evidence suggests that RA patients do not communicate with relatives concerning problems and hurt feelings; and therefore, fatigue, depression and limitations on activities resulting from arthritis might not be well understood by the healthy spouse or close friend (Vignos et al., 1973). Consequently, family members may not be prepared for the patient's depression and irritable moods.

Vignos et al. (1973) evaluated the extent to which family members related to the patient as an equal, the level of mature social relationships, expression of honest feelings in the family and degree of mutual acceptance. Poor social adjustment was found initially in eighty percent of the patients studied. Significant improvement in social adjustment was noted after one year in patients who participated in intensive treatment groups, but not in control groups.

A contributing communication problem is common with people with arthritis. In an attempt to keep their lives, behaviours and interactions with others constant,

arthritis patients often "cover up" their limitations by masking their disability and pain. Patients state that they are fine or attempt to walk as normally as possible in spite of their discomfort. Another technique is "keeping up" or maintaining whatever is perceived as a normal activity level despite the likelihood that increased joint pain may result. People with arthritis who carefully hide their discomfort or disability may wonder why their families and friends are not more helpful or sympathetic. They may be proud because no one knows, yet distressed because no one cares (Potts and Brandt, 1983).

A final observation made by Vignos et al. (1973) is that the impact of severe chronic arthritis may be exacerbated by total or partial confinement to the home. Inability to leave the home removes the stimulation of outside social contacts and breaks down friendships because the arthritis patient frequently cannot respond to invitations or participate in outside activities because of fatigue and pain.

Up until now, we have identified the markedly varied problem area faced by arthritis patients. It is evident that people with arthritis are exposed to various psychological and psychosocial dysfunction, including a range of economic, physical, psychosocial and family

adjustment costs. It is now appropriate to address society's and the health profession's awareness of the disease and their responses to the problem area in general as it has been discussed above.

Societal Awareness of and Response to the Problem Area

Patient Education

By tradition and definition patient education is a "planned combination of learning activities designed to assist people who are having or have had experience with illness or disease in making changes in their behaviour conducive to health" (Green et al., 1979). Recent studies conducted by Lorig et al. (1989), McGowan (1990) and others have demonstrated that positive health outcomes for people with arthritis are possible with the assistance of patient education programs. Levin (1978) stated that the essential purpose of patient education is to teach patients those ideas and skills that will help them cope with their immediate medical problems, to maintain health and avoid disease. During the 1970s, health educators called for more emphasis on the practical contributions of health education in the area of health administration and economic benefits. "It's propitious advantages included fewer broken appointments,

increased bill payments, less likelihood of malpractice suits, more efficient use of professional resources and increased patient compliance with treatment regimens" (Levin, 1978).

Prior to the 1980s, studies in the area of chronic illness and patient education were focused mainly on such programs as hypertension, and diabetes. It was not until the early to mid 1980s that education of arthritis patients in self-care activities was found to greatly influence the symptoms and disability produced by the disease. In particular, people with arthritis are benefiting from patient education in helping themselves maintain functional capabilities by balancing daily rest periods with selected exercises, pacing and planning daily activities, using special devices and body positions to help protect joints and taking medications properly (Knudson et al., 1981).

Patient education becomes increasingly more important as a therapeutic intervention in an age where medical and surgical interventions have a somewhat limited impact on treating a wide scope of arthritic conditions. Although medical and surgical interventions have increased over the last couple of decades, they have had a correspondingly major impact on a relatively small percentage of people with arthritis (Lorig et al., 1987).

On the other hand, arthritis patient education may have the potential to virtually reach most people with arthritis and to assist them with living successfully with their disease. The aims of arthritis patient education differ somewhat from those of other chronic conditions. The patient must be taught to adjust his/her exercise, rest and sometimes medication to the daily disease symptoms. Arthritis patient education is not like a rigidly prescribed treatment program in that the patient must adhere to a physician's instructions without personal discretion. Rather, it assists the patient to make appropriate decisions related to disease activity (Lorig et al., 1987). Moreover, patient education is an important component in the medical care of the chronically ill because it can help the patient not only to become more informed about the nature chronic illness, but it can also help the patient adapt behaviours in accordance with the overall treatment regimen.

Levin (1978) makes a distinction between patient education and self-care education. Patient education assigns a unique social role to the learner, that of a sick person under the care of a professional. In contrast, self-care education does not assume sickness; rather it assigns a generic meaning to care by having individuals look after themselves in an autonomous way.

Patient education goals are initiated in response to a state of disease, whereas self-care educational goals are generally anticipatory. The emphasis on education for people with arthritis is generally placed on self-care patient educational goals because they do not focus on the patient as a sick person having an arthritic personality, but rather, a "person with arthritis" who must learn to live successfully and fully with their condition. In other words, having arthritis is not meant to be central to the patient's life, but rather it is a condition that the patient must learn to cope with, manage and control as much as possible.

Historically, a problem with societal response in developing patient education is that health officials and professionals regulate the process and outcomes, keeping the control in professional hands, resulting in a lack of skills transferring to the patient. The process refers to planning therapy, diagnosing the need, deciding on the acceptable outcomes, selecting a method appropriate to the patient's condition, administering the educational treatment, and observing the results (Levin, 1978).

Beyond regulating behaviour is the potentially serious effect of deprecating, reducing, or even shutting down the patient's autonomous healing capabilities. "The result could be reinforcement of patient dependency with

all of its counter-productive effects, among others, transforming the patient into a malleable component in the professional health care system -- a minor stockholder in the complex firm of medical care" (Levin, 1978).

Determining the Focus of Patient Education

Modern management of individuals with arthritis is similar to the management of other individuals with painful, chronic diseases, which requires them to adopt various new behaviours and make needed changes in their lifestyles. Patient education is one way of increasing the individual's adoption of behaviours aimed at decreasing pain and maintaining function. Despite the apparent importance of patient education in arthritis care, however, few studies have evaluated the impact of these education programs on patients' knowledge of arthritis and changes in their behaviour (Cohen et al., 1986).

Patient surveys have been used to determine educational needs. Lorig et al. (1984) conducted a patient needs assessment using salient belief methodology which asked a sample of people with arthritis what kinds of things come to mind when they think about arthritis. Their primary concerns were pain followed by

disability, fear, depression, and deformity.

Doyle and Brunk (1986) conducted another similar needs assessment for a rural population and the content areas identified were exercise, depression control, energy conservation, joint protection, use of medications, nutrition, diet and sleep. Other areas identified by project staff included evaluating unproven treatments, working with the physician, and helping the family understand.

These outcome variables were established by patients as well as health professionals as criteria for evaluating a patient education course that will be explained in more detail in chapter four. Patient education plays a significant role in helping the patient deal with these variables, and furthermore, it plays an important role in providing some direction for health professionals on selecting the best treatment intervention for the patient.

Working with the physician or improving the doctor-patient relationship is another important area that has been suggested for patient education. Over a one year period, Kirwan (1988) noticed that changes in helplessness correlated with difficulty in performing activities of daily living. Some patients were inclined to hand over responsibility for their disease to the

doctors, which, in turn, mitigates against a sense of personal patient control and self motivation. Kirwan suggested that inappropriate doctor-patient relationships may aggravate chronic disease and that its management might be more effective in group settings.

Social Workers as Educators

Social workers can be instrumental in educating people with arthritis regarding issues like doctor-patient relationships and other educational topics which prove to reduce cost of providing medical care. If the high cost of medical care continues to stimulate movement away from institutional care, many health care professionals, including social workers, will find themselves with expanded responsibilities as self-care consultants (Crane, 1985). Where patient education programs prove to reduce institutional operating costs, social workers will find themselves adopting more responsibility in providing patient education. Within their cost containment responsibilities, line social workers and managerial social workers will be encouraged to accept patient education programs which prove to reduce both intensity of care and length of stay, thereby containing costs without a loss of quality (Bartlett, 1984; Turner, 1978). Alternative health care delivery systems, such as ambulatory care centres, health

maintenance organizations and after care programs, have continued to rapidly expand while patient days have continued to fall. "Self-care, preventive medicine, and wellness concepts are all expanding in health care. Patient education plays an important role in application of these concepts" (Crane, 1985).

The survival and success of quality health care may ultimately depend on the effectiveness of patient education. Medical technology cannot effectively treat many arthritic problems and cannot alter life-style behaviours that bring about or aggravate many of the health problems and disease processes. "Patient education that can produce positive changes in life styles through behaviour modification has the potential to become a major means of health care promotion and, therefore, a major part of the health care delivery system" (Crane, 1985).

The social worker's role in providing effective patient education should accomplish the prevention of adverse health changes and stimulate beneficial health changes. Furthermore, the social worker in this process will be expected to identify target populations of people with arthritis who would benefit from patient education programs, to design implement and administrate patient education programs, and to demonstrate and document cost-

effectiveness of these programs.

Beyond the cost containment argument for increased social work involvement in this field, there is an educational need identified by patients. Knudson et al. (1981) found through informal conversation with staff and patients that many of the educational needs of the patients are not being met. Social workers can be instrumental in picking up this function.

Understanding Psychosocial Concepts

Another concept for improving these areas is the wellness approach whereby patients are encouraged to be healthier than they actually are in spite of having arthritis. Social workers, using a program like the Arthritis Self-Management Program (ASMP), could conceivably fill the gap where educational expertise is needed and assume a larger role in patient education.

Patient education programs like the ASMP provide a basis for understanding personality and emotional states in the physiologic mechanisms of disease and the responses to treatment. The ASMP offers a comprehensive intervention model which includes preventive, therapeutic and rehabilitative components. It is designed to help patients discover the many aspects of their lives that they can control, including diet, exercise, personal

growth, personal habits such as smoking, stress management, attitudes, life style, and nonpharmaceutical pain management. Similarly, the ASMP offers a stress management approach to discover patients' recent emotional states which are sometimes more difficult to determine by using other traditional mental health models for therapy. In particular, it is especially difficult for people with arthritis to discuss their inner feelings in the traditional therapeutic ways. The stress management approach for dealing with psychosocial issues is often more acceptable for people who are hesitant to discuss their feelings and emotions.

In concluding this section, it is important to note that social workers are expanding the field of research in psychosocial issues in the rheumatic diseases and are seeking both to describe the current status of the individual with arthritis and to evaluate the effects of intervention. More emphasis is now placed on the therapeutic value of understanding these issues rather than simply describing an existing personality construct. This problem area is becoming more and more important to the social work profession because with the overall increase in interest of psychosocial factors and support for comprehensive, multidisciplinary arthritis

management, focus is being placed on innovation, implementation and evaluation of creative arthritis management strategies. Emphasis on program evaluation serves to foster more critical thinking among arthritis health professionals.

The growth of behavioral medicine seeks to link biology and pathophysiology of disease and its treatment to associated psychosocial factors. Many new approaches to the psychosocial assessment and intervention have taken into account the physical as well as the emotional or affective aspect of the individual patient, yielding a more unified and cohesive body of information (Banwell and Ziebell, 1985).

In this chapter, it is appropriate to conclude that social workers have a role not only in providing patient education, but in evaluating its effectiveness. Chapter two provides a review of the existing literature. Chapter three clearly sets out the specific issues to be researched and chapter four outlines the research design and rationale. Chapter five discusses the findings of this study and chapter six provides the research implications and conclusions.

CHAPTER TWO

LITERATURE REVIEW

Introduction

This chapter begins with a literature review on the arthritic personality. Next, the influence of psychological factors over RA are identified as determinants of disease development and of patients' ability to adapt to their condition. Third, an evaluation of patient education is examined in light of knowledge, compliance and psychosocial variables thought to influence arthritis health outcomes, including depression, coping, communication and family functioning, and self-efficacy. In addition, pain, functional disability and quality of life are examined. This chapter ends with a critique on methodology.

The Arthritic Personality

Early research in this field concentrated on discovering the "arthritic personality" which was thought to predate the disease. The arthritic personality was hypothesized to be present prior to the onset of the disease which might have predisposed certain individuals to the occurrence of RA (Anderson, 1985). Rheumatoid arthritis patients were thought to be self-punitive, to have authoritarian fathers, distant and aloof mothers,

and repressed rage (Shamoian and Lockshin, 1980). Other subjective findings described the patient as being self-restricted, detached, emotionally calm, dependent and compulsive. The arthritis patient was described as having repressed rebellious resentment against parental dominance, repressed hostility, and intrapunitive (Achterberg-Lawlis, 1982). Early research also documented emotional factors as leading to the development of RA. Emotional trauma such as surgery, poor sexual adjustments, pregnancy, and death or separation were all thought to predate the onset of arthritis. Early studies identified the arthritic personality type as patients who overreacted to their illness, were self-sacrificing, masochistic, frigid, moralistic, conforming, self-conscious, shy, inhibited, and perfectionistic (Baum, 1982). In comments like the following, it is evident that early researchers were somewhat preoccupied with discovering a particular arthritic personality type.

There is some RA personality 'type' which predates the disease and plays some role in the onset and progression of the disease process. Pain and crippling associated with RA forces patients to a common type regardless of their previous makeup (Robinson

et al., 1971).

Much of this early research was post hoc, uncontrolled and of questionable validity. Robinson (1957) and Alexander (1950) produced personality profiles based on case studies and interviews in therapy settings, a research strategy which is subjective and minimally controlled. Cleveland (1954) and Cormier (1957) used a combination of interviews and testing, using the Rorschach, Thematic Apperception Test and Draw a Person Test, to construct personality descriptions unique to persons with arthritis. However, it must be recognized that these tests and the validity of interpretation may be particularly affected by the method of administration, scoring and circumstances of testing.

One must question whether the general medical population or other chronic disease groups are more appropriate as controls than the normal population. The "chronic disease personality" profile may exist among a wide variety of patients rather than being a personality type unique to people with arthritis. Also, one must not overlook the probability that the chronic disease personality can be a result of rather than a precursor to illness. It is more likely that various unconscious or habitual coping preferences appear after the onset of arthritis.

Later, when control groups were used, the findings regarding the premorbid personality conflicted with previous studies. The findings were inconsistent in that many patients with RA did not fit these descriptions and that such constellations are frequently encountered in patients with illnesses other than rheumatoid disorders. "Medical illnesses may be influenced by psychological factors and the psychological state of the individual is affected in turn by the pathology of the organism" (Shamoian and Lockshin, 1980).

Too much focus has been given to the negative psychological characteristics. This focus has revealed little or no information about RA patients' adaptive coping responses or positive characteristics. Alternatively, positive psychological aspects of RA patients may provide valuable information with regard to understanding these subjects and their treatment of RA (Anderson et al., 1985; Anderson et al., 1986).

The arthritic personality literature has suffered from investigators' failure to provide more information on patient characteristics such as age, socio-economic status or education. Although some of the recent literature is filling this void, earlier research paid little attention to various disease parameters, including duration and severity of illness, degree of functional

disability, and type and amount of medication used.

The implications of these early studies present a scenario between a physician and his/her patient which depicts a problem that sometimes occurs.

There is probably nothing more destructive to a patient-practitioner relationship than quickly concluding that the patient is a "psych" case. Although this may not be verbalized, it is quickly conveyed to the patient by the physician's attitude and quality of care delivered. Many patients with an equivocal diagnosis or a rheumatoid disorder often sigh with relief when the diagnosis is finally confirmed: Thank God, now the doctor believes me and doesn't think that I'm a crank (Shamoian and Lockshin, 1980).

In sum, it is important to emphasize that little or no evidence has appeared in the literature for the existence of an arthritic personality that predates the disease and leads to disease onset. Negative personality characteristics noted among people with arthritis are more feasibly explained as reactions to their chronic conditions rather than causal factors (Anderson et al., 1985). Moreover, many of the patterns in the rheumatoid

personality literature are likely the result of the disease process rather than the factors related to the development of RA. The disease activity of RA determines the psychological responses and these personality patterns are more obvious in subjects who have had RA for longer periods of time. Traits related to the disease are "most readily explained on the basis of the symptoms and effects of a disease that is chronic, painful, and potentially dangerous to various degrees" (Baum, 1982).

Given the retrospective nature of the early research on RA personality types, any attempt to establish the existence of premorbid personality traits by testing subjects after the disease onset is not an adequate test of the question. Such a test cannot determine which traits were present prior to the disease onset and which traits resulted from the disease itself. Notwithstanding the prohibitive feasibility and expense involved, an ideal approach would involve a long term study of normal persons in which those who develop RA would be compared to those who did not. A more practical approach would compare the personality characteristics of RA patients in the earliest stages of the disease with chronic RA patients.

Psychological Factors and Rheumatoid Arthritis

Although it is clear that patients with chronic RA exhibit anatomical and psychological changes, evidence is accumulating for the importance of psychological factors as determinants of disease development and of patients' ability to adapt to their condition. Health professionals are also becoming increasingly aware that arthritis and education programs can be improved by paying more attention to the problems patients face in adapting to a chronic disease both physically and psychologically (Brooks and McFarlane, 1983; Jette, 1982; Rogers et al., 1980; Meenan et al., 1981).

Nicassio et al. (1985) investigated the correlation between psychological factors of personal helplessness and the changing difficulty in performing activities of daily living over a one year period.

The inclination of some patients (perhaps supported by the atmosphere of much current medical practice) to hand over responsibility for disease to doctors mitigates against a sense of personal control and self-motivation, suggesting that inappropriate doctor-patient relationships may aggravate chronic disease and that, at least for some patients, disease management could be more effective in group

settings (Oberai and Kirwan, 1988).

McFarlane and Brooks (1987) assessed thirty patients with RA over a three year period and found that psychological factors consistently predicted more of the variance in disability than did disease activity. These investigators also reported that these psychological factors were associated with a tendency to deny the emotional dilemmas caused by having a chronic illness, difficulty in accepting doctors' reassurances about the disease, and clinical depression. Similarly, Summers et al., (1988) worked with sixty-five patients with knee and hip osteoarthritis and concluded that psychological variables were strong indicators of individual differences in functional impairment and pain. These findings suggest that the prognosis for future functional ability may only be formulated when patients' attitudes and psychological states are carefully assessed.

Evaluation of Patient Education

Not until the late seventies did comprehensive patient care and patient education receive increased emphasis with regard to RA. Interdisciplinary teams (Katz et al., 1968), educational programs (Vignos et al., 1976; Kaye and Hammond, 1978) and psychotherapy groups

(Udelman and Udelman, 1977) were formed. Independent or professionally organized patient groups were also created for educational and supportive purposes. Although the arguments for such programs were compelling, few controlled studies had been published. The psychological and social problems identified in the needs assessments discussed in the previous chapter highlight the need for critical evaluation of priorities which should be addressed in patient education programs. More professional attention is needed analyzing the importance of psychosocial factors in the way patients cope with their arthritis. This critical evaluation of priorities is not only important for the establishment of new programs, but it is also important for their development.

In 1979, the Stanford Arthritis Centre initiated a program called the Arthritis Self-Management Patient Education research project. From its inception, the project had two objectives. The first was, to develop and implement a community-based patient education program that would improve health status, lower health care costs and improve patient satisfaction. The second purpose was to introduce a low-cost, easily replicable mass patient education model (Lorig et al, 1984).

Increase in Knowledge

Evaluation of the Arthritis Self-Management Program (ASMP) (which will be described in more detail in Chapter Four), indicated that subjects reported an increase in their knowledge of arthritis. Other investigators which assert that arthritis patient education is effective, primarily in the area of improving patients' knowledge of their illness include Lorig et al. (1987), Mazzuca (1982); Kaye and Hammond (1978); Kaplin and Kozin (1981); Knudson et al. (1981); Gross and Brandt (1981).

Lorig et al. (1987) published a review of the literature evaluating arthritis patient education studies, involving attempt to change psychosocial status. Of the 76 studies included in the review, 34 measured changes in knowledge with 94 percent finding an increase in knowledge of arthritis. The most frequent type of knowledge measured was that of the disease process and/or its treatment.

Kaplin and Kozin (1981) conducted one of the first controlled studies to assess the value of group counselling, which included an educational component in patients with RA. The results indicated that subjects who attended group counselling sessions made gains in knowledge and understanding of their disease.

Kaye and Hammond (1978) evaluated patient education

programs using 48 RA patients of which 94 percent considered the programs helpful in increasing their understanding of their condition. Similarly, Kaplin and Kozin (1981) reported that patient education and counselling improved scores of self concept and factual knowledge. They concluded that these results provide evidence that formal education sessions and group counselling may be an important part of the patients' management of their RA.

Knudson et al. (1981) found that outpatient education for RA patient groups was higher in their cognitive score compared to controls and that the treatment group also improved its behavioral scores in the long term more so than the control group. The behavioral scores were taken from the subjects' self-care activities in accordance with their treatment regimen.

Gross and Brandt (1981), like the above investigators, found educational support groups for patients with ankylosing spondylitis to significantly increase the patients' knowledge about the disease and its treatment. Udelman and Udelman (1978), too, concluded from their study that educational support groups resulted in increasing patients' understanding of their disease, however, this conclusion was not based on a controlled study. In another study, Potts and Brandt

(1983) found education support groups for patients with RA showed that their participation increased their knowledge about the disease process.

Cohen et al. (1986) found in their study of arthritis subjects who participated in a self-management educational program that some differences existed between experimental subjects and controls, particularly the aforementioned group acquiring greater knowledge on how to care for their arthritis than the latter group who received no educational instruction.

An increase in knowledge among treatment subjects is consistent with the results of many other studies of arthritis patient education, however, determining the degree to which knowledge of self-management influences behaviour remains problematic. Many studies remain inconclusive with regard to what factors cause improvement in targeted behaviours.

Although publications in this field have increased (Rippey et al., 1987; Spiegel et al., 1987; Lorig et al., 1985; 1986a; 1986b; 1986c; and 1987), education objectives rarely include an attempt to change more than the patients' knowledge. The evidence suggests that an increase in knowledge alone will rarely improve health (Mazzacu, 1982; Williams and Wood, 1986; and Affleck et al., 1987). "It seems likely that patients will also

need to acquire skills to cope with specific aspects of their illness (such as a flare in a specific joint) together with an appropriate attitude to their disease, which will enable them to apply their knowledge and skills and take a greater control of their own management" (Oberai and Kirwan, 1988).

Increase in Compliance

Educational components have also been investigated as part of interventions to improve compliance. Mazzuca (1982) discusses a literature review published by R.B. Haynes (1976) that covers all "clinical maneuvers" designed to increase compliance with either preventive or therapeutic regimens. Haynes used an ad hoc rating system to integrate statistical and clinical significance of the results. He found that interventions which sought to improve compliance by increasing the patients' knowledge alone had 64 percent success rating. In contrast, behavioral strategies received a success rating of 85 percent and combined educational and behavioral strategies received a success rating of 88 percent. Therapeutic outcomes for educational, behavioral and combined strategies were estimated at 50, 82 and 75 percent success ratings respectively.

A couple of unanswered questions emerge in Haynes

review of the literature, including, first, the degree to which the reported interventions actually improved a patient's health. And second, one must question whether a summary of studies across a broad spectrum of common medical disorders is an accurate representation for chronic disease. It can be argued that a summary of results across all medical disorders is likely to inflate the estimated effects for patients with chronic disease (Mazzuca, 1982).

Notwithstanding this criticism of Haynes, the literature clearly shows that behavioral or regimen orientated instruction has therapeutic value. Patients need to put less emphasis on learning about the pathophysiology of their disease and more emphasis on integrating new behavioral demands into their daily routine. Patient health education must instigate this change. Regular contact with the same health care professionals, control over stimuli and rewards for progress and daily self-care rituals were among the more successful interventions (Mazzuca, 1982).

Patient education is prescribed by health professionals to increase patient participation in his/her own health care and thus maximize the therapeutic benefit. A more critical analysis of this presumption indicates that it often goes untested. The question

remains: how can the degree to which patient education improves the course of chronic disease be determined?

Keeping in mind that a wider range of dependent measures ought to be measured, Lorig et al. (1987) reviewed the patient education literature and found that studies of associations between compliance behaviour and health status were not strongly substantiated. The conclusion was drawn that little evidence exists to support the assumption that behaviour change is linked to health status change.

Whatever their ultimate explanation and generalizability, these results underscore the need for careful evaluation of educational programs about chronic disease. Certainly, patient education can bring about changes in behaviour and in health status, but the mechanisms involved are not clear. Assumptions that behaviour change is sufficient in itself, or that a particular behaviour change will lead to a desired outcome might be erroneous or insufficient (Lorig et al., 1989b).

In their review of studies which utilized educational techniques designed solely to disseminate knowledge, Sackett and Haynes (1976) found that these

studies ignored the attitudes that were more closely linked to compliance behaviour. The investigators noted that patients showed a low correlation between knowledge of their condition and their compliance. Perhaps ignoring attitudinal change as an educational objective may be part of the explanation for this low correlation.

Many studies reviewed had no pre-test or entry assessment of either the patients' knowledge or attitudes prior to exposure to the educational program, which precluded any precise estimate of the effect of the program upon these attributes. Also, repeated measurements were frequently ignored in longitudinal follow-up studies. Many of the studies reviewed confined themselves to measures of perception and ignored the actual behaviour of patients (Sackett and Haynes, 1976).

These results indicate the need for compliance research to be limited to those clinical conditions for which treatment has been demonstrated to be efficacious. Researchers must acknowledge that the list of clinical conditions that would qualify within this criteria is probably quite small; therefore, an obvious need exists for improved information that will identify those conditions where treatment has been demonstrated to be efficacious. It follows that future arthritis patient education research and practical applications ought to

conform to rigorous research methodology and clinical conditions for which treatment has been empirically demonstrated to be efficacious.

A high priority exists for a broader yet more precise definition of learning.

There has been a failure of many studies to look beyond a limited number of educational outcome and compliance measures. There is a clear need to look harder for both anticipated and unanticipated results of an educational maneuver. For example, will patients do themselves harm by acting on incomplete or misunderstood information? Will they become more dependent on the health system and increase the demands on health professionals, having been given a little knowledge? Could it be that some of the "drop-outs" in compliance studies have incurred increased anxiety about their condition as a result of the educational maneuver and are doctor-shopping elsewhere or not coming in at all? What are the indirect costs of patient education maneuvers? (Sackett and Haynes, 1976).

Psychosocial Variables

Lorig et al. (1987) note that a wide range of behaviours are thought to influence arthritis health or psychosocial status. The behaviours that seem to influence pain, disability, and depression are exercise, relaxation and joint protection among others. These investigators identified 48 measures of behaviour change with 77 percent in the direction of increased practice of desired behaviours [See Table 2.1]. They concluded that patient education does appear to influence a variety of arthritis related behaviours.

Even though a wide variety of psychosocial areas have been studied, existing scholarly literature is generally void of documentation that suggests that these areas are a problem to people with arthritis. Therefore, one needs to be cautious in judging the success of patient education interventions that influence these variables.

Nonetheless, when psychosocial variables are measured, the interventions chosen tend to produce significant changes. An overview of psychosocial variables studied in the field by the numerous researchers documented in Lorig's et al. review of the literature is illustrated in Table 2.2. According to

Table 2.1

Summary of Arthritis Patient Education Studies Involving Attempts to Change Behaviours

Behaviours	No. of studies measuring behavioral changes	No. with positive changes	Percent
Exercise (a)	14	11	79
Relaxation	14	12	86
Compliance (b)	9	7	78
Change in use of medication	5	3	60
Sleep	3	3	100
Joint protection	3	1	33

(a) Exercise includes stretching, strengthening, and endurance, or aerobic activities.

(b) Compliance with prescribed regimes and/or appointment keeping.

Source: Lorig et al., 1987.

Table 2.2**Summary of Arthritis Patient Education Studies Involving Attempts to Change Psychosocial Status**

Psychosocial variables	No. of studies measuring psychosocial variables	No. with positive changes	Percent
Depression	17	9	53
Mood/morale (a)	9	5	56
Coping	7	6	86
Anxiety	6	5	83
Family communications	5	4	80
Self-Efficacy (b)	4	3	75
Locus of control	4	1	25
Social roles	3	2	67
Stress	3	2	67
Self-esteem	2	1	50
Social support	2	1	50
Satisfaction	2	0	0
Loneliness	1	1	100
Anger	1	0	0

(a) Includes attitude of acceptance and hopefulness.

(b) Includes belief to control arthritis symptoms and manage health outcomes.

Source: Lorig et al., 1987.

this table, the first seven most commonly documented psychosocial variables include (1) depression, (2) mood/morale, (3) coping, (4) anxiety, (5) family communications, (6) self-efficacy, and (7) locus of control. The variable that received the most research attention is depression with 17 studies measuring it, 9 of which documented positive changes. Mood/moral, which includes attitudes of acceptance of arthritis and hopefulness, was evaluated by 9 studies, 5 of which recorded positive changes. Their respective changes in a positive direction, due to the various arthritis patient education trials in the studies, are documented in the table. The same can be seen for the latter seven most commonly documented psychosocial variables, which include (8) social roles, (9) stress, (10) self-esteem, (11) social support, (12) satisfaction, (13) loneliness, and (14) anger. Of the 76 studies included in this review, it is significant to note that very few psychosocial variables were actually measured, considering that these variables are likely accountable for considerable changes in health status (Lorig et al., 1987).

Depression

Kaplin and Kozin (1981) found that subjects

experienced a reduction in their depression levels immediately following educational sessions. This reduction was maintained in the experimental group, but not in the control group. Although, the differences in depression between the groups were not statistically significant, a combination of education and short term group counselling led to the general trends of improved self-esteem and an increase in satisfaction of overall needs in the experimental group.

Lorig et al. (1989) found that along with an increase in knowledge and adoption of taught behaviours, pain and depression declined significantly in comparison to controls in a four year follow-up study. Like improvements in the psychosocial factors of coping and family communication, some investigators have also reported improvements in depression (Kaye and Hammond, 1978; Udelman and Udelman, 1978; Gross and Brandt, 1981; Kaplan and Kozin, 1981; Wetstone et al., 1982; Schwartz et al., 1978).

Coping

Potts and Brandt's (1983) study of educational support groups for patients with RA, involving nineteen subjects and a similar number of controls, revealed that while a significant increase in patients' knowledge of RA

occurred, the groups had little effect on patients' ability to cope with arthritis or on their compliance with prescribed treatment. Coping with arthritis was defined as the patients' ability to ask for help in completing household tasks, explain the disease to others, verbalize feelings of depression or frustration, and engage in their customary degree of sexual activity.

These results allowed the investigators to conclude that participation in the educational support groups did not necessarily enhance the overall ability of patients to cope with RA. These results are similar to those of the ankylosing spondylitis study and the explanation offered is that possibly the relatively brief duration of the educational support groups (four weeks) did not provide sufficient time for the participants to resolve their difficulties in coping with their illness.

Communication and Family Functioning

Numerous studies suggest that patient education results in an increase in patients' communication with their doctor and/or family. In Kaye and Hammond's study (1978) of 48 RA patients, 93 percent said that patient education enhanced their communication with their family. The authors concluded that patient education is effective in helping patients understand and comply with

physicians' instructions as well as helping patients assume greater responsibility for their own health care.

Other investigators found improvement in communications. Schwartz et al. (1978) found enhanced communications with physicians and family members. Although their findings were not based on a controlled study, Udelman and Udelman (1978) found that educational support groups allowed patients to identify strengths and adequate techniques of coping and healthier family communication.

Self-Efficacy and Health Outcomes

A variable which is similar to health locus of control is perceived self-efficacy. Self-efficacy is the belief that one can perform a specific behaviour or task in the future. Lorig et al. (1989), found a significant growth in self-efficacy among subjects in the Arthritis Self-Management Program (ASMP), and a high association between the increase in perceived self-efficacy and the decline in pain. With regard to the self-efficacy measure developed for this study, the authors state that "the instrument performed well during its development and in a preliminary test, discriminating patients who received educational intervention from patients in the control group," who did not receive educational

intervention.

They also found that health outcomes correlated with a perceived ability "to do things" (perceived self-efficacy) that would yield the desired outcomes. Patients' perceived their ability "to do things" grew during the ASMP. More specifically, perceived self-efficacy correlated with health outcomes both before and after the course, and as these outcomes improved during the course, perceived self-efficacy grew.

Prior to the development of a instrument designed to measure perceived self-efficacy, Lorig et al. (1989b) and Lenker and Lorig (1984) questioned the traditional assumptions underlying the educational process.

The Arthritis Self-Management Program (ASMP) has evidentially been successful in improving knowledge of arthritis, increasing behaviours thought to be beneficial and decreasing levels of pain. However, while the results of some of the patient education studies reported in this literature review have been positive, the methods of education and evaluation have varied, preventing conclusions concerning the most effective means of conducting the programs. Most programs reviewed have been based on a conventional educational concept whereby the cause-and-effect process is directly linked. Moreover, it is assumed that education leads to the

adoption of particular practices or behaviours which, in turn, lead to beneficial changes in health. However, most patient education studies have not tested the validity of this sequence.

Lorig et al. (1989b) found weak correlations between participants' adoption of taught behaviours and improved health outcomes. Involving a large number of subjects, the ASMP permitted an examination of the association between knowledge increases and adoption of taught behaviours (exercise, relaxation, and walking) and health outcomes; that is, decreased pain, disability and depression. Since this association proved to be weak, the usual sequential educational mechanism appeared to be insufficient. Moreover, while the weak associations do not exclude an effect of incremental behavioral changes on health status, they do suggest that other mediating factors are present.

The weak associations prompted Lorig et al. (1989) to interview 54 participants and evaluate their experiences in the ASMP. The participants were asked why they found the course helpful or not helpful. One half of the subjects interviewed stated that their pain and/or disability had decreased, while the other half stated that their pain and/or disability had not changed or had increased. The former group believed that their benefits

were due to an increased sense of influence or control over the consequences of arthritis, while the latter group believed that they had no control or could do little to improve their situation.

The authors attributed these findings to the subjects' sense of personal ability to affect the consequences of their arthritis. They concluded that this ability to effect change (akin to confidence) is similar to the psychological concept of perceived self-efficacy and that this self-efficacy was strong in some subjects and relatively weak in others. They also concluded that the perceived self-efficacy interacted with the course to create the health outcomes.

Lenker et al. (1984) also found a lack of association between improved health behaviours and improved health status. Persons with arthritis who attended a twelve hour self-management course generally showed improved health behaviours and improved health outcomes, however, the investigators found no association between the two. They interviewed 54 course participants to determine the factors that were associated with positive and negative health status outcomes. Persons having positive health outcomes indicated that they had more control over their disease and a positive emotional status, while persons with negative health outcomes

indicated that they had a lack of control and generally a negative emotional status. The differences between these two groups were statistically significant.

Two studies (Lenker et al., 1984; and DeVellis et al., 1986) which presented measures of association between behaviours and health status, assumed that the associations were not strongly substantiated. Van Deusen and Harlowe studied the effectiveness of the ROM (range of motion) Dance in which control subjects significantly increased the frequency of their exercise and rest, but did not demonstrate significant health status changes. On the other hand, the treatment group did not significantly increase their expected behaviours, but did improve their health status. Four other studies assessed both behaviours and health status (Achterberg et al., 1981; Cohen et al., 1986; Rippey et al., 1987; Geoppinger et al., 1987). Although three studies demonstrated significant changes in behaviour, they did not demonstrate changes in health status (Cohen et al., 1986; Rippey et al., 1987; Geoppinger et al., 1987). In addition, one study (Achterberg et al., 1981) demonstrated negative health status.

Failure to establish a link between behavioral changes and health status changes may be due to faulty assumptions or to measurement error. In any case, future

studies should be based on sound theoretical models and should be empirically tested for their assumptions. Based on these findings, little evidence exists to support the assumption that behaviour change is linked to health status change.

Pain, Functional Disability and Quality of Life

Table 2.3 summarizes the studies which included health status as an outcome variable (Lorig et al., 1987). The health status variables included in the table are pain, functional disability, disease activity, physical activity level, work capacity, count of painful joints, stiffness, mobility, total health score and grip strength. Ninety-six measures of health status were identified of which 59 (61 percent) demonstrated improvement.

Lorig and her colleagues (1985) found that with an increase in particular exercises and relaxation behaviours, a trend toward decreased disability and a lower number of physician visits per year occurred than before the educational program. Not only did Lorig and her colleagues find these effects immediately following the intervention, but for the variables of knowledge, exercise and relaxation behaviours, and pain, the effects remained twenty months after completion of the program.

Table 2.3

Summary of Arthritis Patient Education Studies Involving Attempts to Change Health Status

Health status variables	No. of studies measuring health status	No. with positive change	Percent
Pain	29	19	66
Functional disability	14	8	57
Disease activity (a)	10	5	50
Physical activity level	8	3	38
Work capacity/walking and exercise time	8	7	89
Count of painful joints	7	5	71
Stiffness	6	3	50
Mobility	6	4	67
Total health score	5	3	60
Grip strength	3	2	67

(a) Disease activity includes clinical measures, sedimentation rates, and immunological tests.

Source: Lorig et al., 1987.

More specifically, in this randomized trial of 190 people with arthritis, the investigators found that pain was diminished by approximately twenty percent. No significant improvement in the average degree of disability was observed, but there was no deterioration either. These results add to the evidence that health education benefits persons with chronic disease.

A research project studying the impact of an arthritis education program on functional ability, pain and quality of life, was conducted by Parker et al. (1984) using the Arthritis Impact Measurement Scales (AIMS). Additional dependent outcome variables also included knowledge of arthritis and depression. Twenty-two men with RA were randomly assigned to either a patient education group which received standard inpatient medical care in addition to a formal educational program, or a control group which received only the inpatient medical care. Members of the groups were not significantly different in terms of their age, degree of stress, socioeconomic status, education level, or years since the onset of RA.

A summary of their findings indicates that the arthritis patient education program did not confer major advantages on the treatment group compared to the control group. In terms of most of the variables studied,

subjects in the control group displayed outcomes similar to those found in the patient education group. The investigators' findings did not confirm positive patient outcomes suggested by some of the other studies that we have reviewed. This discrepancy appears to be related to the fact that the early investigations did not use randomized control groups, validated dependent measures and prospective designs.

Parker et al. (1984) did find negative outcomes of increased pain and impaired physical activity in the patient education group. The investigators argue that pain is a multidimensional phenomenon which includes cognitive and emotional determinants, as well as a sensory substrate. Consequently, patient education programs which highlight the disease process in education materials may inadvertently modify or emphasize the cognitive dimension of the subjects pain experience. This phenomenon could be operating when pictures of joints are displayed or concepts such as "joint erosion" are used to explain the underlying pathology of RA.

Since the literature (Sternbach, 1978) has illustrated that pain is greatly affected by the individual's mental set, it is reasonable to assume that certain education materials

might result in a reinterpretation (and possibly magnification) of the pain experience.... With regard to the paradoxical findings of more impaired physical activity among patients who have received more education, a similar process may be operating. Patient education programs frequently use the concept of "joint protection" to teach lifestyle changes to individuals with RA. This concept may inadvertently heighten the sense of vulnerability in some patients, and a sensitization may occur in which patients assume too strong a relationship between movement and potential joint damage. This study's results strongly suggest that patients place their own cognitive interpretation on the educational process, and that such interpretations are not always those which are intended by the educator (Parker et al., 1984).

Critique on Methodology

As the number of arthritis patient education studies grow, so do the questions about appropriate evaluation strategies, including design and instrumentation. Most

patient education critics have urged the adoption of randomized control designs. These designs usually assume that first, if an intervention is effective, the treatment group will improve in its dependent variables while the control group will remain unchanged. Second, given an adequate group size and sampling procedures, these effects will be normally distributed. However, a problem occurs when many studies do not support these assumptions. In looking at the problems with the first assumption, it is important to note that arthritis tends to wax and wane over time, and because of the cyclical nature of this disease, subjects typically enter the study when they are having problems. Thus, regardless of the treatment or, in this case, the patient education program, both treatment and control groups tend to improve. Also confounding the results are the control participants who often seek other forms of relief such as changing medications or entering an exercise program. Therefore, both regression toward the mean and the help seeking behaviour of control subjects can mask the potential study effects on any of the variables measured. In their review of the literature, Lorig et al. (1987) noted six studies that demonstrated improvement by controls on behavioral, psychological, or health status variables in spite of the fact that no treatment was

provided (Bradley et al., 1984; Parker et al., 1984; Bradley et al., 1985; Shearn and Fireman, 1985; O'Leary et al., in press; VanDeusen and Harlowe, 1987).

Regarding the second assumption of normality and sample size, a compromise in the heterogeneity of the study population may have occurred in some studies. A wide variation occurs in the symptoms and activity levels among people with the same diagnosis and functional classification. Variation around the mean is often 30 to 50 percent of the mean value (Achterberg et al., 1981; Bradley, 1984; Feedman et al., 1984; Bradley et al., 1985). Given this heterogeneity, it is essential that the sample size in these studies be large enough to provide power to detect treatment effects and to reduce the probability of a type II error. For example, Shearn and Fireman (1985) conducted a study in which the sample size was too small to detect a statistically significant treatment effect. In other words, the treatment group improved substantially more (eg., pain reduction was 14 percent for the stress management group and 18 percent for the support group) than the control group, but the changes were not statistically significant (Lorig et al., 1987).

Another methodological problem with patient education studies is the choice of appropriate

instrumentation. Several excellent, validated self-report scales for measuring pain and disability do exist, however, the measurement of psychological variables is more problematic. With a few exceptions, most of these scales have been validated on normal and/or psychiatric patients designed to measure psychiatric problems in populations without chronic disease. Two problems exist with these scales: first, they are not sensitive enough to measure preclinical conditions and second, many of the items which measure psychological conditions like depression are compromised with arthritis conditions. For example, the Beck Depression scale might consistently measure arthritis subjects as having a significant amount of depression, but most people with arthritis score high on the fatigue dimension because it happens to be a predominant symptom of the disease. This methodological problem underscores the need for psychological scales to be revalidated when used in populations with chronic illness (Lorig et al., 1987).

Among the few evaluations of arthritis patient education programs, most have had problems with research design and, hence, with the credibility of the conclusions reported. Problems with individual studies have included a lack of randomization (Valentine, 1970; Moll and Wright, 1972; Vignos et al., 1976; Stross and

Mikkelsen, 1977; Kaye and Hammond, 1978; Gross and Brandt, 1981; Knudson et al., 1981), absence of pretest intervention assessment (Valentine, 1970; Moll and Wright, 1972; Vignos et al., 1976) and an absence of multiple education strategies (Valentine, 1970; Vignos et al., 1976; Stross and Mikkelsen, 1977; Kaye and Hammond, 1978; Lorig et al., 1981). Inconsistent test of group differences and non-comparable outcome measures represent problems with these studies. Although their investigators contend that education improves patient knowledge, the results are inconclusive regarding the efficacy in changing behaviour patterns.

As mentioned, one common weakness to earlier studies is the absence of using control groups. Without a control group, the investigator cannot determine how scores might change in the absence of an educational program. Knudson et al. (1981) used a control group to find that their scores did, in fact, improve, although not nearly to the degree as in the treatment group. Therefore, one cannot assume that the knowledge increase of the treatment group was due entirely to the educational program. Alternatively, other variables, such as the testing effect or concurrent education of life experiences, might be responsible for part of this gain. A control group, then, helps to eliminate the

possibility of incorrectly assessing the impact of a program on program objectives.

A summary of the problems with past research includes one or more of the following weaknesses: inadequate research design; poorly defined research strategies; lack of long term follow-up measures; failure to assess program impact on patient behaviour; and failure to assess patient satisfaction with the program in lieu of objective cognitive assessment (Knudson et al., 1981).

This study attempts to deal with some of these problems outlined in past research; however, because of some of its methodological limitations of a small sample size and self-selection by subjects, not all of these problems cannot be overcome. A quasi-experimental design has been employed in this study to reduce the methodological problems associated with single group and single case study designs. It is assumed that some level of comparison can be made between the two groups employed in the present study, which is not necessarily the case for single group designs. In addition to this research strategy, qualitative interviews were conducted with the treatment group subjects to gain greater depth in the analysis of results. In particular, the interviews serve to assess the impact of the educational

program on patient behaviour and patient satisfaction with the program.

The foregoing discussion has been, by and large, an attempt to critically outline some of the past research studies and an analysis of some methodological issues related to this thesis topic. The following chapter will discuss the research problem and the specific issues employed by this project.

CHAPTER THREE

THE RESEARCH PROBLEM AND ISSUES TO BE RESEARCHED

Introduction

This chapter essentially addresses two topics. First, it describes the format of the arthritis patient education program chosen for this study in the light of how it was developed by Lorig and her colleagues. This study evaluates Lorig's program in terms of its implications for people with scleroderma in the Vancouver Lower Mainland area. Second, this chapter discusses the dependent variables chosen for this study, its purpose and its hypotheses.

Development of the Arthritis Self-Management Program

Lorig et al. (1987) recognized that the aims of arthritis patient education were somewhat different from those of other chronic conditions. Unlike hypertension and diabetes, for example, compliance is not always the prime importance. Arthritis waxes and wanes almost on a daily basis; therefore, the person with arthritis must be taught to adjust to his or her exercise, rest and sometimes even medication to the daily disease symptoms. Rather than prescribing a medical regimen which must be followed rigidly, the arthritis patient must be helped to

make appropriate decisions related to the daily disease activity.

The ASMP was developed on the basis of a patient needs assessment conducted by Lorig and her colleagues (1982). In planning the Arthritis Self-Management Program (ASMP), five different assessments were conducted. First, eight people with arthritis were visited in their homes and indepth, non-structured interviews were held to determine how these people live in the community and how they perceive the effects of the disease on their daily lives. The single most important outcome of this study was that the patients wanted to be discussed separately from their disease. "They did not see themselves as 'arthritis', but rather 'people with arthritis'". An important distinction emerges here. "Arthritis" see the disease as being central to his/her being and the focus of life, whereas "people with arthritis" see their disease as a part of their lives and to be dealt with in perspective. Second, as a part of the needs assessment, 100 people answered three questions which were (a) What do you think of your arthritis?; (b) What things do you do to make your arthritis better?; and (c) What things make your arthritis worse? These questions were aimed at determining the salient or most important beliefs held by

patients regarding their disease. The number one concern was pain, followed by disability, and a variety of emotional problems grouped as fear and depression. Disfigurement was a distant fourth concern.

Third, also a part of the needs assessment, were 50 rheumatologists who were asked several questions. The assessment showed that physicians and patients agree very closely on what can be done to make the disease either better or worse. However, physicians underestimated the patients' knowledge of how to treat their illness. Fourth, the researchers interviewed a variety of other professionals, including nurses, occupational therapists, physiotherapists, and social workers. Fifth, a literature review was conducted on arthritis patient education models and information on evaluating such models in terms of their effectiveness. The researchers found that, in rehabilitation modalities, "conventional wisdom" often took priority over proven effectiveness. For example, the literature review revealed little agreement on the amount of exercise for people with arthritis or the effectiveness of occupational therapy for these people. Even less documentation was found on the effectiveness of relaxation for pain control.

In addition to the needs assessment, further rationale for the selection of the issues in Lorig's

study relates to the patients' preferences for control over their disease. Actual and perceived control in coping with stressful situations suggests that patients desire control in connection with receiving medical aid which might influence their reactions to the disease. Indirect evidence provided in research suggests that enhancing actual and perceived control in medical settings may positively affect health outcomes.

An important concept related to the patient's desire for control over their condition is aid as opposed to medical aid. Aid is the provision of resources that facilitate recipient's desire for goal attainment. It promotes the reality that the recipient can improve their health status as a result of receiving help. In contrast, medical aid benefits the patient similar to aid intended to meet important human needs; however, there is a problem with traditional medical aid. Accepting medical aid places arthritis patients under the authority of a rheumatologist or other physicians in an asymmetrical power relationship that is similar to the dependency engendered in many other helping relationships. Like many forms of aid, medical help is often a mixed blessing. It may be beneficial in that it provides symptom relief, improves health status and satisfaction with care, but it may contain elements of

subservience to the physician and dependency that, in turn, precipitate dissatisfaction and rejection of help. For these reasons, this study addresses the issues of locus of control as a dependent health status outcome to be measured.

As a part of the ASMP, six two hour sessions were developed as an educational package covering many topics from knowing more about arthritis to practising exercise and relaxation techniques to learning more about medications, diet, problem-solving processes and physician-patient communication. For a more detailed description of the ASMP, the following will outline in some detail the six sessions and their content.

The Arthritis Self-Management Program Format

Session One

Seven activities are allocated to session one. It begins by having the two lay leaders and the program participants introduce themselves to each other. Ten minutes is then spent on clarifying group members' expectations, determining their needs and providing an overview of the course. Activity three is a short lecturette on explaining the purpose, location, and description of the services offered by the Arthritis Society. An overview of self-help principles comprises

activity four. They include explaining to the participants that no cure for arthritis exists, however, a variety of known treatments aimed at controlling arthritis do exist. The ASMP is designed to give the participants the knowledge and skills necessary to take a more active part in their arthritis care. Activity five offers thirty minute lecture and discussion on introducing the participants to the definition of arthritis, anatomy of the joint, and the differences between various common types of arthritis. Next, the participants are asked to brainstorm a number of ways in which their minds can be distracted or used in other ways to manage pain. The final activity of the first session, as in all the sessions, is the closing in which people are thanked for coming and asked to refer to the Arthritis Helpbook for a review of the topics covered in the present session and some background reading as an introduction to the topics to be covered in the next session.

Session Two

Activity one consists of introducing any new members to the class and asking people how they have used distraction or other ways of using their minds to manage pain. Activity two involves a twenty minute lecturette/demonstration/brainstorm format on the uses of

stress management exercises and a description of the stress-depression-pain cycle. A relationship between mood and pain are discussed in activity three. In addition, the participants are asked to refer to a Pain/Mood Diary and to complete it on their own at home during the next several weeks. Activity four introduces the participants to exercises covering stretching, strengthening and endurance, and their respective benefits. The following activity involves the group in a discussion on ways in which to prevent and reduce pain that is associated with exercising. Activity six engages the participants in a discussion on other principles of exercise and various cautions. The participants in activity seven receive a short lecturette, discuss, and demonstrate stretching or range of motion exercises. They are then asked to complete a self administered contract which records the joint to be exercised, the number of repetitions, the number of times per day and days per week. Participants are also asked to record on a scale of zero to 100, how sure they are that they will be able to execute this exercise contract. Activity eight is the closing in which group members are asked to practice their pain management and relaxation techniques so that they are prepared to discuss their experiences at the next session.

Session Three

This session has ten activities: first, the introduction; second, feedback about home exercising, relaxation and pain management; third, a review of the pain/mood diaries; fourth, a review of stretching exercises; fifth, a lecturette/demonstration of strengthening exercises; sixth, a lecturette on endurance exercises; seventh, a brief lecturette on exercise diaries; eighth, a discussion on preventing and slowing osteoporosis; ninth, a demonstration of a relaxation exercise; and tenth, the closing.

Session Four

This session is comprised of seven activities with the first, being an introduction to the session; second, feedback on exercise, stress, and pain management; third, a discussion on medications; fourth, a discussion about problems of daily living; fifth, the problem solving process; sixth, a relaxation exercise demonstration; and seventh, the closing.

Session Five

Session five has seven activities with the first being an introduction; second, a feedback session; third, a discussion on depression; fourth, a discussion on

nutrition; fifth, an evaluation of diets and other nontraditional treatments; sixth, a relaxation exercise demonstration; and seventh, the closing.

Session Six

This session consists of activities covering the following topics: an introduction to the session; feedback on exercise, stress, and pain management; joint protection and solving problems with everyday activities; doctor patient relationships and communication; closing items and stress management exercises.

Given the content of the program, Lorig emphasizes that the planning process is different than just teaching. She advocates the use of several different patient education processes to assist patients in achieving positive behavioral change. Groups are taught by pairs of trained program leaders, one of whom has arthritis. The advantages of this approach is that the program can reach large numbers of patients at a very reasonable cost. All groups are taught in community settings such as senior citizen centres, and recreation complexes. "This reinforces the idea that one can live with arthritis and that it can be managed in the community without the often frightening sterile feeling

of a medical setting" (Lorig, 1982). Each patient is encouraged to bring a friend or family member to the program because they provide powerful inducements to behavioral change and offer a strong support system or social network. All classes are experiential in that no lecture is longer than ten minutes and that they are designed to give the patient the opportunity to participate actively and verbally in every discussion. For example, everyone demonstrates at each session the exercises they have practised at home during the past week. Everyone also participates in the relaxation exercises. Many sessions have small group discussions, problem solving and/or brainstorming. At the end of each session, subjects are asked to name the self-help activities that they will practice in the upcoming week. This type of formal contracting before a group is intended to be a strong inducement for behaviour change (Lorig, 1982; Lorig and Fries, 1986).

Pain and depression diaries are kept for one week of the course and discussed at the next session in order to assist the subjects in understanding the relationship between pain and depression. All program content is published in the Arthritis Helpbook; therefore, if any topics are not clear, or a reminder is needed, each subject can refer to the book.

One of the most important processes in this program is group integration. Patients are encouraged to work on mutual problem solving with their friends and community resources. The program is aimed at empowering people to manage their arthritis, using health professionals as consultants when appropriate.

Dependent Variables

According to Lorig's et al. (1984) needs assessment, the salient beliefs of people with arthritis and rheumatologists were determined. The results of this needs assessment indicated that first concern of people with arthritis was pain, followed by disability, fear, and depression. Given these concerns, it seemed appropriate to address them in this study involving people with scleroderma. In addition to pain, disability, and depression, the concerns of quality of life, self-efficacy and health locus of control were included in this study as dependent variables to be measured before and after the implementation of the ASMP intervention. Each of these six variables will be briefly discussed in turn.

Pain

The dominant concern of arthritis patients is pain.

It became evident from discussions held during the ASMP and from the interviews conducted after the ASMP, that pain was also a major concern for most of the treatment group subjects with scleroderma. The purpose of including pain as a dependent variable in this study was to determine if the ASMP had any impact on it in comparison to the control group which did not receive the ASMP. Pain is a dominant concern for people with arthritis because it is usually chronic and unrelenting in nature.

Disability

Another major concern for people with arthritis is physical disability. Depending on the severity and course of arthritis, physical disability can vary from one individual to another. The mere fact that arthritis does inflame the joints, producing varying degrees of pain and disease activity, is enough to cause joint damage and a corresponding progression of physical disability. Now it is correct to recognize that scleroderma does not consistently conform to this disease process which occurs in people with rheumatoid arthritis and osteoarthritis, for example. But, the disease process in people with scleroderma does restrict physical mobility and promotes deformity. The most common

physical disability and loss of mobility is in the fingers and toes. It may also occur in the facial area of the body. Joint mobility is restricted when the skin becomes thick and hardened. Physical disability also becomes the result of the systemic problems caused by the scleroderma disease process.

Depression

Although it is not generally thought of as a physical problem, depression does commonly become a psychological barrier to high quality of life for people with arthritis. However, these people are probably more prone to developing clinical depression than the normal population which might consist of some physiological characteristics. Notwithstanding the physiological characteristics, though, exceedingly high levels of pain, disability, deformity, and stress are likely to cause exceedingly abnormal levels of depression. Since people with scleroderma, like other people with arthritis, are more likely to experience varying degrees of depression, it was considered to be an important dependent variable in this study.

Quality of Life

The culminating effect of the above dependent

variables is likely going to have some impact on one's quality of life. It is reasonable to assume that with exceedingly high or abnormal levels of pain, disability, and depression, people with arthritis do experience a lower quality of life. There is no reason to suspect that this phenomenon would be any different for people with scleroderma since they, too, experience various levels of life stress as a result of pain, disability, and depression. Quality of life is understandably very difficult to define because of the many different characteristics and values people assign to quality of life. But what is important in this study is the subjects' own perception and interpretation of their quality of life and how they differ from time one to time two; that is, the pre and post tests.

Self-Efficacy

Lorig et al. (1989) offer self-efficacy as a cognitive factor in mediating behaviour change, or, in other words, a mediating variable which operates in the educational process. They maintain that people's beliefs in their "ability to do things," or their personal judgements of their abilities to perform given courses of action are a part of people's thoughts about themselves that influence whether or not they can undertake and

succeed at specific behaviour changes. S e l f - efficacy affects behaviour choices or those activities people will attempt to do and those they will avoid. If a behaviour seems impossible, people will not attempt it even if the skills required are actually within their capacity. Self-efficacy will also affect how much effort people will expend and how long they will persist with a specific behaviour or action in the face of obstacles. People with increased self-efficacy for a specific task or behaviour will stay with it longer and will make renewed efforts even after failed attempts. Finally, self-efficacy will affect how much anxiety or distress people experience during their efforts to execute a specific behaviour or task.

The self-efficacy enhancing strategies incorporated in the ASMP include: (1) skills mastery, (2) modelling, (3) reinterpretation of physiological signs and symptoms, and (4) persuasion. Skills mastery is the most effective strategy. This activity provides one with the opportunity of direct experience or practice with a task. It is important that these be successful experiences. With modelling, it is important to choose models that are believable and similar to clients. Coping models are used as well as models who can demonstrate mastery. Reinterpretation of physiological signs and symptoms

helps people to change what and how they think about their disease or condition. Persuasion can also be used to get people to believe that they have the ability to attain goals (Lorig, 1990).

Health Locus of Control

The final dependent variable that was measured in this study is health locus of control. It is similar to self-efficacy in that the application of the instrument used to measure health locus of control attempts to predict people's internal and external control over their health behaviours. However, locus of control is different from self-efficacy in that it is not behaviour specific. Health locus of control is a generalized measure of expectancy as opposed to beliefs in the ability to perform specific behaviours. Internal health locus of control refers to one's personal or internal health expectancy, whereas, external health locus of control refers to one's external health expectancies; that is generalized events external or beyond the control of oneself (Wallston and Wallston, 1976).

Research Purpose and Hypotheses

The overall purpose of this thesis research study is to evaluate the effectiveness of Lorig's Arthritis Self-

Management Program (ASMP) on a population of people with scleroderma. The uniqueness of this study lies with the fact that this program has never been evaluated exclusively with this particular population of people. More importantly, however, people with scleroderma do not closely resemble other people with arthritis in their diagnosis, prognosis or symptomology. In other cases of arthritis, joint pain, inflammation, disability, deformity, and fatigue are among some of the more notable concerns offered by people with arthritis other than scleroderma. Although people with scleroderma have some of the same concerns, particularly disability, deformity and fatigue, their other major concerns related to pain in the skin of the body's extremities, systemic problems, and cold temperatures.

The ASMP offers some limitations to dealing with persons with scleroderma. First, it does not provide specific enough information on the diagnosis, prognosis, and ways of coping with scleroderma. Alternatively, the ASMP is designed for the more general issues relating to other types of arthritis that are more prevalent in society, particularly rheumatoid arthritis and osteoarthritis.

Second, because the course of scleroderma and its symptomology manifests somewhat differently than other

types of arthritis, the intervention techniques of the ASMP, involving exercises, nutrition and medications, are probably not the best suited techniques for people with scleroderma. For example, much of the ASMP suggest techniques that address joint pain, inflammation and disability resulting from such conditions common to rheumatoid arthritis and osteoarthritis; but which are somewhat limited in their application to people with scleroderma who do not primarily complain about joint pain and mobility. The point being made is not meant to suggest that people with scleroderma do not experience these difficulties from time to time, but it is important to acknowledge that the mechanics of the scleroderma disease process are somewhat different from other forms of arthritis. Thus, it is pertinent to recognize that the ASMP presents some limitations to helping people with scleroderma manage their disease as well as persons with other types of arthritis.

Notwithstanding these limitations, this study attempts to demonstrate that people with scleroderma will, like people with rheumatoid arthritis and osteoarthritis, improve their physical and psychosocial health status after their participation in the ASMP. The global null hypothesis is that persons with scleroderma will not demonstrate improvements (or no differences) in

their health status scores before and after the implementation of the program.

Specific null hypotheses regarding the six dependent, or health outcome, variables are stated as follows:

1. Scleroderma patients will experience no difference in their perceived level of pain before and after their participation in the ASMP.

2. Scleroderma patients will experience no difference in their perceived level of disability before and after their participation in the ASMP.

3. Scleroderma patients will experience no difference in their perceived level of depression before and after their participation in the ASMP.

4. Scleroderma patients will experience no difference in their perceived quality of life before and after their participation in the ASMP.

5. Scleroderma patients will experience no difference in their perceived self-efficacy before and after their participation in the ASMP.

6. Scleroderma patients will experience no difference in their perceived locus of control before and after their participation in the ASMP.

CHAPTER FOUR

RESEARCH DESIGN

Introduction

This chapter sets out the research design for the present study. It, first, includes an introduction to the methodological orientation. Second, the procedure for this study is outlined, including an explanation of how the subjects were selected and a description of the level of design. Third, the limitations of the design are discussed. Fourth, the measures which correspond to the six dependent variables are discussed in terms of their validity, reliability, and implementation. Fifth, this chapter highlights the plan of analysis for this study along with a brief discussion on the strengths and limitations to the qualitative interview format. Finally, ethical issues, surrounding the use of human subjects and how they were dealt with according to the University of British Columbia's ethical review committee, are presented.

Methodology

This is a quasi-experimental study designed to evaluate the effects of a particular educational program with a population of people with scleroderma. Both quantitative and qualitative methodological orientations

were used in this study. Standardized quantitative questionnaires were used to collect responses measuring the six dependent variables of pain, disability, depression, quality of life, self-efficacy, and health locus of control. The subjects' quantitative responses were further validated by the open ended interviews during the follow-up period. The additional qualitative interviews provided greater depth to the results obtained from the standardized questionnaires.

Procedure

Sampling Design

A nonprobability sampling design was used. More specifically, an availability sampling procedure was used which was particularly useful with a very special population of limited size (Grinnell, 1988). The scleroderma population is relatively small compared to RA and OA populations.

The procedure consisted of obtaining a membership list of people with scleroderma from the Scleroderma Association. Letters of introduction to the study were mailed to each of the 75 members in the Vancouver Lower Mainland. The criteria for selecting the sample were that members volunteered for the study, spoke English, and were diagnosed as having scleroderma. The letter was

followed up with a telephone call to determine the respondents' interest in participating in the study. Twelve people expressed their interest in participating in the comparison group while six people stated their interest in participating in the treatment group which received the patient education program. The eighteen subjects who participated in the study self selected either the control group or the treatment group and, therefore, were not randomly selected from the population, nor were they randomly assigned to the two groups. Each participant had a definite interest in either belonging to the control group or the treatment group.

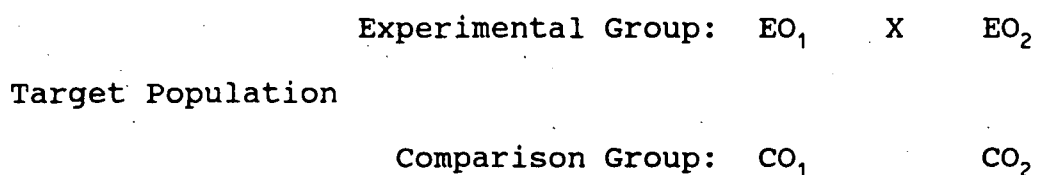
The Level of Design

As alluded to in the preceding section, the level of design employed for this study included a pretest-posttest nonequivalent comparison group design with various limitations; notably a absence of random selection of subjects from the population and an absence of random assignment to the two groups. The two groups are probably not equivalent since the participants were not randomly assigned to the two groups. The configuration of the design presented in Figure 4.1 below consists of a treatment group which received the

Arthritis Self-Management Program (ASMP) and a comparison group, which of course, did not received the ASMP.

Figure 4.1

Quasi-Experimental Design



Where: EO_1 = First experimental observations of the dependent variables.

X = Independent variable.

EO_2 = Second experimental observations of the dependent variables.

CO_1 = First comparison group observations of the dependent variables.

CO_2 = Second comparison group observations of the dependent variables.

Limitations of the Design

Because this design represents a quasi-experimental design, it does not possess the strengths of a true experimental design having randomization of subjects. As

a result, lack of randomization affects both the internal and external validity of the research study and limits the researcher from making generalizations about the sample to the scleroderma population.

A lack of internal validity will prevent us from making statements that infer causality. It will be impossible to conclude in our analysis that changes in the dependent variables resulted only from the independent variable. In addition, it will be impossible to rule out the inevitable cohort of intervening variables. Finally, we must acknowledge the other general factors which might pose a threat to the internal validity of this study. The nine possible threats to internal validity include: (1) history, (2) maturation, (3) testing, (4) instrumentation, (5) statistical regression, (6) differential selection of subjects, (7) mortality, (8) reactive effects, and (9) interaction effects.

"External validity is the degree to which the results of a research study are generalized to a larger population or to setting outside the research situation or setting" (Grinnell, 1988). Because of the previously noted limitations and a relatively small sample size, it is impossible to demonstrate conclusively that the sample selected for this study is representative of the

population from which it was drawn. Absence of randomization prevents us from demonstrating that the treatment group and the comparison group are equivalent at the beginning of the study. Nor is it possible to demonstrate that nothing happened during the course of the study, except for the introduction of the independent variable, that changed either the representativeness of the sample or the equivalence of the groups. The six threats to the representativeness of the sample and thus to the external validity of this research study are: (1) pretest-treatment interaction, (2) selection-treatment interaction, (3) specificity of variables, (4) reactive effects, (5) multiple-treatment interference, and (6) researcher bias.

Measures

The five dependent variables in this study included pain, disability, depression, quality of life, self-efficacy, and health locus of control. The measures employed for this study include the following.

Pain

The Visual Analogue Pain Scale (VAS) measures the intensity of pain. The VAS is a horizontal line which is usually ten centimetres in length. The line is taken to

represent the continuum of some experience like pain. The scale enables the patient to express the severity of his/her pain in such a way that it can be given a numerical value. This scale was chosen because it is simple to administer and it is universal and robust. The VAS pain scores correlate with verbal rating scales and Melzack's McGill Pain Questionnaire. Correlation coefficients between successive measurements of pain on a VAS have been as high as 0.99, which suggests that reproducibility is not a big problem with patients (Dixon and Bird, 1981).

Disability

The Health Assessment Questionnaire (HAQ) was selected to measure disability outcomes for persons with arthritis and other chronic diseases. It measures performance in activities of daily living such as dressing, arising, eating, walking, hygiene, and grip. The HAQ has undergone extensive validation with coefficients of 0.47 to 0.88 between the questionnaire and the actual performance ratings. Reliability of 0.60 to 0.85 has been obtained between two methods of administration: self-administered and interview (Fries et al., 1980).

Depression

The Centre for Epidemiological Studies of Depression (CES-D) Scale was selected because it is designed to measure symptoms of depression in epidemiological research in the general population. It is a valuable tool for the identification of those people "at risk" or in need of treatment. The validation of the CES-D Scale with the Hamilton Clinician's Rating scale and with the Raskin Rating scale had correlations of 0.69 to 0.75. Measures of reliability reflect alpha coefficient of about 0.85 in the general population and 0.90 in a patient sample (Radloff, 1977).

Quality of Life

The Cantril Quality of Life Scale was selected because it assesses the affective component of quality of life. It is a self-anchored scale in which ratings are made relative to each persons conception of his/her own maximum or minimum life satisfaction. In terms of validity, the scale has a median coefficient of 0.70. The scale has an average test-retest reliability of 0.70 (Cantril, 1965).

Self-Efficacy

The Arthritis Self-Efficacy Scale was chosen to

measure a patient's perceived control over arthritis. Perceived self-efficacy is defined by Bandura as "one's belief that one can perform a specific behaviour or task in the future." This instrument asks patients how certain they are that they can perform tasks related to pain, symptom control and physical functioning. The patients rate their responses on three corresponding subscales. The concurrent validity coefficient is 0.61 between stated self-efficacy for performance and actual performance on the functional subscale. Construct validity demonstrates a significant relationship between self-efficacy and health status, and change in self-efficacy after educational intervention. Test-retest reliability coefficients are 0.85 to 0.90 and alpha coefficients of internal consistency reliability range from 0.75 to 0.90 (Lorig et al., 1989).

Health Locus of Control

The Health Locus of Control (HLC) Scale was selected to measure area-specific expectancies regarding locus of control developed for the prediction of health-related behaviour. This scale is constructed with a 6-point, Likert-type format and an item pool consisting of eleven face-valid measures of expectancies regarding locus of control related to health. The concurrent validity

coefficient is a 0.33 correlation with Rotter's Internal-External Locus of Control Scale. The alpha reliability coefficient is 0.72 (Wallston et al., 1976).

Data Analysis

Quantitative Analysis

Mean differences between pre and post measures for the comparison group on each variable were computed. Similarly, the mean differences between pre and post measures for the experimental group were computed. These mean differences for the comparison and experimental groups on each variable were then subject to a t-test.

As referred to in the previous section, the standardized questionnaire primarily addresses the six dependent variables of pain, disability, depression, quality of life, self-efficacy, and locus of control. In addition, this questionnaire asks the scleroderma subject for some basic demographic data, and some brief information about physical activities and/or therapies for arthritis. The questionnaire also asks one question about the number of times the subject saw his/her doctor (with the doctor's suggestion) for arthritis related reasons in the past four months, and one question about the number of times the subject visited the doctor (without the suggestion of his/her doctor) for arthritis

related reasons in the past four months.

The demographic data and the two questions related to the number of doctor visits are scored in a straight forward manner. The scoring for the other six dependent variables are easily scored according to their respective creators' instructions. Essentially, all of the data are given a numerical score or code which is then transferred to a computer coding sheet for input into a computer.

One table is presented in chapter five to illustrate the between group comparisons of the difference of the difference of the means for pre and post changes in pain, disability, depression, quality of life, self-efficacy, and health locus of control. Two other tables are presented as appendices one and two to illustrate the within group differences in the means. Appendix one is a table of the means and standard deviations for the pre and post measures of the treatment group regarding all six dependent variables. Appendix two is a table of the mean and standard deviation for the pre and post measures of the comparison group regarding the six dependent variables. Essentially, the follow diagrams illustrate the presentation of the tables:

Figure 4.2**Descriptions of the Tables**

For the following experimental configuration:

EO ₁	X	EO ₂	(Treatment Group)
CO ₁		CO ₂	(Control Group)

The following tables are provided:

$$EO_1 - EO_2 = a \quad (\text{Appendix 1})$$

$$CO_1 - CO_2 = b \quad (\text{Appendix 2})$$

$$a - b = c \quad (\text{Figure 5.1})$$

Qualitative Analysis

The type of qualitative interview conducted subscribes to a "standardized open-ended interview" format. The exact wording and sequence of the questions were determined in advance. All five of the scleroderma subjects were asked the same basic questions in the same order.

The qualitative interview questionnaire was designed to elicit subjected responses from the six experimental subjects about their general impressions of the ASMP. As

mentioned in the outset of this chapter, the qualitative analysis component of this study is intended to provide greater depth in the findings. The qualitative analysis is done according to the methods that are described by Strauss (1987) and Patton (1980).

Approximately one hour long taped interviews were held with each of the experimental subjects. The tapes were then transcribed and analyzed. The analysis consisted of reading each transcript to identify and label major themes and categories in the information provided by the respondents.

The strengths of this format are such that all of the respondents answer the same questions which, in turn, increases the comparability of responses. The data are complete for each person on the topic addressed in the interview. This format reduces interviewer effects and bias that might otherwise occur in asking the questions using an informal conversational approach or interview guide approach. The standardized open-ended interview format permits the Arthritis Society professionals and decision makers to see and review the instrumentation used in the evaluation. This format also facilitates the organization and analysis of the data (Patton, 1980).

The limitations to this format are evident by virtue of there being less flexibility in relating the interview

to particular individuals and circumstances. The standardized wording of the questions may constrain and limit naturalness and relevance of questions and answers (Patton, 1980).

The plan of the presentation of results include descriptive paragraphs of both the quantitative and qualitative data. These data are also presented in various summary tables.

The analysis methods used include various frequencies tables produced by SPSS:x and the qualitative techniques referred to by Patton (1980) and Strauss (1987). We are interested in ascertaining from the data whether or not differences in behaviour and health status appear between the pretest baseline period and the posttest follow-up. The six dependent variables measured at the second follow-up phase are thus compared to the first baseline of all treatment group and comparison group scleroderma subjects. The findings, then, are compared between the two groups to determine whether the null hypotheses, set out in chapter three, can be rejected or accepted.

The last section of this chapter relates to the ethical issues faced in this research.

Ethical Issues

The ethical questions of this research conform to the University of British Columbia Behavioral Sciences Screening Committee for Research and Other Studies Involving Human Subjects. In short, the U.B.C. Ethics Committee required that their ethical guidelines be followed in order for this research project to be conducted. The title, a brief description of the purpose of the project and all procedures that were carried out involving the subjects were set out in a letter of introduction to the study and written consent form. They outlined the assurance that the subjects identity would be kept confidential. The amount of time required by each subject was stated. We offered in the letter and consent form to answer any inquiries concerning the procedures by stating our names, addresses, and telephone numbers. The letter and consent form offered a statement of the subject's right to refuse to participate or withdraw at any time and that such withdrawal would not jeopardize further treatment or medical care. Finally, the consent form offered a place for the subject's signature consenting to participate in the research project. Copies of the letter of initial contact and consent form are located in the appendix.

CHAPTER FIVE

QUANTITATIVE FINDINGS

Profile of Subjects

The data used to describe this sample of 18 respondents with scleroderma include: age, sex, ethnic origin, years of education, symptom date, marital status, and employment status. The treatment group comprised 6 (33 percent) individuals while the comparison group consisted of 12 (67 percent) individuals. Ages of the subjects varied between 35 years of age to 86 years of age, with the average age consisting of 54. Almost all the subjects were female except for 2 males in the comparison group. All but 3 subjects were Caucasian. Fifteen subjects (or 80 percent of the sample had either completed secondary or post secondary education. The average symptom date, or the average date at which the subjects were first diagnosed with scleroderma, is 14 years ago. Eleven (61 percent) of the respondents were married compared to 7 (39 percent) people who were either separated, divorced, widowed or single. A third of the subjects were employed while the rest were not.

Pre/Post Test Analysis

Analysis of mean pre-post differences between the experimental and control groups indicated that none of the changes in any of the six dependent variables reached statistical significance. Notwithstanding these findings, it is still important to analyze each of the null hypotheses individually with their respective means, variability and probability scores to determine if, in fact, trends in the data are suggested. Results pertinent to each hypothesis will be discussed in turn.

Pain Reduction

The first null hypothesis was stated in the form that scleroderma patients will experience no difference in their level of pain before and after their participation in the ASMP. Appendices 1 and 2 show that the pretest mean score for pain in the treatment group is 57.0 and that the posttest mean score is 35.5, yielding a total reduction of 21.5. The latter figure is recorded in figure 5.1.

Variance in this result is considerable, with a standard deviation of 26. For the comparison group, the pretest mean of 39 and posttest mean of 39.8 represents

a relatively small mean difference of -0.8 in comparison to the treatment group. Once again, the variability in these scores is considerable.

Similarly, table 5.1 shows no statistical significance in between group comparisons for the mean difference in the pain variable. The mean difference for pain for the treatment group is reported as being -21.5 while the mean difference for the comparison group is reported as being 0.8. Although the negative value indicates less pain, the probability level for these results is 0.09. However, because the comparison group's variability of mean scores are almost equally large as the treatment group (24.5 versus 26.0 respectively), statistically significant results were not obtained.

When looking at individual cases in this study, the insignificant results obtained can also be explained in part by their respective variability in the scores pertaining to each variable. For example, with reference to the pain variable in appendix 3, the treatment group shows three subjects who had rather large improvements in their pain scores with negative differences (ie., better scores) of -44.00, -49.00, and -38.00. Once again, this individual observation shows

Table 5.1

Mean Differences in Pre/Post Changes in Pain,
Disability, Depression, Quality of Life,
Self-Efficacy, and Health Locus of Control

Measure	Treatment Group		Comparison Group	
	Mean	SD	Mean	SD
Pain	-21.5	26.0	0.83	24.45
Disability	- 0.09	0.3	0.17	0.42
Depression	- 2.17	3.76	1.83	9.83
Quality of Life	- 2.16	17.76	2.0	15.06
Self-Efficacy				
Function	- 2.22	11.13	- 4.45	22.86
Symptoms	1.95	4.88	-11.25	26.87
Pain	0.33	12.74	- 6.0	27.01
Health Locus of				
Control	0.67	5.47	3.33	8.08

that the comparison group's variability of mean scores are almost equally large.

Although the above findings indicate no significant probability levels in which to reject the null hypothesis, a trend is suggested when one examines the means and their differences between the two groups. Since the dependent variables were measured on either ordinal or interval scales, it is possible to identify the general direction of the mean values as being either better or worse for the two groups. For example, in looking at the pain variable, the mean value of -21.50 for the treatment group is better (that is, less pain) than 0.83 as indicated for the comparison group.

Disability

The second null hypothesis pertains to disability. It was stated as follows: scleroderma patients will experience no difference in their level of disability before and after their participation in the ASMP. Appendix 1 represents a within group comparison of results and subsequently displays means of 1.25 for the pretest and 1.17 for the posttest in the treatment group. The difference between these means is 0.09 as recorded in

Table 5.1. The comparison group in appendix 2 displays means of 0.77 and 0.94 for the pretest and posttest scores respectively. Little difference between the means are noted as being -0.17.

When looking at table 5.1 for the between group comparison of the mean differences, the treatment group displays a mean difference of -0.09 and the comparison group shows a mean difference of 0.17. The negative value indicates a small, but positive or improved disability level, for the treatment group, however, as the probability level of 0.2 indicates, this result is not statistically significant. The standard deviations for these groups remains relatively small which suggests that the subjects did not vary much in their disability scores between the pretest and the posttest. Consequently, the null hypothesis that there is no difference between the treatment and comparison groups in disability must not be rejected.

Appendix 4 is offered to show individual comparisons of results for the treatment and comparison groups. A quick visual scan of the table indicates that neither group varied much in their scores. Nor were there marked improvements for the treatment group.

As with pain, a trend is evident for disability whereby the treatment group has a mean value of -0.09 compared to the comparison group with a mean value of 0.17. The smaller or negative value is better in that the treatment group has less disability.

Depression

As with disability and pain, the null hypothesis regarding depression must not be rejected because of statistically insignificant results. The third null hypothesis is that scleroderma patients will experience no difference in their level of depression before and after their participation in the ASMP. Appendix 1 documents similar within group pre/post mean scores of 33.7 and 31.5 for the treatment group. A small difference of 2.17 is indicated in table 5.1. In appendix 2, the comparison group shows pre/post mean scores of 36.3 and 38.1 respectively. The comparison group's mean scores for the pretest and the posttest results indicate a small difference of -1.8. Although this result shows a small deterioration in depression for the comparison group, it is not significant.

The between group comparisons of mean differences

displayed in table 5.1 show that the treatment group slightly improved with a mean value of -2.17. This score contrasts slightly with the comparison mean score of 1.83. Variability is slightly larger for the comparison group with a standard deviation of 9.8 versus 3.8 for the treatment group.

By and large, appendix 5 indicates little change in depression for the treatment group individuals and a slightly larger measure of change for the comparison group individuals. A visual inspection of the table show slightly larger variability in scores among the comparison group. In both groups, some subjects depression levels increased while others decreased; however, to no significant degree.

The trend that is noted in the results for depression is evident with the mean value for the treatment group being -2.17 versus 1.83 for the comparison group. The lesser value indicates less depression.

Quality of Life

Quality of life represents the third health outcome variable with the null hypothesis being that scleroderma

patients will experience no difference in their quality of life before and after their participation in the ASMP. A relatively small difference in the means between the pretest and posttest findings is evident in appendix 1 for this treatment group variable. It is 2.17 and is not statistically significant. The comparison group mean difference is -2.0 which indicates a slight deterioration in quality of life, however, an statistically insignificant one.

As appendix 1 indicates, a slight improvement in quality of life for the treatment group, the between group comparisons in table 5.1 similarly show a slight improvement in this group over the comparison group. The mean value of -2.2 for the treatment group is a slight improvement over the 2.0 mean value for the comparison group. The variability or standard deviation in the scores is 17.8 for the treatment group and 15.1 for the comparison group. This variability, as seen from a visual inspection of appendix 6, shows that some subjects in both groups either increased or decreased their quality of life. No particular pattern emerges, and as a result, the null hypothesis must not be rejected.

Self-Efficacy

The fifth null hypothesis was offered as being that scleroderma patients will experience no difference in their self-efficacy before and after their participation in the ASMP. Once again the separate self-efficacy variables of function, symptoms and pain support the sustain the null hypothesis. For the treatment group in appendix 1, a small difference in the means between the pretest and posttest scores is 2.22 in contrast to the comparison group's difference of 4.45 noted in appendix 2. Neither results are statistically significant. Variability is, however, relatively large for both groups. The same analysis can be applied to the other self-efficacy variables of symptom and pain.

Furthermore, a parallel analysis is accurate for the between group comparisons of the mean difference in the pre/post test changes. For all three self-efficacy variables, a positive change in the mean scores indicate a positive, or slight improvement, in self-efficacy for the treatment group, although to no significant probability level. This can be accounted for by the greater variability in the scores for the comparison group. Their respective standard deviations for the

three self-efficacy variables are 22.9, 26.9 and 27.0 respectively, in contrast to 11.1, 4.8, and 12.7 respectively for the treatment group. These results are supported and complimented by individual pretest and posttest scores recorded in appendices 7, 8 and 9.

Health Locus of Control

The sixth and final dependent variable is health locus of control. The null hypothesis states that scleroderma patients will experience no difference in their health locus of control before and after their participation in the ASMP. As noted in appendix 1, the treatment group's pretest/posttest mean scores are almost the same (39.0 and 39.7 respectively). Thus, health locus of control for the treatment group did not change much at all, but once again this finding is not statistically significant. For the comparison group, the pretest and posttest scores are 36.75 and 40.08 respectively. A slight increase in the score, representing a difference of 3.3, indicates greater external health locus of control for the comparison group. Table 5.1 compliments this finding in which the lower value for the treatment group indicates greater

internal health locus of control and the higher value for the comparison group indicates greater external health locus of control.

The between group comparisons noted in figure 5.1 indicate no statistical significance as well, with the mean for the treatment group being 0.67 and 3.33 for comparison group. Individual scores reported in appendix 10 show that subjects followed no consistent pattern in that some showed an improvement in their internal health locus of control while others did not. The variability for each group is about the same (5.5 and 8.1 respectively). In essence, then, all null hypotheses must not be rejected.

QUALITATIVE FINDINGS

Four major themes were found to characterize the treatment group. First, the respondents identified health problems that they currently had which were or were not associated with their scleroderma. Second, family stress was discussed, including events in their lives which presented problems to their daily living. Third, the respondents identified some ASMP limitations, and fourth, they commented on some ASMP benefits.

Health Problems

The main theme in this section is that the majority (or half) of the subjects had other health problems that were of concern during the study. However, while a few subjects indicated associated pain, this was not the general trend.

The majority of respondents reported that they were experiencing health problems that were possibly related to their scleroderma. One respondent said that she had increased pain due to what she thought might have been the progression of the disease. She remarked that the increased pain in her head and limbs might have been due to raynaud's phenomenon, a common disease with scleroderma, which occurs in the hands of 90 percent of

all patients, and in the toes, earlobes, tip of the nose and tongue (Melvin et al., 1984). In addition, she said that osteoporosis and osteoarthritis might be aggravating her condition. Another subject commented on her shoulder being painful during the recent weeks prior to the interview, but again she and her doctors were not certain about the cause of the pain. More generally, she mentioned an increase the scleroderma symptoms such as increased stiffness in her joints, insomnia, fatigue, stomach complications with digestion, and disfigurement. Pain for these two subjects seems to have increased. Additional scleroderma symptoms appeared for another respondent in that she had increased lung and breathing problems because of her disease and the recent hot weather. And another subject replied that had increased blood pressure due to scleroderma conditions and medications. The majority of treatment subjects, however, denied pain had increased for them which corresponds with the trend toward decreased pain in the quantitative data which were obtain from standardized pain scales.

Family Stress

Stress caused by families' inability to fully understand the nature of the consequences of the disease

was a commonly reported theme among respondents. A significant finding under this category is the claim by virtually all respondents that a lack of understanding exists on the part of friends and family members regarding the disease. They all agreed that scleroderma is not visible in many instances. It is hidden for the most part and makes understanding of the disease difficult because it does not always manifest its symptoms and problems externally. The subjects referred to disease symptoms such as pain, disability, depression, fatigue and the systemic nature of the disease. They said the result leads to a lack of understanding and a lack of empathy and sympathy by others. To illustrate this point, two subjects made the following comments:

E. ...sometimes the family members don't understand what the person is going through. And sometimes, maybe, they think that they are complainers; complaining for the least little thing, whereas, if they knew about scleroderma and the arthritis, then they would understand, you know, the mother or the father, or the parent or the child or whatever would understand more.

.... my girlfriend said to me one day last week

when I met her for lunch and we parked on the street. There was just a little incline but when we go into this little place when we go in there, I said to her let's go eat in the car because I have my air conditioning. And by the time I got up this little incline, it was tough and my friend said to me, you know sometimes I don't realize that you are sick. That this little incline affects you the way it does, especially in the heat anyways. Sometimes I just forget that you are sick. And that's I guess because you look so healthy and you don't realize sometimes.

M. ...scleroderma and raynaud's disease is something that nobody can see unless you are all crippled up. But with me, having raynaud's and scleroderma, people cannot see it. People say that you are looking good. Like with your family, if your family was interested in it or was into it by going to some of the meeting, then they would realize that you do have something bad. And it would help them (family) a lot to understand what is going on with me.

...you can talk to them and they think that you are doing fine when you are in fact not.

....People think, oh well, but they really don't have a clue about what it is all about.

Sure it is good to do things at this age, but it is really hard to do things in so much pain.

Several people offered suggestions to improve the lack of understanding of significant others. Participation in the ASMP by family members and friends could help increase their understanding of scleroderma generally, its symptoms, diet limitations, lack of physical signs of being ill, side effects of medication and so forth. Moreover, participation in the ASMP could increase understanding about how individuals must cope with chronic disease. Empathy with individuals might be increased. Another suggestion was that one or two sessions of the ASMP be devoted to how significant others can cope and understand persons with scleroderma. This measure could help draw family members and friends closer together. It might help persons with scleroderma overcome guilt, of complaining and being dependent on others for support. Finally, a suggestion was offered to establish a small support group for scleroderma patients

to discuss issues and feelings. A residual benefit of such a group would also include a component of socializing with others who have this disease.

ASMP Limitations

Extent of Coverage of Topics

Several content areas were identified as being insufficient. The ASMP did not include enough information and time spent on discussing diet and nutrition. Nor was there enough information and discussion on the doctor/patient relationship and communication, and problem solving. The respondents also suggested that more information and discussion could have been provided on the stress/depression/pain cycle and coping with it in daily life. More learning is needed on dealing with frustrations of not being physically and emotionally competent as they once were before the onset of scleroderma.

The foregoing concerns suggest that perhaps the structure of the ASMP needs improvement. It is obvious from some of the respondents' comments that either not enough time or information was offered regarding certain topics. Observations of this sort suggest, as stated earlier, that not enough specialized knowledge of scleroderma was provided.

It is conceivable that the general structure of the ASMP placed limitations on the learning process. Although the group process was a foremost feature of the ASMP, it seems that on the basis of some of the participants' feedback that not enough time and information was provided in addressing certain topics. The sessions could have been longer, and that a greater number of participants could have improved the quality of interaction and group dynamics in the learning process.

One subject stated that more program participants could have contributed more richly to the learning experience. She made the following comment:

E. I wish more people would have come out to the sessions. It would be nice for a group like that meet say once a month where we could talk rather than have these meetings with the whole scleroderma group. It would be nice to sit around in smaller groups where we could have discussions and sit around with coffee and discuss everything, like more of a social gathering. The scleroderma meetings are only every three months and it is not really enough. It is just getting everybody out to them because they (the patients) are so

scattered and it is so far to drive. It would be nice if we could meet at each others house once a month; you know what I mean, go from one house to another. Also we could raise money that way, the way other groups do.

The above comments highlight several points that were common to some other participants. The regular scleroderma association meetings, which are normally held once every three months, were identified as being very enjoyable, positive and informative for the members and their significant others or spouses. The socializing element was identified as being important to those meetings and the ASMP meetings held for six weeks as a part of this study. A common theme among the participants was that the association meetings are not held frequently enough, nor did a smaller support group exist in which to discuss personal coping issues regarding scleroderma. As the above comments indicate, these smaller support meeting could be established to accommodate the socializing element and the need to know more about scleroderma and coping strategies.

Lack of Specialized Knowledge on Scleroderma

Most respondents were not able to identify

limitations or propose improvements for the ASMP. However, in addition to the above suggestion regarding smaller support groups, one suggestion for improvement was that the ASMP was not specialized enough for scleroderma patients. It could benefit from more "tailoring" of its content regarding exercises, for example, in terms of preventing harm or injury. The ASMP content is designed to address the needs of many types of arthritis. Because of its general application, several respondents identified the ASMP's lack of specificity in such areas as exercise and symptoms. Scleroderma is a rather rare form of arthritis and does not affect many people in the population. As a result, few people even know about its existence, its course, or its symptoms. A corresponding lack of research attention, specific and general knowledge is available on this disease. Typically patients who have taken the ASMP in the past come with the expectation of learning not only how to improve their coping with their respective type of arthritis, but also the expectation of learning more about the nature and specifics of the disease. The course participants in this study were evidently disappointed with the lack of more specific information on scleroderma.

Timing of Intervention

Several respondents commented that perhaps the timing of this course was inappropriate in that they could have benefited from the ASMP more if it had been offered to them around the time of initially being diagnosed with scleroderma, when coping and acceptance of the disease was particularly difficult. They mentioned that because they have been affected with scleroderma for a considerable part of their life, they have received no substantial benefits from the ASMP. These respondents stated that they have already learned to cope with scleroderma over the years. Notwithstanding the longevity of her disease, one respondent did not perceive herself as handicapped or disabled in any way. Another respondent said that she failed to incorporate the ASMP recommendations or suggestions because of her lack of initiative and interest in self discipline. She said that she did not allow her established daily routine to incorporate the self-management activities, so she continued with her old habits. This subject felt that she was "beyond the course." Her comment was offered as follows:

J. I wasn't all that diligent at doing it
(ie., participating in the course) because it

seems that you go day after day and you have a routine and you do the same things.

...And you get busy and you resort to your old routine patterns. So it is hard to actually discipline yourself to do all what is suggested in the book.

It is evident, therefore, that the timing of the ASMP was inappropriate in relation to the onset of the disease.

ASMP Benefits

Comparison and Affiliation with Others

An experience shared by almost all subjects was the opportunity to see others with the same disease who had the same or similar problems. When the discussions regarding personal and emotional issues occurred, the subjects experienced a sense of common bonding. Comfort in knowing that they were not the only people having troubles presented a common theme. One subject typifies this common ground by offering the following comment:

... I think it (her positive attitude) has helped because when I went to the course, I realized that there were others there that

were worse than me. I mean, I just have the breathing to cope with. I don't have the pain and depression and everything to cope with. So that made me thankful when I saw these people and learned what they were going through. Because they were able to tell us what they were going through. So that made me thankful that I am not badly off as they are.

Most subjects agreed that, as a result of the ASMP, they have learned to live with scleroderma more successfully. They have found it easier to accept their disease especially since they have realized that other people are "worse off" with more serious conditions and symptoms. One respondent said that she was left with a feeling of thankfulness, "not being the only one with the disease." Determination too was expressed by several subjects as being a key to persevering with scleroderma. Everyone agreed that they were initially overwhelmed by the disease symptoms, conditions and their diagnosis, but the ASMP provided determination to cope with scleroderma on a daily basis. This is evident as one respondent stated that she must "keep on trying" (to cope).

M. I guess a person could just give up, but

what's the use, I've still got it (raynaud's and scleroderma) anyway. You have to do what you can do.

The course helped me realize that I was not the only person with problems. I met others with arthritis that were having a lot of difficulty too. From the sessions I attended, they gave me the feeling that I must cope with scleroderma and raynaud's and that life does go on. You know, you can't give up trying. You must keep on doing the things you can do.

Improved Confidence and Coping

Along with a more positive identification and determination, the ASMP develops confidence in abilities relaxation, and in accommodating ASMP exercise activities into daily life routines. Increased confidence helped one individual overcome some of her fears associated with the progression of the disease. The ASMP, she said, supported her situation where she must ask for help and outside support such as in the use of a homemaker. Another subject remarked that the ASMP offered many suggestions and tips that could be implemented around the home as one proceeds with their homemaking duties.

Several other respondents said that the ASMP definitely helped them in coping with scleroderma symptoms, such as increasing their coping with fatigue, physical limitations around the home, and their diet limitations. In addition, they believed that the increased practice of exercises improved their health status in that relaxation exercises were helpful in falling asleep for example. Another example is the increased practicing of stretching, strengthening, and endurance exercises which helped several individuals limber their joints, decrease stiffness and improve their physical condition generally. These findings correspond to the positive trends suggested in the quantitative data on disability, quality of life, self-efficacy and health locus of control.

Increased Knowledge

Most subjects favourably commented on the self help information offered by the ASMP. The book they received in the course was a helpful reminder of previous sessions. One respondent remarked that the book offered factual information that her doctor does not provide on medications for example. And another subject said that the ASMP was useful in demonstrating self help particularly in showing subjects what exercises to use

and how they can learn to perform them for themselves.

E. Well, I think I got a lot out of the course, because with that book you gave me, I was able to follow through with the exercise programs. They helped me a lot. it was helpful to take my mind off of other things.

... I still do those stretching exercises which help my legs quite a bit because they have got very stiff. So the stretching exercises were most of the ones that I were doing and that has helped me a lot.

J. Well, the practical things and the exercises too I thought were excellent. That was good to show people how to do things. That I think is very good when you get together in a group that the participants can learn something and can do for themselves. If things are shown to people they are apt to do it. Whereas you can read it in the book, but if the exercises are not demonstrated, it won't be of any value.

Socialization and Positive Interaction

The socializing element that the course offered was important to the subjects. It provided an opportunity for meeting new friends and visiting already established acquaintances. The course organization was liked by everyone because it allowed everyone to contribute to the discussions and demonstrations of exercises. They like the way everyone talked about themselves; their inner and personal feelings. Moreover, the ASMP organization helped everyone think about their problems in new ways and possible solutions to these problems.

In particular, the respondents enjoyed the brainstorming strategy inviting everyone to speak in a relaxed, non-threatening or non-offensive way. No pressure was placed on any one individual for a right or wrong answer to questions and left the impression that the subjects were "going to be okay," one subject said. Brainstorming allowed round robin participation and a good exchange of ideas, she added.

The problem solving session helped several individuals to overcome physical limitations they were faced with, to accept that some problems cannot be solved, and to recognize the natural problem solving process within oneself, including common sense solutions and other less obvious ways of solving problems.

A couple of respondents expressed their interest in the session on the doctor/patient relationship and communication process in that it was helpful in achieving a mutual understanding about some medical issues, in understanding the strained relationship one patient had with her doctor, and in learning to be assertive with their doctor without being confrontational. Overall, favourable comments were offered on the topic of overcoming fears of being afraid to talk to the doctor and asking the right questions.

A summary of these qualitative findings suggests that the subjects were able to identify some benefits of the ASMP, along with some limitations and commonly shared concerns. With the exception of two subjects, pain associated with scleroderma appeared not to increase four months after their participation in the ASMP. A commonly reported theme was the stress caused by the subjects' families inability to fully understand the nature and consequences of scleroderma. Regarding the ASMP limitation, the subjects generally commented on the lack of time and information provided in addressing certain topics. They thought that more time could have been devoted to some subject areas, including scleroderma itself. The final theme which emerged is the opportunity

for the subjects to share common experiences and problems, and to affiliate with others in the program who had similar scleroderma conditions. Most subjects agreed that the ASMP experience provided a positive impact in their lives in terms of living with scleroderma more successfully.

CHAPTER SIX

DISCUSSION AND CONCLUSIONS

The results of this study have failed to demonstrate the effectiveness of the ASMP in improving the levels of pain, disability, depression, quality of life, self-efficacy and health locus of control among a group of scleroderma patients. Moreover, the subjects did not experience a statistically significant improvement in their health outcomes. However, positive changes in health status were observed although they were statistically insignificant.

This discussion is not limited to the declaration that the ASMP was not effective at all. As noted, statistical significance was not reached in this study. There is no suggestion in this analysis that the ASMP had no positive impact on the subjects. In fact, when referring the means of each dependent variable, a positive trend or positive change in the subjects' health status can be identified. Although it is difficult to define with the same preciseness as statistical significance at the 0.05 level, it is fair to say that these positive trends in health status represent clinically significant results. The fact that positive trends were observed leaves room to conclude that

clinical significance was obtained; that is, the posttest results indicate "some" improvement in health status of treatment group subjects that exceeds the health status prior to the implementation of the intervention or the ASMP.

Essentially, pain exhibited the greatest improvement in the treatment subjects in contrast to the comparison group. Notwithstanding the lack of statistical significance, it is fair to conclude that the level of pain in each of the treatment subjects was reduced. Where the results indicate small, but positive, behavioral and health status improvements, it is reasonable to conclude that the ASMP had no deteriorating effects on the individuals in the treatment group. These positive trends suggest that these results are similar to other recent studies on the effectiveness of the ASMP on other groups of individuals with other types of arthritis.

Changes observed in pain levels did not reach statistical significance, in part, because of high variability in subject scores. Considerable variability in pain scores were obtained for the treatment group and the comparison group. Because the variability of mean scores were all very large, the magnitude of change would have had to be great in order for it to reach statistical

significance. The variability for some individuals in each group is rather large in each direction which partly explains the insignificant results. Some subjects in each group experienced either a relatively large or small increase in the pain levels between their pretest and posttest measurements. No consistent pattern emerged to indicate that there was a significant difference in the pain scores between the treatment group and the comparison group.

Similar results were obtained for the other variables in which two main conclusions can be made about the findings. First, the trends in the results indicate small positive changes, but these changes failed to reach statistical significance because of the small sample size and high variability. Second, some of the variables remained constant in that no deteriorating effects were observed.

Regarding disability, the results indicate that neither the treatment group or the comparison group subjects perceived their respective disability to get substantially better or worse. As it was noted for the pain variable, the treatment subjects demonstrated a slight improvement in their disability, although not at a statistically significant level. Because of this observed positive trend, it can be concluded that the

ASMP did not result in any deterioration of the treatment subjects perceived disability when compared to the comparison subjects.

The results were similar for the subjects' levels of depression. Although not statistically significant, a positive trend was indicated. The treatment group experienced slightly less depression levels than the comparison group. A statistically significant result was not obtained for this variable because of relatively high variability and a small sample size.

A similar interpretation of the results can be offered for the quality of life variable. This variable failed to reach statistical significance, once again, because of high variability and small sample size. No consistent pattern emerged to demonstrate a significant difference in the quality of life scores between the treatment group and the comparison group. And, as with pain, disability and depression, the results indicate a slight improvement trend for the treatment group in that they did experience a slightly higher quality of life than that of comparison group after the ASMP.

Similarly, although the results were insignificant because of high variability and small sample size, a small positive change was observed for the three self-efficacy dimensions of function, symptoms and pain. The

treatment group subjects perceived slightly greater control over their disability, scleroderma symptoms and pain than the comparison group. Notwithstanding the lack of significance in these results, however, it is reasonable to conclude that the ASMP did not contribute to any deterioration in the treatment subjects' self-efficacy.

Finally, the results for the subjects' health locus of control deserve a similar interpretation to what has already been discussed in light of the other dependent variables. Again, the results indicate a small positive change in the treatment subjects' health locus of control, but they failed to reach statistical significance because of relatively high variability and small sample size. For the most part, health locus of control remained constant without the ASMP resulting in deteriorating effect to this variable.

Although pain showed the greatest positive improvement or change, positive improvements in the other five variables were also demonstrated in so far as the treatment group subjects did not experience a decline in their health status during the study. In other words, their health status generally did not become worse, but rather, they maintained their original level or slightly improved level of health. These results correspond to

the work produced by Kate Lorig and others in the past decade.

The consistent message in this discussion is that no statistical significance was achieved in the results which thwarts our attempt to reject the null hypotheses. Alternatively, we are forced to accept the null hypotheses; that is, the ASMP had no effectiveness in improving the scleroderma subjects' health status from a statistically significant point of view. It is plausible to conclude that the limits of the study have tempered the expectation that people with scleroderma would improve their health status as a result of participating in the ASMP. Small sample size and high variability in the dependent variables are the most notable limitations of this study. In addition, a more scientifically prudent methodological research design would have included random selection of the sample from the population and random assignment of these individuals to the treatment group and control group. Achieving insignificant results could have conceivably been a consequence of the research limitations.

Limitations of Study

First, this study does not represent a true experimental design. The subjects were not randomly

selected from the population, and second, they were not randomly assigned to either the treatment group or the comparison group. Instead, the participants who belonged to each of the two groups were determined by their interest in participating in the ASMP and their subsequent self selection of the group that they preferred to belong to, even in light of the fact that the comparison group was also promised enrolment in the ASMP at a later date. An object of this study was to satisfy all ethical requirements, including the promise to offer the ASMP to the comparison group a short time after the treatment group's completion of it.

Third, the sample size of eighteen subjects is a relatively small sample. A more suitable size required for such findings would be thirty subjects or more.

Fourth, some subjects in the treatment group did not attend all six sessions of the ASMP. Because scleroderma is such a severe chronic health condition in that its flare ups can cause illness serious enough to substantially restrict a person's physical and mental activity, the non attendance to all six sessions by some individuals in this group was not surprising. This problem presents the limitation that those who did not attend all sessions probably did not acquire the full learning experience and benefit the program had to offer.

Implications and Recommendations

The qualitative analysis of this study indicates that the six subjects who participated in the ASMP found it enjoyable and effective in helping them cope with their particular type of arthritis, scleroderma, some four months after the ASMP was implemented. Specifically, the participants liked the group process, the socializing component of the ASMP and the positive interaction with others who shared a common disease. In addition, testimony from all participants indicated that the ASMP involved a worthwhile learning experience because it was informative and offered new insight into how to help oneself in coping with a chronic disease. This program inspired interest from a small group of individuals who came from varied backgrounds, ages, and education.

The timing of the program in relation to the timing of initial diagnosis of scleroderma was considered critical in dealing with health crises. For subjects' whose scleroderma was diagnosed a considerable time before the ASMP resulted in resolving many of the psychosocial problems and issues. This finding points to the recommendation that such a patient education program should be advertised in the medical community so that greater, more timely contact could be made with the

program. Similarly, greater advertising of this program in the arthritis patient community would increase more appropriate contact with the ASMP.

Furthermore, if the ASMP is to be sensitive and suitable to scleroderma factors and symptoms, it should be designed accordingly to meet specific requirements of this disease. This study did show that the ASMP was relevant to subjects with scleroderma in rather general psychosocial areas such as stress, depression, doctor/patient communication, medications, problem solving, pain management and nutrition. In this light and in addition to these subject areas applying rather appropriately to other arthritis groups, the ASMP is general enough to be effective with arthritis groups such as people with scleroderma. Thus, this general application is one of the program's major advantages. However, more specialized knowledge on scleroderma, its course, its symptoms and exercises should be provided in the future to accommodate the particular interests that people with scleroderma have in relation to their individual needs.

Similarly, not only could the ASMP be specialized more to meet these needs, perhaps the instruments used to measure the subjects' physiological and psychosocial factors could be developed in order to be more applicable or sensitive to specific scleroderma variables.

Scleroderma is a rather unique type of arthritis and its disease process bares little similarity to other types of arthritis. Although no subjects complained about completing the questionnaire, no systematic procedure or experimentation was used to test the suitability and sensitivity of the instruments to measure pain, disability, quality of life, self-efficacy, depression, and health locus of control. Since it is believed that this study is the only study to date that has investigated the effectiveness of the ASMP on a exclusive group of people with scleroderma, more studies and investigations of this nature should be designed to test the effectiveness and suitability of the measures used on this particular group of people.

The results of this investigation are encouraging and might be thought as a preliminary study to a larger more comprehensive one in the future. This study might also be thought of as a pilot study to a larger one with a stronger design to include a larger population and sample size with a stronger adherence to a true experimental design, involving random selection of subjects from the population, random assignment of them to either a treatment or control group, and perhaps more points of measurement, such as a longer follow-up time period.

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APPENDICES

APPENDIX 1

Pretest and Posttest Measures for the Treatment Group

Measure	Pretest		Posttest	
	Mean	SD	Mean	SD
Pain	57.0	31.13	35.5	26.94
Disability	1.25	0.71	1.17	0.62
Depression	33.67	9.79	31.5	9.71
Quality of Life	54.0	38.66	51.83	29.74
Self-Efficacy				
Function	68.33	24.96	66.11	28.46
Symptoms	66.39	24.96	68.34	23.38
Pain	58.67	21.57	59.0	28.64
Health Locus of				
Control	39.0	11.88	39.67	9.75

APPENDIX 2

Pretest and Posttest Measures for the Comparison Group

Measure	Pretest		Posttest	
	Mean	SD	Mean	SD
Pain	39.0	24.0	39.83	29.75
Disability	0.77	0.63	0.94	0.78
Depression	36.25	10.65	38.08	10.07
Quality of Life	37.67	24.14	39.67	24.03
Self-Efficacy				
Function	72.04	25.92	67.59	27.53
Symptoms	70.14	21.26	58.89	27.26
Pain	60.33	26.14	54.33	32.08
Health Locus of				
Control	36.75	5.66	40.08	8.02

APPENDIX 3

PAIN

Subject	Pretest	Follow-up	Difference
<u>Treatment Group</u>			
Subject 1	10	0	-10
Subject 2	47	3	-44
Subject 3	45	61	16
Subject 4	99	50	-49
Subject 5	59	55	- 4
Subject 6	82	44	-38
<u>Comparison Group</u>			
Subject 1	53	75	22
Subject 2	51	51	0
Subject 3	46	33	-13
Subject 4	54	18	-36
Subject 5	78	95	17
Subject 6	30	53	23
Subject 7	8	10	2
Subject 8	13	17	4
Subject 9	64	11	-53
Subject 10	23	48	25
Subject 11	0	0	0
Subject 12	48	67	19

APPENDIX 4

DISABILITY

Subject	Pretest	Follow-up	Difference
<u>Treatment Group</u>			
Subject 1	2	1	-0.38
Subject 2	0	0	-0.13
Subject 3	1	1	0.50
Subject 4	2	2	-0.25
Subject 5	1	1	-0.13
Subject 6	2	1	-0.12
<u>Comparison Group</u>			
Subject 1	1	2	1.38
Subject 2	2	2	0.38
Subject 3	1	1	0.00
Subject 4	0	0	-0.25
Subject 5	2	2	0.25
Subject 6	0	0	0.00
Subject 7	0	0	0.13
Subject 8	1	1	0.00
Subject 9	1	1	0.12
Subject 10	1	1	-0.13
Subject 11	0	0	0.00
Subject 12	1	1	0.13

APPENDIX 5

DEPRESSION

Subject	Pretest	Follow-up	Difference
<u>Treatment Group</u>			
Subject 1	41	34	- 7.00
Subject 2	23	25	2.00
Subject 3	28	28	0.00
Subject 4	34	28	- 6.00
Subject 5	49	50	1.00
Subject 6	27	24	- 3.00
<u>Comparison Group</u>			
Subject 1	32	52	20.00
Subject 2	40	42	2.00
Subject 3	34	45	11.00
Subject 4	38	25	-13.00
Subject 5	51	52	1.00
Subject 6	36	37	1.00
Subject 7	31	28	- 3.00
Subject 8	23	39	16.00
Subject 9	41	38	- 3.00
Subject 10	31	29	- 2.00
Subject 11	20	23	3.00
Subject 12	58	47	-11.00

APPENDIX 6

QUALITY OF LIFE

Subject	Pretest	Follow-up	Difference
<u>Treatment Group</u>			
Subject 1	61	50	-11
Subject 2	5	5	0
Subject 3	48	57	9
Subject 4	95	94	- 1
Subject 5	98	67	-31
Subject 6	17	38	21
<u>Comparison Group</u>			
Subject 1	72	75	3
Subject 2	52	72	20
Subject 3	64	44	-20
Subject 4	12	10	- 2
Subject 5	58	53	- 5
Subject 6	35	59	24
Subject 7	11	19	8
Subject 8	14	32	18
Subject 9	53	26	-27
Subject 10	28	30	2
Subject 11	0	0	0
Subject 12	53	56	3

APPENDIX 7

SELF-EFFICACY FUNCTION

Subject	Pretest	Follow-up	Difference
<u>Treatment Group</u>			
Subject 1	69	69	0.00
Subject 2	94	99	4.45
Subject 3	78	92	14.44
Subject 4	33	26	- 7.77
Subject 5	59	41	-17.78
Subject 6	77	70	- 6.67
<u>Comparison Group</u>			
Subject 1	86	31	-54.45
Subject 2	42	24	-17.78
Subject 3	47	58	11.11
Subject 4	98	100	2.22
Subject 5	36	38	2.22
Subject 6	89	90	1.11
Subject 7	96	97	1.11
Subject 8	49	49	0.00
Subject 9	42	79	36.67
Subject 10	96	82	-13.34
Subject 11	91	100	8.89
Subject 12	94	63	-31.11

APPENDIX 8

SELF-EFFICACY SYMPTOMS

Subject	Pretest	Follow-up	Difference
<u>Treatment Group</u>			
Subject 1	53	60	6.67
Subject 2	100	100	0.00
Subject 3	85	87	1.67
Subject 4	33	42	8.34
Subject 5	50	45	- 5.00
Subject 6	77	77	0.00
<u>Comparison Group</u>			
Subject 1	100	20	-80.00
Subject 2	50	35	-15.00
Subject 3	48	57	8.34
Subject 4	82	95	13.33
Subject 5	50	32	-18.33
Subject 6	67	73	6.66
Subject 7	82	80	- 1.67
Subject 8	80	87	6.67
Subject 9	47	58	11.66
Subject 10	90	87	-03.33
Subject 11	100	67	-33.33
Subject 12	47	17	-30.00

APPENDIX 9

SELF-EFFICACY PAIN

Subject	Pretest	Follow-up	Difference
<u>Treatment Group</u>			
Subject 1	48	50	2.00
Subject 2	70	90	20.00
Subject 3	86	88	2.00
Subject 4	28	28	0.00
Subject 5	46	26	-20.00
Subject 6	74	72	- 2.00
<u>Comparison Group</u>			
Subject 1	100	16	-84.00
Subject 2	18	14	- 4.00
Subject 3	40	22	-18.00
Subject 4	90	100	10.00
Subject 5	32	36	4.00
Subject 6	76	74	- 2.00
Subject 7	68	80	12.00
Subject 8	62	76	14.00
Subject 9	48	62	14.00
Subject 10	72	74	2.00
Subject 11	86	86	0.00
Subject 12	32	12	-20.00

APPENDIX 10

HEALTH LOCUS OF CONTROL

Subject	Pretest	Follow-up	Difference
<u>Treatment Group</u>			
Subject 1	41	37	- 4.00
Subject 2	35	39	4.00
Subject 3	25	27	2.00
Subject 4	51	55	4.00
Subject 5	54	46	- 8.00
Subject 6	28	43	6.00
<u>Comparison Group</u>			
Subject 1	48	42	- 6.00
Subject 2	40	39	- 1.00
Subject 3	45	54	9.00
Subject 4	35	24	-11.00
Subject 5	41	43	2.00
Subject 6	30	38	8.00
Subject 7	35	41	6.00
Subject 8	33	37	4.00
Subject 9	30	44	14.00
Subject 10	36	31	- 5.00
Subject 11	33	37	4.00
Subject 12	35	51	16.00

12 Summary of methodology and procedures (Must be typewritten in this space).

This study will incorporate a randomized, cross-over experimental design to measure the effectiveness of the independent variable (the ASMP). The design looks like the following:

	EO	X	EO
Target Population	R		
	CO	CO	X
			CO

Subjects will be randomly assigned to either a control group which will not receive the intervention, or an experimental group which will receive the ASMP. The course, consisting of six two-hour sessions, will be given weekly. Four months later the control groups will receive the ASMP. To compensate for the treatment effect of giving the experimental group the ASMP, the control group will receive a lecture on scleroderma. Two lay-leaders who have received a three day leader's training course and who have been certified as ASMP leaders will deliver the course.

Data will be collected by self-administered questionnaires issued at the first session. Subjects will complete the questionnaires and return them during the first session. Four months later the subjects will be issued the same questionnaire.

The following instruments to be included in the questionnaire include the following:

Variable	Measurement
Pain	Visual Analogue Pain Scale (Dixon and Bird, 1981).
Disability	Health Assessment Questionnaire (Fries et al., 1980).
Depression	CES-D Scale (Radloff, 1977).
Quality of Life	Modification of the Ladder Scale developed by Cantril, (1965).
Self-Efficacy	Arthritis Self-Efficacy Scale (Lorig et al., 1989).
Locus of Control	Wallston's Health Locus of Control Scale (Wallston et al., 1976).

DESCRIPTION OF POPULATION

13 How many subjects will be used? Thirty subjects in total will be used. (Fifteen in each group).
How many in the control group? Fifteen subjects in the control group will be used.

14 Who is being recruited and what are the criteria for their selection?

Subjects who have scleroderma will be recruited for this study. The criteria for their selection will be that their diagnosis is scleroderma and that they volunteer for the study.

<p>15 What subjects will be excluded from participation?</p> <p>Patients without scleroderma will be excluded from participation and those who cannot speak English.</p>
<p>16 How are the subjects being recruited? (If initial contact is by letter or if a recruitment notice is to be posted, attach a copy.) NOTE that UBC policy absolutely prohibits initial contact by telephone.</p> <p>Subjects will be recruited by advertising the program in the Scleroderma Association News Letter. Members of the association will also be asked to participate. Initial contact will be by letter explaining the details of the study. [See appendix].</p>
<p>17 If a control group is involved, and if their selection and/or recruitment differs from the above, provide details.</p> <p>Recruitment of the control group will not be different from the above.</p>

PROJECT DETAILS

<p>18 Where will the project be conducted? (room or area)</p> <p>It is expected that the project will be conducted at two community centres, not yet determined, in the greater Vancouver area.</p>
<p>19 Who will actually conduct the study?</p> <p>A leader having scleroderma named Judy Hunter and UBC MSW student Jay Lees will be conducting the study under the supervision of the Arthritis Society's Director of Social</p>
<p>20 Will the group of subjects have any problems giving informed consent on their own behalf? Consider physical or mental condition, age, language, or other barriers.</p> <p>No.</p>
<p>21 If the subjects are not competent to give fully informed consent, who will consent on their behalf?</p> <p>Not applicable.</p>
<p>22 What is known about the risks and benefits of the proposed research? Do you have additional opinions on this issue?</p> <p>This research offers no risks. On the contrary, it offers benefits in the discovery of self-efficacy theory in arthritis.</p>

23 What discomfort or incapacity are the subjects likely to endure as a result of the experimental procedures?

None.

24 If monetary compensation is to be offered the subjects, provide details of amounts and payment schedules.

Not applicable.

25 How much time will a subject have to dedicate to the project?

The ASMP will be offered for six weeks with classes being held one day or evening per week for two hours. A total of twelve hours are offered over a six week period.

26 How much time will a member of the control group (if any) have to dedicate to the project?

Twenty minutes.

DATA

27 Who will have access to the data?

The only people who will have access to the data include: Patrick McGowan, Arthritis Society Director of Social Work Services; Dr. Mary Russell, Committee Chairperson for MSW thesis; and Jay Lees, MSW Student.

28 How will confidentiality of the data be maintained?

Confidentiality of the data will be maintained by assigning numbers to the subject's questionnaires in substitution for their names and identifying information.

29 What are the plans for future use of the data (beyond that described in this protocol)? How and when will the data be destroyed?

Because my MSW research thesis project is an adjunct to a much larger Arthritis Society research project, the data will be used to fulfill the Society's research requirements. Destruction of the data will occur at the completion of the study.

30 Will any data which identifies individuals be available to persons or agencies outside the University?

The British Columbia Arthritis Society will have access to this data.

CHECKLISTS

page

31 Will your project use: (check)

- ☒ Questionnaires (submit a copy)
- ☐ Interviews (submit a sample of questions)
- ☐ Observations (submit a brief description)
- ☐ Tests (submit a brief description)

INFORMED CONSENT

32 Who will consent? (check)

- ☒ Subject
- ☐ Parent/Guardian
- ☐ Agency Official(s)

In the case of projects carried out at other institutions, the Committee requires written proof that agency consent has been received. Please specify below:

- ☐ Research carried out in a hospital - approval of hospital research or ethics committee.
- ☐ Research carried out in a school - approval of School Board and/or Principal. (Exact requirements depend on individual school boards; check with Faculty of Education Committee members for details)
- ☐ Research carried out in a Provincial Health Agency - approval of Deputy Minister
- ☒ Other, specify: *B.C. ARTHRITIS SOCIETY*

33 UBC Policy requires written subject consent in all cases other than questionnaires which are completed by the subject. (see item #34 for consent requirements) Please check each item in the following list before submission of this form to ensure that the written consent form attached contains all necessary items.

- ☒ Title of project
- ☒ Identification of investigators (including a telephone number)
- ☒ Brief but complete description IN LAY LANGUAGE of the purpose of the project and of all procedures to be carried out in which the subjects are involved.
- ☒ Assurance that identity of the subject will be kept confidential and description of how this will be accomplished
- ☒ Statement of the total amount of time that will be required of a subject
- N/A* ☐ Details of monetary compensation, if any, to be offered to subjects.
- ☒ An offer to answer any inquiries concerning the procedures to ensure that they are fully understood by the subject and to provide debriefing if appropriate
- ☒ A statement of the subject's right to refuse to participate or withdraw at any time and a statement that withdrawal or refusal to participate will not jeopardize further treatment, medical care or influence class standing as applicable. NOTE: This statement must also appear on letters of initial contact.
- ☒ A place for signature of subject CONSENTING to participate in the research project, investigation or study.
- ☒ A statement acknowledging receipt of a copy of the consent form including all attachments.
- ☒ Parental consent forms must contain a statement of choice providing an option for refusal to participate. (e.g. "I consent/I do not consent to my child's participation in this study."

QUESTIONNAIRES (completed by subjects)

page

34 Questionnaires should contain an introductory paragraph which includes the following information. Please check each item in the following list before submission of this form to insure that the introduction contains all necessary items.

- ☒ Title of project
- ☒ Identification of investigators (including a telephone number)
- ☒ A brief summary that indicates the purpose of the project
- ☒ The benefits to be derived
- ☒ A full description of the procedures to be carried out in which the subjects are involved
- ☒ A statement of the subject's right to refuse to participate or withdraw at any time without jeopardizing further treatment, medical care or class standing as applicable
NOTE: This statement must also appear on explanatory letters involving questionnaires.
- ☒ the amount of time required of the subject must be stated
- ☒ The statement that if the questionnaire is completed it will be assumed that consent has been given
- ☒ Assurance that identity of the subject will be kept confidential and description of how this will be accomplished.
- ☒ For surveys circulated by mail submit a copy of the explanatory letter as well as a copy of the questionnaire

ATTACHMENTS

35 Check items attached to this submission if applicable. (incomplete submissions will not be reviewed)

- ☒ Letter of initial contact (item 16)
- ☒ Advertisement for volunteer subjects (item 16)
- ☒ Subject consent form (item 33)
- ☒ Control group consent form (if different from above)
- ☒ Parent/guardian consent form (if different from above)
- ☒ Agency consent (item 32)
- ☒ Questionnaires, tests, interviews, etc. (item 31)
- ☒ Explanatory letter with questionnaire (item 34)
- ☐ Description of debriefing if deception is involved
- ☐ Other, specify:

PRE

LEAVE
THIS AREA
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197

APPENDIX 17

Arthritis Branch Community Support Project
Arthritis Society

TORR

NAME _____ (H1) Birthdate _____ (H3)

P1 date

Street Address _____ (H14)

City, Province, Postal Code _____ (H9)

H2 medrec

Telephone Number (Home) _____ Sex _____ (H4)

H3 brthdat

(Work) _____

H4

Ethnic Origin _____ (H5)

H5

Please circle the highest year of school completed. (H6)

1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 above 22
 (primary) (high school) (college) (graduate school)

H6

In what month and year did your arthritis begin? _____ (H7)

H7

The last time I saw a doctor for arthritis was _____
month yearAre you currently: (check only one) (H10)

1. ____ single 4. ____ divorced
 2. ____ married 5. ____ widowed
 3. ____ separated

H10

Are you: (check only one) (H11)

1. ____ employed full time 5. ____ retired
 2. ____ employed part time 6. ____ disabled
 3. ____ seeking work 7. ____ other (describe) _____
 4. ____ homemaker _____

H11

If employed, what kind of work do you do? _____ (H12)

H12

If retired, what kind of work did you do mostly? _____ (H12)

H16

What kind of arthritis do you have? _____ (H16)

H13

site

H17

ASH

Physical Activities/Therapies for Arthritis

During the past month, on an average, how many times per week did you do each of the following? Please fill in each space with a zero or other number.

Stretching exercise for arthritis to improve joint movement.	_____ times per week	5 _____
Strengthening exercise for arthritis to strengthen muscles and joints.	_____ times per week	6 _____
Practice relaxation techniques.	_____ times per week	151 _____
List which ones: _____		
Massage.	_____ times per week	7 _____
Walking for exercise.	_____ times per week	8 _____
Each time you walk for exercise, how many minutes do you walk?	_____ minutes	11 _____
Each time you walk for exercise, how many blocks do you walk?	_____ blocks	14 _____
Swimming (i.e., of lap swimming).	_____ times per week	9 _____
Each time that you swim, how many minutes do you swim?	_____ minutes	12 _____
Bicycling (regular or stationary).	_____ times per week	10 _____
Each time that you bicycle, how many minutes do you bicycle?	_____ minutes	13 _____

PLEASE GO ON TO THE NEXT PAGE. . .

Please check the one response which best describes your usual abilities OVER THE PAST WEEK: 199

	<u>Without ANY</u> <u>Difficulty</u>	<u>With SOME</u> <u>Difficulty</u>	<u>With MUCH</u> <u>Difficulty</u>	<u>UNABLE</u> <u>to do</u>	
DRESSING & GROOMING					
Are you able to:					
- Dress yourself, including tying shoelaces and doing buttons?	_____	_____	_____	_____	
- Shampoo your hair?	_____	_____	_____	_____	35 _____
ARISING					
Are you able to:					
- Stand up from an armless straight chair?	_____	_____	_____	_____	
- Get in and out of bed?	_____	_____	_____	_____	36 _____
EATING					
Are you able to:					
- Cut your meat?	_____	_____	_____	_____	
- Lift a full cup or glass to your mouth?	_____	_____	_____	_____	37 _____
WALKING					
Are you able to:					
- Walk outdoors on flat ground?	_____	_____	_____	_____	
- Climb up five steps?	_____	_____	_____	_____	38 _____

* Please check any AIDS OR DEVICES that you usually use for any of these activities:

_____ Cane	_____ Devices Used for Dressing (button hook, zipper pull, long-handled shoe horn, etc.)
_____ Walker	_____ Built Up or Special Utensils
_____ Crutches	_____ Special or Built Up Chair
_____ Wheelchair	_____ Other (Specify: _____)

* Please check any categories for which you usually need HELP FROM ANOTHER PERSON:

_____ Dressing & Grooming	_____ Eating
_____ Arising	_____ Walking

Please check the one response which best describes your usual abilities OVER THE PAST WEEK:

	Without ANY Difficulty	With SOME Difficulty	With MUCH Difficulty	UNABLE to do
--	---------------------------	-------------------------	-------------------------	-----------------

HYGIENE

Are you able to:

- | | | | | |
|--------------------------------|-------|-------|-------|-------|
| - Wash & dry your entire body? | _____ | _____ | _____ | _____ |
| - Take a tub bath? | _____ | _____ | _____ | _____ |
| - Get on and off the toilet? | _____ | _____ | _____ | _____ |

39 _____

REACH

Are you able to:

- | | | | | |
|---|-------|-------|-------|-------|
| - Reach & get down a 5 pound object (such as a bag of sugar) from just above your head? | _____ | _____ | _____ | _____ |
| - Bend down to pick up clothing from the floor? | _____ | _____ | _____ | _____ |

40 _____

GRIP

Are you able to:

- | | | | | |
|--|-------|-------|-------|-------|
| - Open car doors? | _____ | _____ | _____ | _____ |
| - Open jars which have been previously opened? | _____ | _____ | _____ | _____ |
| - Turn faucets on and off? | _____ | _____ | _____ | _____ |

41 _____

ACTIVITIES

Are you able to:

- | | | | | |
|---|-------|-------|-------|-------|
| - Run errands and shop? | _____ | _____ | _____ | _____ |
| - Get in and out of a car? | _____ | _____ | _____ | _____ |
| - Do chores such as vacuuming and yardwork? | _____ | _____ | _____ | _____ |

42 _____

* Please check any AIDS OR DEVICES that you usually use for any of these activities:

- | | |
|---|---|
| _____ Raised Toilet Seat | _____ Bathtub Bar |
| _____ Bathtub Seat | _____ Long-Handled Appliances for Reach |
| _____ Jar Opener (for jars previously opened) | _____ Long-Handled Appliances in Bathroom |
| _____ Other (Specify: _____) | |

43 _____

* Please check any categories for which you usually need HELP FROM ANOTHER PERSON:

- | | |
|---------------|-----------------------------------|
| _____ Hygiene | _____ Gripping and Opening Things |
| _____ Reach | _____ Errands and Chores |

44 _____

How many arthritis and related visits did you make for routine check-ups? (That is, the doctor suggested the visit.) Do not include visits while in the hospital.

In the past 4 months _____

47 _____

How many arthritis and related visits did you make for a specific problem? (That is, you made the appointment without the suggestion of your doctor.)

In the past 4 months _____

48 _____

We are interested in learning whether or not you are affected by pain because of your illness. Please mark an X on the line below to describe your arthritis pain in the recent past.

Pain as bad as could be _____ No pain
SEVERE MODERATE SLIGHT

45 _____

Take a moment and think of the best possible life and the worst possible life. Now, on the line below, place an X to indicate where your life is now.

Worst possible life _____ Best possible life

153 _____

We would like to know how confident you are in performing certain daily activities. For each of the following questions, please circle the number which corresponds to your certainty that you can perform the tasks as of now without assistive devices or help from another person. Please consider what you routinely can do, not what would require a single extraordinary effort. Here is an example of the way someone might answer the question:

EXAMPLE

AS OF NOW, HOW CERTAIN ARE YOU THAT YOU CAN:

Dial a telephone in 10 seconds:

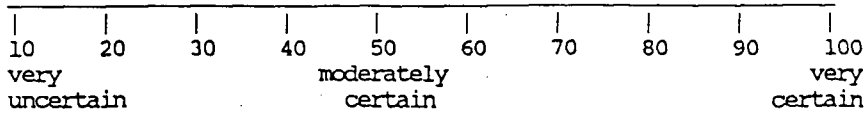
10 20 30 40 50 60 70 80 90 100
very very
uncertain moderately certain very
certain

This person is uncertain that she could dial a telephone in 10 seconds.

Now, please answer the following questions using the same format....

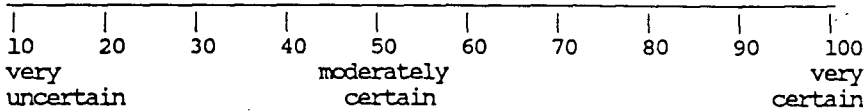
AS OF NOW, HOW CERTAIN ARE YOU THAT YOU CAN:

1. Walk 100 feet on flat ground in 20 seconds?



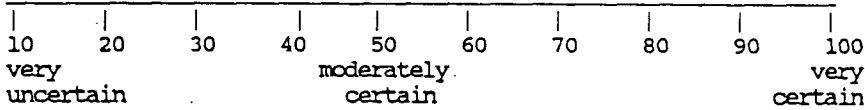
83 _____

2. Walk 10 steps downstairs in 7 seconds?



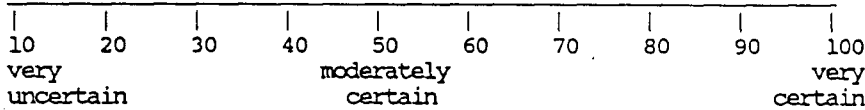
84 _____

3. Get out of an armless chair quickly without using your hands for support?



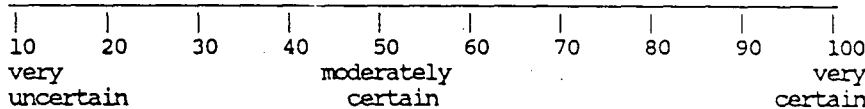
85 _____

4. Button and unbutton three medium-size buttons in a row in 12 seconds?



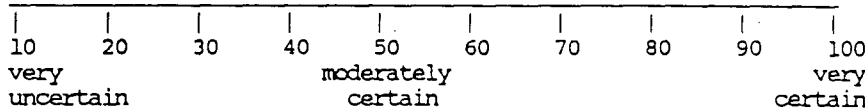
86 _____

5. Cut 2 bite-size pieces of meat with a knife and fork in 8 seconds?



87 _____

6. Turn an outdoor faucet all the way on and all the way off?

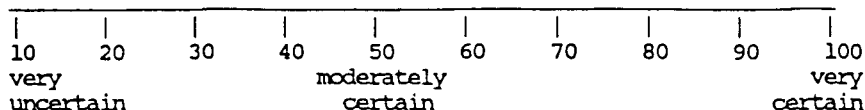


88 _____

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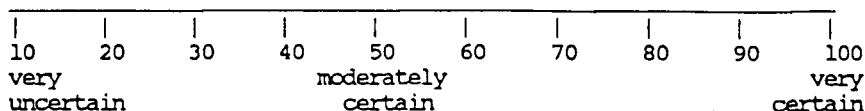
AS OF NOW, HOW CERTAIN ARE YOU THAT YOU CAN...

7. Scratch your upper back with both your right and left hands?



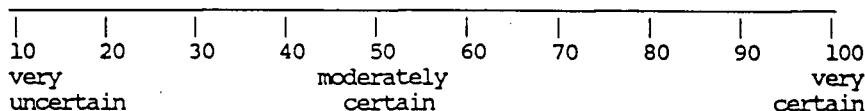
89 _____

8. Get in and out of the passenger side of a car without assistance from another person and without physical aids?



90 _____

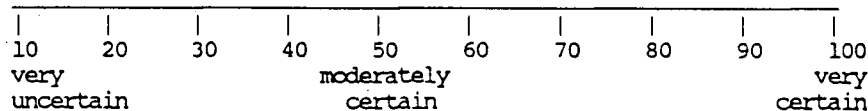
9. Put on a long-sleeve front opening shirt or blouse (without buttoning) in 8 seconds?



91 _____

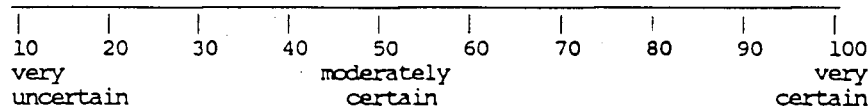
In the following questions we'd like to know how you feel about your ability to control your arthritis. For each of the following questions please circle the number which corresponds with the certainty that you can now perform the following activities or tasks.

1. How certain are you that you can control your fatigue?



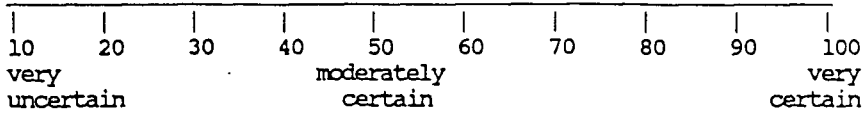
92 _____

2. How certain are you that you can regulate your activity so as to be active without aggravating your arthritis?



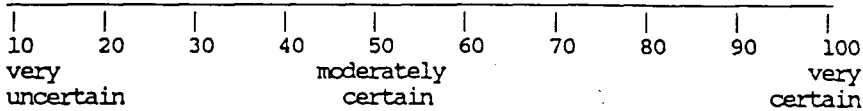
93 _____

3. How certain are you that you can do something to help yourself feel better if you are feeling blue?



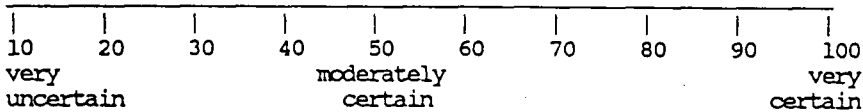
94 _____

4. As compared to other people with arthritis like yours how certain are you that you can manage arthritis pain during your daily activities?



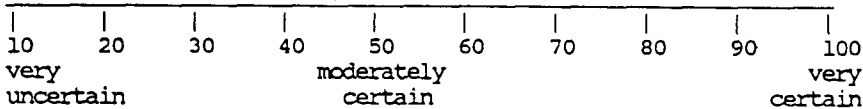
95 _____

5. How certain are you that you can manage your arthritis symptoms so that you can do the things you enjoy doing?



96 _____

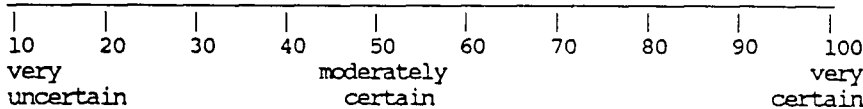
6. How certain are you that you can deal with the frustration of arthritis?



97 _____

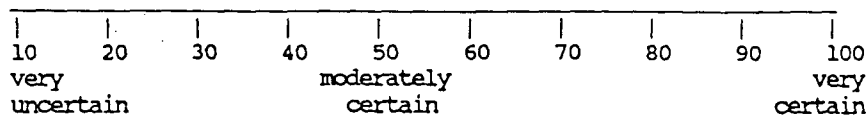
In the following questions, we'd like to know how your arthritis pain affects you. For each of the following questions please circle the number which corresponds to your certainty that you can now perform the following tasks.

1. How certain are you that you can decrease your pain quite a bit?



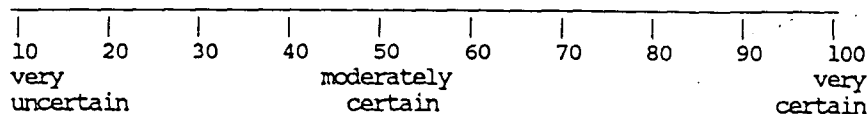
98 _____

2. How certain are you that you can continue most of your daily activities?



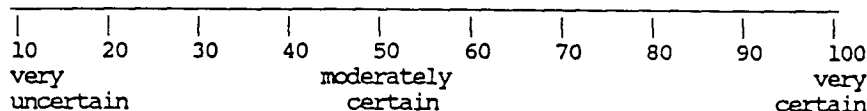
99 _____

3. How certain are you that you can keep arthritis pain from interfering with your sleep?



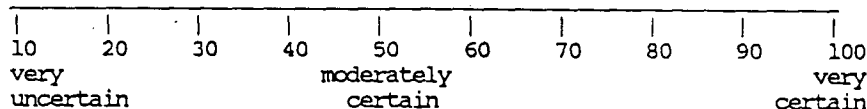
100 _____

4. How certain are you that you can make a small-to-moderate reduction in your arthritis pain by using methods other than taking extra medication?



101 _____

5. How certain are you that you can make a large reduction in your arthritis pain by using methods other than taking extra medication?



102 _____

Please go on to the next page...

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Below is a list of some of the ways you may have felt or behaved. Please indicate how often you have felt this way during the PAST WEEK by checking the appropriate space.

	Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	All of the time (5-7 days)	
1. I was bothered by things that usually don't bother me.	_____	_____	_____	_____	105 _____
2. I did not feel like eating; my appetite was poor.	_____	_____	_____	_____	106 _____
3. I felt that I could not shake off the blues even with the help from my family.	_____	_____	_____	_____	107 _____
4. I felt that I was just as good as other people.	_____	_____	_____	_____	108 _____
5. I had trouble keeping my mind on what I was doing.	_____	_____	_____	_____	109 _____
6. I felt depressed.	_____	_____	_____	_____	110 _____
7. I felt that everything I did was an effort.	_____	_____	_____	_____	111 _____
8. I felt hopeful about the future.	_____	_____	_____	_____	112 _____
9. I thought my life had been a failure.	_____	_____	_____	_____	113 _____
10. I felt fearful.	_____	_____	_____	_____	114 _____
11. My sleep was restless.	_____	_____	_____	_____	115 _____
12. I was happy.	_____	_____	_____	_____	116 _____
13. I talked less than usual.	_____	_____	_____	_____	117 _____
14. I felt lonely.	_____	_____	_____	_____	118 _____
15. People were unfriendly.	_____	_____	_____	_____	119 _____
16. I enjoyed life.	_____	_____	_____	_____	120 _____
17. I had crying spells.	_____	_____	_____	_____	121 _____
18. I felt sad.	_____	_____	_____	_____	122 _____
19. I felt that people disliked me.	_____	_____	_____	_____	123 _____
20. I could not get "going".	_____	_____	_____	_____	126 _____

Indicate your agreement or disagreement with the following items by circuling the number for each item that corresponds to your response according to the following key:

- 1 Strongly Disagree
- 2 Disagree Moderately
- 3 Disagree Somewhat
- 4 Agree Somewhat
- 5 Agree Moderately
- 6 Strongly Agree

Scale Items:

- | | | | | | | | |
|-----|---|---|---|---|---|---|---|
| 1. | If I take care of myself, I can avoid illness. | 1 | 2 | 3 | 4 | 5 | 6 |
| 2. | Whenever I get sick it is because of something that I've done or not done. | 1 | 2 | 3 | 4 | 5 | 6 |
| 3. | Good health is largely a matter of good fortune. | 1 | 2 | 3 | 4 | 5 | 6 |
| 4. | No matter what I do, if I am going to get sick I will get sick. | 1 | 2 | 3 | 4 | 5 | 6 |
| 5. | Most people do not realize the extent to which their illnesses are controlled by accidental happenings. | 1 | 2 | 3 | 4 | 5 | 6 |
| 6. | I can only do what my doctor tells me to do. | 1 | 2 | 3 | 4 | 5 | 6 |
| 7. | There are so many strange diseases around that you can never know how or when you might pick one up. | 1 | 2 | 3 | 4 | 5 | 6 |
| 8. | When I feel ill, I know it is because I have not been getting the proper exercise or eating right. | 1 | 2 | 3 | 4 | 5 | 6 |
| 9. | People who never get sick are just plain lucky. | 1 | 2 | 3 | 4 | 5 | 6 |
| 10. | People's ill health results from their own carelessness. | 1 | 2 | 3 | 4 | 5 | 6 |
| 11. | I am directly responsible for my health. | 1 | 2 | 3 | 4 | 5 | 6 |

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What medications are you taking for your arthritis? (Please circle YES or NO
FOR EACH GROUP.)

Aspirin/Aspirin-Like Product

1 0

Aspirin, Bufferin, Ascriptin, Anacin, Excedrin,
Ecotrin, Empirin, Trilisate, Disalcid, other aspirin
Tylenol, other acetaminophen - - - - - YES NO

127 _____

Nonsteroidal Anti-inflammatory

Advil, Anaprox, Ansaid, Butazolidin, Clinoril, Dolobid,
Feldene, Ibuprofen, Indocin, Meclomen, Motrin, Nalfon,
Naprosyn, Nuprin, Orudis, Rufen, Tandearil, Tolectin,
Tolmetin, Voltaren - - - - - YES NO

128 _____

Immunosuppressive Agents

Auronofin, Ridaura, (oral gold)
Gold injections, Myochrisine, Solgonal - - - - - YES NO
Penicillamine, Cuprimine, Depen - - - - - YES NO
Plaquenil, Hydroxychloroquine - - - - - YES NO

129 _____

130 _____

131 _____

Chemotherapeutic Agents

Imuran, Cytoxan, Azathioprine, Cyclophosphamide,
Methotrexate - - - - - YES NO

132 _____

Steroids

Prednisone, Cortisone, Hydrocortisone, Decadron - - - YES NO

133 _____

Others for Arthritis

Darvon, Darvocet, Codeine, Percodan, Percocet, Talwin,
Dilaudid, Vicodin - - - - - YES NO

134 _____

List on the line any others: _____ YES NO

135 _____

THANK YOU !

PLEASE CHECK BACK TO MAKE SURE THAT ALL PAGES ARE COMPLETE

PLEASE SHARE ANY ADDITIONAL THOUGHTS OR CONCERNS ON THE BACK OF THIS PAGE

coded

checked

entered

APPENDIX 19

POST

LEAVE
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Arthritis Society

210

NAME _____

Address _____

Telephone Number (Home) _____ (Work) _____

Of the 6 Arthritis Self-Help classes, how many did you attend? _____

TORR

1 date

125
clsPhysical Activities/Therapies for Arthritis

During the past month, on an average, HOW MANY TIMES PER WEEK did you do each of the following? Please fill in each space with a zero or other number.

Stretching exercise for arthritis to
improve joint movement. _____ times per week

5 _____

Strengthening exercise for arthritis
to strengthen muscles and joints. _____ times per week

6 _____

Practice relaxation techniques. _____ times per week

151 _____

List which ones: _____

Massage. _____ times per week

7 _____

Walking for exercise. _____ times per week

8 _____

Each time you walk for exercise,
how many minutes do you walk? _____ minutes

11 _____

Each time you walk for exercise,
how many blocks do you walk? _____ blocks

14 _____

Swimming (i.e., of lap swimming). _____ times per week

9 _____

Each time that you swim,
how many minutes do you swim? _____ minutes

12 _____

Bicycling (regular or stationary). _____ times per week

10 _____

Each time that you bicycle,
how many minutes do you bicycle? _____ minutes

13 _____

LEAVE
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Please check the one response which best describes your usual abilities OVER THE PAST WEEK:

	<u>Without ANY</u> <u>Difficulty</u>	<u>With SOME</u> <u>Difficulty</u>	<u>With MUCH</u> <u>Difficulty</u>	<u>UNABLE</u> <u>to do</u>	
DRESSING & GROOMING					
Are you able to:					
- Dress yourself, including tying shoelaces and doing buttons?	_____	_____	_____	_____	
- Shampoo your hair?	_____	_____	_____	_____	35 _____
ARISING					
Are you able to:					
- Stand up from an armless straight chair?	_____	_____	_____	_____	
- Get in and out of bed?	_____	_____	_____	_____	36 _____
EATING					
Are you able to:					
- Cut your meat?	_____	_____	_____	_____	
- Lift a full cup or glass to your mouth?	_____	_____	_____	_____	37 _____
WALKING					
Are you able to:					
- Walk outdoors on flat ground?	_____	_____	_____	_____	
- Climb up five steps?	_____	_____	_____	_____	38 _____

* Please check any AIDS OR DEVICES that you usually use for any of these activities:

_____ Cane	_____ Devices Used for Dressing (button hook, zipper pull, long-handled shoe horn, etc.)
_____ Walker	_____ Built Up or Special Utensils
_____ Crutches	_____ Special or Built Up Chair
_____ Wheelchair	_____ Other (Specify: _____)

* Please check any categories for which you usually need HELP FROM ANOTHER PERSON:

_____ Dressing & Grooming	_____ Eating
_____ Arising	_____ Walking

Please check the one response which best describes your usual abilities OVER
THE PAST WEEK:

	Without ANY Difficulty	With SOME Difficulty	With MUCH Difficulty	UNABLE to do
--	---------------------------	-------------------------	-------------------------	-----------------

HYGIENE

Are you able to:

- | | | | | |
|--------------------------------|-------|-------|-------|-------|
| - Wash & dry your entire body? | _____ | _____ | _____ | _____ |
| - Take a tub bath? | _____ | _____ | _____ | _____ |
| - Get on and off the toilet? | _____ | _____ | _____ | _____ |

39 _____

REACH

Are you able to:

- | | | | | |
|---|-------|-------|-------|-------|
| - Reach & get down a 5 pound object (such as a bag of sugar) from just above your head? | _____ | _____ | _____ | _____ |
| - Bend down to pick up clothing from the floor? | _____ | _____ | _____ | _____ |

40 _____

GRIP

Are you able to:

- | | | | | |
|--|-------|-------|-------|-------|
| - Open car doors? | _____ | _____ | _____ | _____ |
| - Open jars which have been previously opened? | _____ | _____ | _____ | _____ |
| - Turn faucets on and off? | _____ | _____ | _____ | _____ |

41 _____

ACTIVITIES

Are you able to:

- | | | | | |
|---|-------|-------|-------|-------|
| - Run errands and shop? | _____ | _____ | _____ | _____ |
| - Get in and out of a car? | _____ | _____ | _____ | _____ |
| - Do chores such as vacuuming and yardwork? | _____ | _____ | _____ | _____ |

42 _____

* Please check any AIDS OR DEVICES that you usually use for any of these activities:

- | | |
|---|---|
| _____ Raised Toilet Seat | _____ Bathtub Bar |
| _____ Bathtub Seat | _____ Long-Handled Appliances for Reach |
| _____ Jar Opener (for jars previously opened) | _____ Long-Handled Appliances in Bathroom |
| _____ Other (Specify: _____) | |

43 _____

* Please check any categories for which you usually need HELP FROM ANOTHER PERSON:

- | | |
|---------------|-----------------------------------|
| _____ Hygiene | _____ Gripping and Opening Things |
| _____ Reach | _____ Errands and Chores |

44 _____

How many arthritis and related visits did you make for routine check-ups? (That is, the doctor suggested the visit.) Do not include visits while in the hospital.

In the past 4 months _____

47 _____

How many arthritis and related visits did you make for a specific problem? (That is, you made the appointment without the suggestion of your doctor.)

In the past 4 months _____

48 _____

We are interested in learning whether or not you are affected by pain because of your illness. Please mark an X on the line below to describe your arthritis pain in the recent past.

Pain as bad as could be |-----| No pain
SEVERE MODERATE SLIGHT

45 _____

Take a moment and think of the best possible life and the worst possible life. Now, on the line below, place an X to indicate where your life is now.

Worst possible life |-----| Best possible life

153 _____

We would like to know how confident you are in performing certain daily activities. For each of the following questions, please circle the number which corresponds to your certainty that you can perform the tasks as of now without assistive devices or help from another person. Please consider what you routinely can do, not what would require a single extraordinary effort. Here is an example of the way someone might answer the question:

EXAMPLE

AS OF NOW, HOW CERTAIN ARE YOU THAT YOU CAN:

Dial a telephone in 10 seconds:

10 20 30 40 50 60 70 80 90 100
very very
uncertain moderately certain
certain

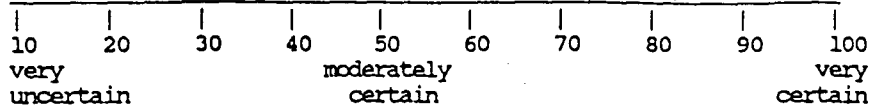
This person is uncertain that she could dial a telephone in 10 seconds.

Now, please answer the following questions using the same format....

LEAVE
THIS AREA
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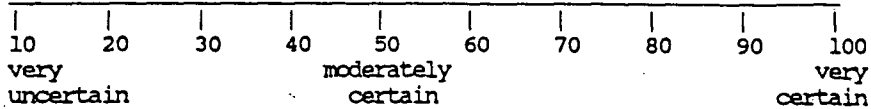
AS OF NOW, HOW CERTAIN ARE YOU THAT YOU CAN:

1. Walk 100 feet on flat ground in 20 seconds?



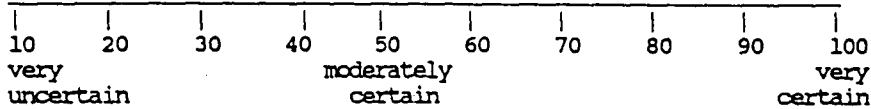
83 _____

2. Walk 10 steps downstairs in 7 seconds?



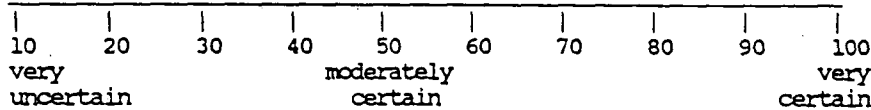
84 _____

3. Get out of an armless chair quickly without using your hands for support?



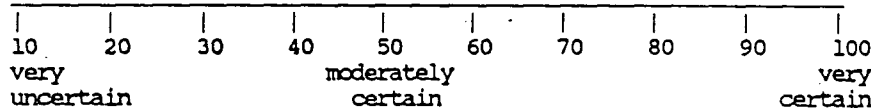
85 _____

4. Button and unbutton three medium-size buttons in a row in 12 seconds?



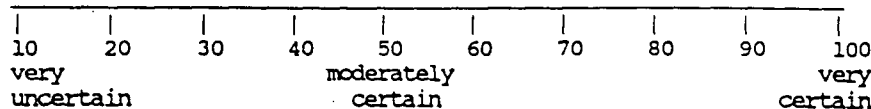
86 _____

5. Cut 2 bite-size pieces of meat with a knife and fork in 8 seconds?



87 _____

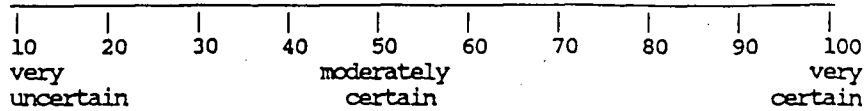
6. Turn an outdoor faucet all the way on and all the way off?



88 _____

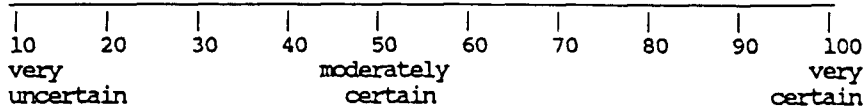
AS OF NOW, HOW CERTAIN ARE YOU THAT YOUR CAN...

7. Scratch your upper back with both your right and left hands?



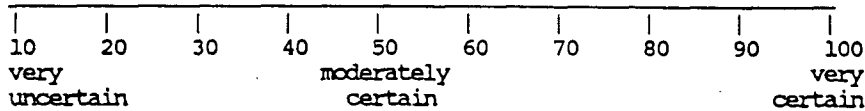
89 _____

8. Get in and out of the passenger side of a car without assistance from another person and without physical aids?



90 _____

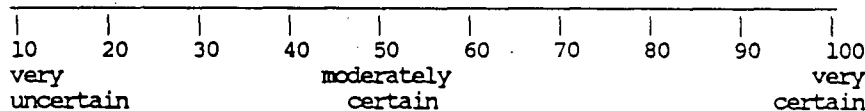
9. Put on a long-sleeve front opening shirt or blouse (without buttoning) in 8 seconds?



91 _____

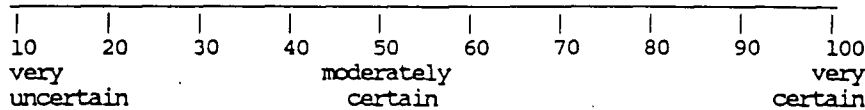
In the following questions we'd like to know how you feel about your ability to control your arthritis. For each of the following questions please circle the number which corresponds with the certainty that you can now perform the following activities or tasks.

1. How certain are you that you can control your fatigue?



92 _____

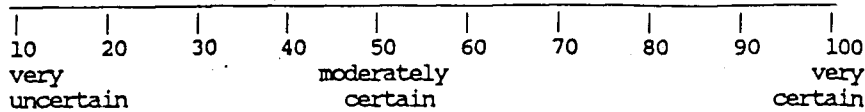
2. How certain are you that you can regulate your activity so as to be active without aggravating your arthritis?



93 _____

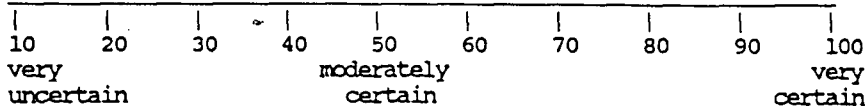
LEAVE
THIS AREA
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3. How certain are you that you can do something to help yourself feel better if you are feeling blue?



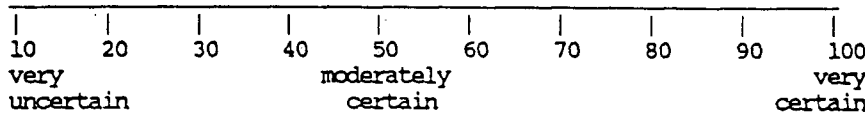
94 _____

4. As compared to other people with arthritis like yours how certain are you that you can manage arthritis pain during your daily activities?



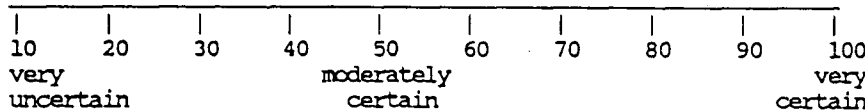
95 _____

5. How certain are you that you can manage your arthritis symptoms so that you can do the things you enjoy doing?



96 _____

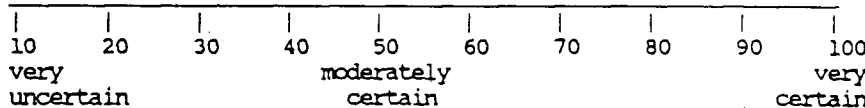
6. How certain are you that you can deal with the frustration of arthritis?



97 _____

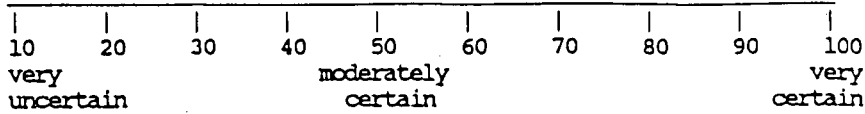
In the following questions, we'd like to know how your arthritis pain affects you. For each of the following questions please circle the number which corresponds to your certainty that you can now perform the following tasks.

1. How certain are you that you can decrease your pain quite a bit?



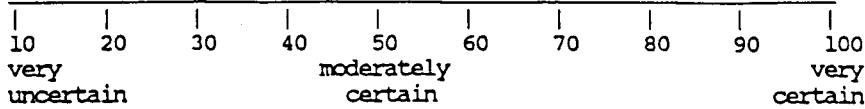
98 _____

2. How certain are you that you can continue most of your daily activities?



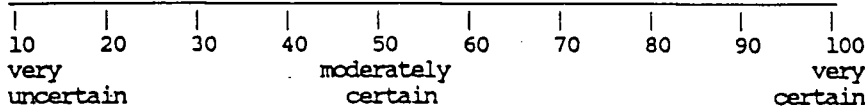
99 _____

3. How certain are you that you can keep arthritis pain from interfering with your sleep?



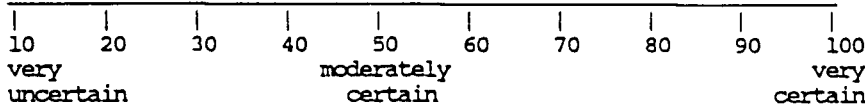
100 _____

4. How certain are you that you can make a small-to-moderate reduction in your arthritis pain by using methods other than taking extra medication?



101 _____

5. How certain are you that you can make a large reduction in your arthritis pain by using methods other than taking extra medication?



102 _____

Please go on to the next page...

Below is a list of some of the ways you may have felt or behaved. Please indicate how often you have felt this way during the PAST WEEK by checking the appropriate space.

	Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	All of the time (5-7 days)	
1. I was bothered by things that usually don't bother me.	_____	_____	_____	_____	105 _____
2. I did not feel like eating; my appetite was poor.	_____	_____	_____	_____	106 _____
3. I felt that I could not shake off the blues even with the help from my family.	_____	_____	_____	_____	107 _____
4. I felt that I was just as good as other people.	_____	_____	_____	_____	108 _____
5. I had trouble keeping my mind on what I was doing.	_____	_____	_____	_____	109 _____
6. I felt depressed.	_____	_____	_____	_____	110 _____
7. I felt that everything I did was an effort.	_____	_____	_____	_____	111 _____
8. I felt hopeful about the future.	_____	_____	_____	_____	112 _____
9. I thought my life had been a failure.	_____	_____	_____	_____	113 _____
10. I felt fearful.	_____	_____	_____	_____	114 _____
11. My sleep was restless.	_____	_____	_____	_____	115 _____
12. I was happy.	_____	_____	_____	_____	116 _____
13. I talked less than usual.	_____	_____	_____	_____	117 _____
14. I felt lonely.	_____	_____	_____	_____	118 _____
15. People were unfriendly.	_____	_____	_____	_____	119 _____
16. I enjoyed life.	_____	_____	_____	_____	120 _____
17. I had crying spells.	_____	_____	_____	_____	121 _____
18. I felt sad.	_____	_____	_____	_____	122 _____
19. I felt that people disliked me.	_____	_____	_____	_____	123 _____
20. I could not get "going".	_____	_____	_____	_____	124 _____

Indicate your agreement or disagreement with the following items by circling the number for each item that corresponds to your response according to the following key:

- 1 Strongly Disagree
- 2 Disagree Moderately
- 3 Disagree Somewhat
- 4 Agree Somewhat
- 5 Agree Moderately
- 6 Strongly Agree

Scale Items:

- | | | | | | | |
|--|---|---|---|---|---|---|
| 1. If I take care of myself, I can avoid illness. | 1 | 2 | 3 | 4 | 5 | 6 |
| 2. Whenever I get sick it is because of something that I've done or not done. | 1 | 2 | 3 | 4 | 5 | 6 |
| 3. Good health is largely a matter of good fortune. | 1 | 2 | 3 | 4 | 5 | 6 |
| 4. No matter what I do, if I am going to get sick I will get sick. | 1 | 2 | 3 | 4 | 5 | 6 |
| 5. Most people do not realize the extent to which their illnesses are controlled by accidental happenings. | 1 | 2 | 3 | 4 | 5 | 6 |
| 6. I can only do what my doctor tells me to do. | 1 | 2 | 3 | 4 | 5 | 6 |
| 7. There are so many strange diseases around that you can never know how or when you might pick one up. | 1 | 2 | 3 | 4 | 5 | 6 |
| 8. When I feel ill, I know it is because I have not been getting the proper exercise or eating right. | 1 | 2 | 3 | 4 | 5 | 6 |
| 9. People who never get sick are just plain lucky. | 1 | 2 | 3 | 4 | 5 | 6 |
| 10. People's ill health results from their own carelessness. | 1 | 2 | 3 | 4 | 5 | 6 |
| 11. I am directly responsible for my health. | 1 | 2 | 3 | 4 | 5 | 6 |

LEAVE
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What medications are you taking for your arthritis? (Please circle YES or NO
FOR EACH GROUP.)

Aspirin/Aspirin-Like Product

1 0

Aspirin, Bufferin, Ascriptin, Anacin, Excedrin,
Ecotrin, Empirin, Trilisate, Disalcid, other aspirin
Tylenol, other acetaminophen - - - - - YES NO

127 _____

Nonsteroidal Anti-inflammatory

Advil, Anaprox, Ansaid, Butazolidin, Clinoril, Dolobid,
Feldene, Ibuprofen, Indocin, Meclomen, Motrin, Nalfon,
Naprosyn, Nuprin, Orudis, Rufin, Tandearil, Tolectin,
Tolmetin, Voltaren - - - - - YES NO

128 _____

Immunosuppressive Agents

Auronofin, Ridaura, (oral gold)
Gold injections, Myochrisine, Solgonal - - - - - YES NO
Penicillamine, Cuprimine, Depen - - - - - YES NO
Plaquenil, Hydroxychloroquine - - - - - YES NO

129 _____

130 _____

131 _____

Chemotherapeutic Agents

Imuran, Cytoxan, Azathioprine, Cyclophosphamide,
Methotrexate - - - - - YES NO

132 _____

Steroids

Prednisone, Cortisone, Hydrocortisone, Decadron - - - YES NO

133 _____

Others for Arthritis

Darvon, Darvocet, Codeine, Percodan, Percocet, Talwin,
Dilaudid, Vicodin- - - - - YES NO
List on the line any others: _____ YES NO

134 _____

135 _____

THANK YOU !

PLEASE CHECK BACK TO MAKE SURE THAT ALL PAGES ARE COMPLETE

PLEASE SHARE ANY ADDITIONAL THOUGHTS OR CONCERNS ON THE BACK OF THIS PAGE

coded

checked

entered

APPENDIX 20

THE EFFECTIVENESS OF AN ARTHRITIS SELF-MANAGEMENT PROGRAM WITH A POPULATION OF PERSONS WITH SCLERODERMA

QUALITATIVE INTERVIEW SCHEDULE

Purpose of
Question

Question

-
- | | |
|---|--|
| 1. To determine external influences and major life events. | So tell me, how have you been doing lately? How has life been treating you in general? |
| 2. To determine what the participant like best. | When you think back to the things that we did in the course over the six sessions, what did you like the best about the course? What is the one part that you liked best of all, better than anything else? In other words, if you could only attend one or two sessions, which sessions would they be? Why? |
| 3. To determine what the participant did not like about the program. | Think about the course in general, and if you had to change one or two parts of the Arthritis Self-Management Program, which parts would you change and why? |
| 4. Impact of ASMP managing scleroderma. | Are there anythings from the course that you on found helpful in managing your scleroderma? |
| 5. Impact of ASMP managing life in general. | Is there anything from the course that helps you manage your life in general? |
| 6. Feelings regarding the process; the difference between didactic, to information giving, to | Remember how the course was organized? Either Judy or I would give a little, short talk and then open up the topic for discussion with the rest of the people taking the course. In addition to group discussions we also asked for individual participation where you would give us some feedback. Also, we would |

**Purpose of
Question**

Question

- | | |
|---|--|
| participation. | sometimes brainstorm some ideas. We generally would sit at the table and go around to get everyone's ideas. What did you think about this organization?, that is, the way everyone was involved? |
| 7. Impact/use of stress management. | In the course we talked about the stress, depression, and pain cycle and how one thing seems to lead to another. Also we talked about how we could reduce this stress in this cycle or break it entirely. We came up with some ideas on how to break the cycle. Have you used any of these methods and do they seem to be working? |
| 8. Doctor/patient communication. | Remember we talked about doctor/patient communication and some of the things we could do to make this better. Do you think that any of these ideas improve the way you talk to your doctor? If so, which ones? Have you tried any of them? |
| 9. Problem solving. | Remember we did a session on problem solving and the steps we followed. Have you been able to use this process with any of your problems so far? If no, do you think that you could use the steps sometime in the future? |
| 10. The ASMP's influence on how the participants feels that they can control the management of their scleroderma. | Now that you have taken the Arthritis Self-Management Program, do you feel that you have more control over the management of your arthritis? |
| 11. Usefulness of ASMP to the participant. | Again, now that you have taken the course, do you think people with scleroderma or some other type of arthritis would benefit from taking the course? Do you think that spouses or other family members would benefit from taking the course and why? |

**Purpose of
Question****Question**

12. A chance to say something the course that I have not asked them so far.

Those are all the questions that I wanted to ask you. Is there anything that we have about missed? Is there anything that we should talk about more or add? Anything at all?

THANK YOU VERY MUCH FOR YOUR INPUT AND FEEDBACK. IT WILL BE OF GREAT HELP TO ME AND THE ARTHRITIS SOCIETY.