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An exploratory study of common themes regarding quality of life for persons with rheumatoid arthritis

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San Jose State University, 1991

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AN EXPLORATORY STUDY OF COMMON THEMES REGARDING QUALITY
OF LIFE FOR PERSONS WITH RHEUMATOID ARTHRITIS

A Thesis

Presented to

The Faculty of the Department of Occupational Therapy

San Jose State University

In Partial Fulfillment

of the Requirements for the Degree

Master of Science

By

Jeanette Schumacher-Davis, O.T.R.

May, 1991

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ABSTRACT

AN EXPLORATORY STUDY OF COMMON THEMES REGARDING QUALITY OF LIFE FOR PERSONS WITH RHEUMATOID ARTHRITIS

by Jeanette Schumacher-Davis, O.T.R.

Because an exploration of the literature revealed few studies describing the patient's perspective of rheumatoid arthritis, this study employed case study methodology aimed at discovering how this disease affects the quality of the daily lives of those who live with the disease. Data were collected by in-depth interviews with six women.

The data were analyzed to reveal nine common themes. The relationship of these themes to the theoretical framework of The Model of Human Occupation was discussed.

Implications for the profession of occupational therapy were drawn from the results of this study. Two important roles identified for occupational therapists are: as educator, to both patient and family, and as an advocate for the patient to increase public awareness and understanding of the effects of rheumatoid arthritis and to dispel the myths that surround the disease.

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This study is dedicated to my mother Dixie Maxine Schumacher, who lived with rheumatoid arthritis for 34 years.

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CHAPTER 1

INTRODUCTION

Purpose

The purpose of this study was to explore the perceptions held by a sample of persons with rheumatoid arthritis regarding their quality of life and ability to function independently. This study provides insights for occupational therapy into understanding what life is like from the perspective of persons who live with rheumatoid arthritis. The insights are drawn from the subject's unique experiences of coping with and handling the disease.

Statement of the Problem

Few studies in the literature explore needs, problems, and quality of life as perceived by persons who live with disabling conditions. According to one study, little is known of the feelings, beliefs, attitudes and knowledge concerning the illness held by persons with arthritis (Edwards, Calabro, & Wied, 1964).

There is recognition of the importance of addressing psychological and functional outcomes of the disease process in addition to the

outcomes based on laboratory tests and physical examinations. Yet there is still a current need for clinicians and researchers to devote attention to the patient's beliefs, attitudes and perspectives of their illness (Bradley, 1985).

Too often assumptions are made about a client's needs without understanding the client's life and concerns. It is important for health care professionals to understand what their clients value as meaningful in their daily lives and what they perceive their needs to be in order for treatment to be efficient and effective. Studies also stress the need to go beyond function-dysfunction scales to tap variables that are not traditionally used in the definition of health (Stewart, Ware, Brook, 1977).

This study will examine the lives of a small sample of persons who have rheumatoid arthritis to seek out the aspects which they view as important to their quality of life and ability to function.

Questions

The questions to be answered in this study were the following:

- 1) What are the variables which persons with rheumatoid arthritis identify as valued for their quality of life?
- 2) What are the variables which persons with rheumatoid arthritis identify as essential to their ability to function independently?

3) Are there common variables among a sample of persons with rheumatoid arthritis?

4) What is the perception of persons with rheumatoid arthritis of the role of occupational therapy intervention to influence quality of life and ability to function independently?

Definitions

Adjustment to disability: Defined by some disabled persons as "learning how to live with it," "making the most of what you have," and "trying to lead as normal a life as possible" (Athelstan, 1981).

Anger: A reaction to disability which may be described as hostility, hate, resentment, rage, or fury. A response to feelings of helplessness, misperception, a fear of losing control, anxiety, and/or the threat of abandonment (Versluys, 1983).

Arthritis personality: A distinct personality pattern supported by literature in the 1950's and 1960's but refuted in the 1970's and 1980's, that is characterized by repressed hostility and self-punishment (Spergel, Ehrich, & Glass, 1978).

Body image: The subjective image or picture that an individual has of his/her physical appearance based on their personal observations and the reactions of others (Thomas, 1981).

Cultural influence: Attitudes and values acquired from childhood that influence the way an individual looks at health, disability, and acceptance of disability.

Denial: Refusal to admit the reality of, or to acknowledge the presence or existence of something. A defense mechanism.

Depression: A response to disability and functional loss, also a response to loss of self-esteem and perceived helplessness (Versluys, 1983).

Disabling conditions: A condition that results when a person cannot perform a set of functions, either desired or required, in a specific environment (Stolov, 1981).

Functional independence: The ability of an individual to independently perform basic skills of activities of daily living such as eating, dressing, hygiene and grooming, functional mobility with or without assistive devices, and including more advanced skills such as the development of leisure and work related skills and interests.

Occupational therapy intervention: The services rendered by a registered occupational therapist for the treatment of rheumatoid arthritis for a minimum of five visits.

Persons with rheumatoid arthritis: Persons who have been diagnosed with rheumatoid arthritis by a rheumatologist as either possible, probable, definite, or classic.

Quality of life: The state/condition of an individual's life, partly measured by how satisfied each subject is with his/her life on self-report.

Rheumatoid arthritis: A classification of arthritis where the membrane lining the joint becomes inflamed. The disease is further characterized by symptoms such as morning stiffness, pain and swelling in one or more joints, muscle aches, and fatigue.

Self-worth: The regard for one's self and one's life as meaningful, worthy and productive.

Assumptions

Several assumptions have been made for this study. They are described as follows:

- 1) The individuals to be interviewed will be candid and honest about their life experiences and how rheumatoid arthritis has impacted their lives.
- 2) The population to be studied will have an accurate and sufficient memory of their past experiences and will be able to relate these experiences and feelings in a meaningful way.
- 3) The research population will be truthful and open about their feelings regarding their experience with occupational therapy services.

Limitations

The limitations for this study have been identified as follows:

1) The research findings cannot be generalized to similar populations of diagnoses, age, or background. This descriptive study will cover a small sample of individuals with rheumatoid arthritis and additional studies will be needed to further substantiate or refute the findings.

2) The results of this study could be affected by researcher bias and interpretation of the data collected from open ended questions. Every effort will be made to control researcher bias through objectivity and logical reasoning thus keeping the contamination of the findings to a minimum.

Significance of the Study

According to the Arthritis Foundation (1986), about one percent of the adult population has rheumatoid arthritis, which is about two-and-a-half million people. RA can limit a person's ability to carry out activities of daily living through increased pain, loss of function, and physical deformities. In addition, RA can affect an individual's psychological make-up often leaving a sufferer feeling anxious, frightened, vulnerable, and depressed.

A review of the literature indicates that there exists a need to further explore patient's beliefs, attitudes, and perspectives of their illness (Bradley, 1985). One study found that there was a discrepancy between the patient's image of him or herself and the image held by the physician (Edwards, Calabro, & Wied, 1964).

This descriptive study will explore the perceptions held by a small sample of persons with rheumatoid arthritis regarding their quality of life and ability to function independently in an attempt to gain further insight and understanding of life from the perspective of the persons who live with RA.

CHAPTER 2

REVIEW OF THE LITERATURE

The literature review is divided into five areas of focus. The first area will discuss the impact of rheumatoid arthritis, and the different spheres of a person's life that can be affected. Next, the theoretical framework and philosophical base for this study will be explored with its relation to the field of occupational therapy along with the roles and functions of occupational therapy in the management of rheumatic disease.

The third area will review studies of measurements of functional ability in clinical practice and the impact of loss of function associated with the disease. The following area will comprise the bulk of the literature review by discussing studies that focus on the psychosocial and emotional issues associated with rheumatoid arthritis and the so-called "RA personality."

Finally, the few but extremely important articles that discuss attitudes and knowledge from the perspective of the persons with rheumatoid arthritis will be examined.

The Impact of Rheumatoid Arthritis

Rheumatoid arthritis (RA) is a chronic, systemic inflammatory disease that leads to destruction of synovial joints and may involve every system of the body including the lungs, the cardiovascular system, and even the eyes (Porter, 1984). The destruction of the joints, however, is the most common clinical feature. The disease can range from mild to severe and is characterized by periods of exacerbations and remissions. Progression of the disease is usually slow and insidious but it can also have a rapid onset. RA usually involves the bilateral, symmetrical small joints of the hands and feet. These joints are often red, tender, inflamed, painful and stiff. Edema, pain, and joint destruction can significantly limit joint range of motion (Pedretti, 1985). There is no known cause of the disease but there seems to be an unknown immune reaction in synovial tissue that causes inflammation of the synovium, weakening of the capsule, tendons, and ligaments, and destruction of the cartilage and bone. Genetic factors may be attributed to the onset of the disease (Melvin, 1982).

According to the Arthritis Foundation (1986), about one percent of the adult population has rheumatoid arthritis, which equals about two-and-a-half million people in the United States. About three-fourths of these people are women. According to Thompson (1988), RA can limit a person's ability to carry out daily activities depending upon the individual's physical and psychological makeup, and the environment and

society in which he or she lives. Thompson found that two-thirds of patients are concerned more with loss of function than with discomfort. Similarly, another study also found that the main problem for the individual was not the pain, but the frustration of being unable to do the things they did previously and of dependency on others (Cornelissen, Kasker, & Valkenburg, 1988).

The possibilities of increased pain, loss of function, and physical deformities can be extremely frightening at any point in the disease process. The unpredictability of the course of the disease can leave individuals feeling anxious, vulnerable, and depressed. All systems of a patient's life are threatened (Zeitlin, 1977).

Review of the literature indicates that RA affects many spheres of an individual's life including physical, psychological, social, and emotional as well as the roles the individual may assume, such as family member and worker and the ability to function within these roles. Larger systems such as family and society are also impacted by the disease. In a study focusing on the approach to psychological care of adults with rheumatoid arthritis, monitoring the impact on the family was an important dimension in managing the disease (Rogers, Liang, & Partridge, 1982). Costs of the disease are borne not only by individuals with arthritis but by family members and by society as a whole. Stone (1984) found that the lifetime costs of RA are not very different from those for stroke and coronary heart disease. Zeitlin (1977) asserts it is important to consider the family, occupational,

intrapsychic, interpersonal and health care systems and to understand the system's dynamic interactions and complexities in treatment planning for the patient with rheumatoid arthritis.

Theoretical Framework

The Model of Human Occupation describes the human being as an open system. According to Kielhofner (1985):

The purpose of open systems thought is to explicate those characteristics and processes that characterize living phenomena. Thus, openness in a system implies exchange of information and/or matter with the environment and the actualization of potentials. (p. 2).

This model as a theoretical framework for this study was chosen for its characteristics, including descriptions of interaction with the environment, the complexity of human beings and their interactions, looking at the whole of a human being interacting with the environment as ever changing and growing, and integrating not just the physical, but the social and psychological as well (Kielhofner, 1985). It includes spheres close to an individual such as objects and tasks and moves outward extending to social groups, organizations and culture. As stated earlier, RA can affect all spheres and domains of an individual's life and encompasses the larger systems of society and culture. The model of Human Occupation describes the human system as being composed

of three major subsystems. The lowest of the three, the performance subsystem, produces occupational behavior through skills and abilities to perform purposeful behavior and complex interaction with the environment as evident through work, play and self-care. The next subsystem, habituation, organizes behaviors into patterns and routines. The highest level, the volition subsystem, governs the others and is involved in choosing and initiating occupational behavior. Occupational behavior involves the motivation to explore and master the environment with the potential for enjoyment through experience (Kielhofner, 1985).

The Model of Human Occupation is useful and applicable to describe the impact of chronic progressive diseases such as rheumatoid arthritis on the human system. The performance subsystem is affected by joint pain, inflammation, muscle weakness and progressive joint destruction and disrupts the skilled performance of work, play, and self-care. Cognitive, emotional, and personality reactions may result from drug side effects and the unpredictability of the disease.

The habituation subsystem consists of habits and roles. Habits may be disrupted by the exacerbations and remissions of the disease forcing an individual to become more flexible and adapt new habits to cope with changes. Roles such as worker, caregiver, or homemaker may be interrupted or altered due to increased needs for rest, attention to joint protection techniques and medical regimens. These changes and alterations can cause conflicts with family members, co-workers, and friends adding further stress to the situation.

The effects of chronic progressive diseases can be devastating to the volitional subsystem. Reduced ability to perform activities can produce feelings of loss of control over the environment. In addition, hopeful expectations for the future may diminish and be replaced by discouragement and loss of motivation.

Kielhofner (1985) states:

...the disease process may interfere with their own standards of performance, making it necessary to compromise them and sometimes experiencing loss of self-esteem as they are unable to meet their own standards. (p. 176).

He also adds that because of a person's inability to perform at their own standards, there may be a loss in the meaning of an activity (Kielhofner, 1985).

Purposeful activity is the foundation for the practice of occupational therapy. The following statement was adopted in 1979 as the philosophical base for occupational therapy.

Occupational therapy is based on the belief that purposeful activity (occupation), including its interpersonal and environmental components, may be used to prevent and mediate dysfunction, and to elicit maximum adaptation. Activity as used by occupational therapy personnel includes both an intrinsic and a therapeutic purpose (AOTA, 1979. p. 785).

This statement describes the role of occupational therapists as helping patients adapt to their environment successfully. The chronic

nature of rheumatic diseases calls for ongoing assessment and treatment as the disease fluctuates, and as modifications are needed in daily life tasks.

Occupational therapists are trained to analyze activities and help patients to find alternate ways of performing these activities. In the treatment of rheumatic disease, management techniques such as energy conservation, joint protection, stress reduction, therapeutic exercise, and orthotics and splints are commonly used. In addition, therapists address the psychological and social aspects of their patients in treatment planning and implementation (AHPA Task Force, 1986).

Yet for treatment to be truly effective it is imperative that health care workers understand what their patients are going through and how their disease impacts the psychological, social and emotional areas of their life from their perspective. There exists a need for further descriptive research of patient's perspectives regarding their disease (Edwards, Calabro, & Wied, 1964; Bradley, 1985).

Functional Limitations in Activities of Daily Living

Functional limitations in activities of daily living (ADL) are often a result of rheumatoid arthritis. A good deal of research has been conducted on the development and testing of various measurements of functional disability. Many of these measures were developed in the

1970's and consist mainly of questionnaires that evaluate difficulties in ADL such as dressing, self-care, and ambulation (Bradley, 1985).

The Sickness Impact Profile (SIP) measures several categories of physical function. The Arthritis Impact Measurement Scales (AIMS) and the Health Assessment Questionnaire (HAQ) also measures pain in addition to physical disability. These scales include social functions as they relate to changes in mobility, pain, and ADL. These measures are limited due to the closed ended choices the patient is given in answering each question.

Rheumatologists, psychologists, and other health care professionals are beginning to recognize the need to understand patient's perceptions regarding their illness in addition to clinically measuring functional disability (Rogers, Liang, & Partridge, 1982). However, measurement scales that are currently used are quantitative in nature and may limit a patient by not allowing full expression in his or her own words and the exploration of the breadth and depth of problems and concerns of living with rheumatic disease and associated functional limitations.

The HAQ has been modified to include an assessment of patients' perceptions of recent changes in disability status and satisfaction regarding current functional ability (Bradley, 1985). The responses, however, are predetermined choices set by the developer of the measurement tool.

The McMaster Health Index Questionnaire is used as a measure of quality of life for patients with rheumatoid disease. The mode of

administration includes self-completion, telephone interviews and face-to-face interviews but the response categories are on a Likert-type scale (i.e. yes, no, agree, strongly agree) (Chambers, MacDonald, Tugwell, Buchanan, & Kraag, 1982).

Psychological Factors Associated With Rheumatoid Arthritis

Early psychological studies of rheumatoid arthritis relied mainly on data from clinical interviews, therapy settings and projective measures of assessment such as the Rorschach inkblot test (Klopfer and Davidson, 1960). These studies proposed that certain "personality profiles" existed for various psychosomatic disorders.

Moos, Solomon, & Lieberman (1965) described the "arthritis personality" from objective and quantifiable self-report personality inventories. They described the characteristics associated with rheumatoid arthritis as follows:

Arthritic patients appear to be more compliant, subservient, conservative, sensitive to anger, perfectionistic, and self-sacrificing. They appear to react to their disease with fear and depression. However, they attempt to cope with these feelings by struggling for independence, keeping on the move, not expressing anger, being compliant and being stoic and optimistic about their illness. (p. 155)

The 1950's and 1960's literature supported this "rheumatoid arthritic personality" and presented the idea that patients with RA shared a distinct personality pattern in which individuals repressed hostility which produced a rage against their body.

There has been critical review of this evidence and questioning of the basic design and methodology of these studies. Arguments refuting these studies point out that researchers could not demonstrate whether similar emotional factors are found in other disability groups or if psychological characteristics identified are specific to rheumatic disease (Shontz, 1971; Wolff, 1971). These experiments have either not used comparison populations or have used suspicious comparison populations (Spergel, Ehrlich, & Glass, 1978; Rogers, Liang, & Partridge, 1982). They argue that the arthritic patient does display many neurotic traits but that these traits are not exclusive to persons with rheumatoid arthritis but to persons with other physical conditions as well, giving evidence to a "chronic disease personality." They have found that some common psychological problems that occur in patients with chronic diseases include a fear of becoming disabled and dependent, uncertainty about the progression of the disease, possible alteration of body image, devaluation of self, and the inability to cope with feelings of frustration and depression associated with continued disease (Rogers, Liang, & Partridge, 1982).

Zaphiropoulos & Burry (1974) suggest that any person who suffers from a chronically painful and disabling condition is likely to exhibit

similar psychological reactions. Other chronic conditions such as multiple sclerosis can bring about similar emotional and psychological reactions due to the uncertainty of the future and exacerbations and remissions of the disease.

Meyerowitz (1966) described three hypotheses of rheumatic disease. These hypotheses are:

1. A **specificity hypothesis**, which assumes that identifiable psychological characteristics have been present prior to the appearance of the disease,
2. A **disease-onset hypothesis**, which implies that there is a significant association between certain types of life experiences and/or psychological states and the onset of rheumatoid disease, and
3. A **disease-course hypothesis**, which suggests that identifiable psychological responses observed in persons with rheumatoid arthritis have an influence on the course of illness (Meyerowitz, 1966).

Later studies have concluded that there is no convincing evidence for a premorbid personality (Hoffman, 1974; Zeitlin, 1977). Characteristics such as over-reaction to illness, self-sacrifice, rigidity, inhibition, dealing with hostility and aggression are more likely responses to the disease itself. This is more consistent with the third hypothesis rather than the first two. Zeitlin points out that the weight of research suggests a multicausal hypothesis in which genetic, autoimmune, infectious, and psychosocial factors form a "predisposition matrix" (Zeitlin, 1977).

Udelman and Udelman (1981) found two important concepts in their work with rheumatologic patients in both clinical research and psychotherapy. The first is self-concept, which concerns the way a patient views himself or herself as a total person. This may involve role, status, goals and value systems. The second is body-image, which relates to observable physical and physiological modifications that are products of illness (Udelman & Udelman, 1981). Thus patients face both loss of function and diminished physical attractiveness.

Culture has an important impact upon personal worth and self-concept. Geis (1972) states that the emphasis of the American culture is on physical attractiveness and productivity and that feelings of self worth and self esteem tend to be all-or-none in nature. The therapeutic goal according to Geis, is to change one's self-definition. He says that an individual must be able to believe that he or she is worthwhile and valuable without fulfilling any criteria (Geis, 1972).

Patient's Perspectives of Rheumatoid Arthritis

There are few current studies in the literature that explore the daily experiences, difficulties and feelings of well-being associated with living with rheumatoid arthritis from the perspective of the patient. Few studies have used qualitative open-ended questions to gather data.

One article depicted qualitative aspects of rheumatic disease (Liang et al., 1984). Twenty-three ambulatory patients were interviewed and given standard psychological tests including the Minnesota Multiphasic Personality Inventory (MMPI). These patients reported that decreased independence, function, and social interactions were seen as the "biggest problems" caused by their disease. Patients also noted that they had "lowered spirits" for substantial periods of time. What was interesting to note was that approximately 50% of the group said that their illness had a positive effect on their spirits and this was described as "being thankful for what I've got." Patients with RA described their biggest fear and worry as physical disability. Stress was one of the main reasons given for contributing to the onset of the disease. Aspects that patients described as helping them cope with the disease were having a good attitude, rest, keeping busy, and medications. Most of the patients were content with their personal relationships and felt that family and friends understood their illness. A common problem reported was the inner conflict about whether to acknowledge symptoms to others and accept the sick role or to conceal the symptoms and try to appear normal. The major changes that were reported in family situations were increased arguments and sexual problems with their spouse (Liang et al, 1984).

An interesting study on the subjective well-being and life satisfaction of older Americans used open-ended interviews to gather part of the data. This 30-year study, not specific to the arthritis

population but to older Americans in general, revealed that well-being was strongly related to health, followed by socioeconomic factors and degree of social interaction. Marital status and type of living situation were also related to well-being. This study pointed out that survey measures used to determine well-being do not reveal deep psychological factors and give little information on ongoing daily experience. Where in-depth interviews were used to establish day-to-day morale, a high correlation was found with socioeconomic status to assess life satisfaction (Larson, 1978).

The importance of socioeconomic status is further confirmed by a study that compared 50 rheumatoid arthritis patients and a control of 72 non-patients. Patients with higher socioeconomic status were favored in self-esteem, family relations, and work satisfaction. There also appeared to be a significant positive relationship between social adjustment and degree of independence in ADL (Earle et al., 1979).

Rogers, Liang and Partridge (1982) found additional factors that influenced individuals coping with RA were quality of relationships, capacity to receive and ask for help, and ability to control the immediate environment at home or at work.

A patient-oriented survey of chronic disease costs of rheumatoid arthritis found that 76% of workers (38 wage earners and 12 housewives) had undergone major changes in employment status because of the disease and that indirect costs due to lost income and time were at least three times the direct medical costs associated with the disease. This survey

also asked subjects if they had experienced any of the following five specific psychosocial changes: marital disruption; changes in family structure; changes in family employment; changes in place of residence; and major psychiatric problems. Positive responses were recorded in each area and patient's attributed these changes to the effects of the disease (Meenan, Yelin, Henke, Curtis, & Epstein, 1978).

One of the most significant articles found in the literature explored the attitudes and knowledge of patients with arthritis. A 27-item questionnaire was administered to 100 patients with arthritis and compared with information given by their physicians. The belief whether or not their arthritis was curable was correlated with age of the patients. A larger percentage of patients under 45 years of age hoped to be cured. One fourth of the patients surveyed differed with their physicians when asked whether their disease was active or inactive. The major causes of arthritis as described by the patients were nerves, dampness, injury, infection, hard work, and climate and these were related to unpleasant circumstances such as a financial crisis, loss of a family member, illness, an operation, working in a damp environment, and moving. There was a discrepancy between the patients and physicians on therapy that was prescribed and therapy that was followed. There were also differences in symptoms that were both quantitative and qualitative that suggests the patient's image of himself and the image held by the physician were different. There was an expressed need from patients with arthritis to learn more about their disease. The

conclusion of the findings stated that there is a need for physicians to pay greater attention to the questions, doubts, and fears of their patients to improve adherence to therapy and to better understand what their patients are going through (Edwards, Calabro, Wied, 1964).

Summary

In summary, this review of the literature has described studies which investigate the impact of rheumatoid arthritis, functional limitations in activities of daily living, and psychological factors associated with the disease process. The closing section of the literature explored the few yet pertinent studies describing patient's perspectives of rheumatoid arthritis. The theoretical framework used in this study, The Model of Human Occupation, was described.

CHAPTER 3

DESIGN AND METHODOLOGY

Purpose

The purpose of this study was to explore the perceptions held by a sample of persons with rheumatoid arthritis regarding their quality of life and ability to function independently. This study has attempted to give insights into understanding what life is like from the perspective of persons who live with rheumatoid arthritis and to draw insights from their unique experiences of coping with and handling the disease.

Questions

The questions to be answered in this study were the following:

- 1) What are the variables which persons with rheumatoid arthritis identify as valued for their quality of life?
- 2) What are the variables which persons with rheumatoid arthritis identify as essential to their ability to function independently?
- 3) Are there common variables among a sample of persons with rheumatoid arthritis?

4) What is the perception of persons with rheumatoid arthritis of the role of occupational therapy intervention to influence quality of life and ability to function independently?

Sample

The research sample consisted of 6 women, between the ages of twenty-seven and eighty, who have been diagnosed with rheumatoid arthritis by a physician. Because this study is also aimed at discovering the subjects' information and opinion regarding occupational therapy services, each subject has been seen by a registered occupational therapist for a minimum of five visits for the treatment of rheumatoid arthritis prior to the initiation of the interviews.

Four of the six subjects whom were selected for this study were found through contacts with San Jose Medical Center. The fifth subject was selected through contact with Palo Alto Physical Therapy and Sports Injury Center. The sixth subject was chosen through a personal contact of the researcher.

Procedure and Instrument

This was a descriptive study employing case study methodology. The aim of this study was to provide an in-depth examination of a few

individuals to describe characteristics and identify and discuss possible relationships among variables.

Each participant was asked to sign a consent form (Appendix A) that permitted the researcher to send a letter to the participant's doctor to confirm the diagnosis of rheumatoid arthritis, (Appendices B and C) and a letter to the occupational therapist who treated the participant to confirm the number of visits and type of treatment rendered (Appendices D and E).

The data were collected by in-depth interviews. The instrument for collecting data consisted of an interview guideline of open-ended general questions designed by the researcher (see Appendix F). The thesis advisor, readers, and occupational therapists who treat patients with rheumatoid arthritis gave input into designing the interview guideline. During the interviews, the researcher encouraged the participant's to answer each question freely, allowing as much time as the participant wished to express her thoughts and feelings.

The average length of total interview time for each participant was 4 hours and 20 minutes, with the shortest total interview lasting 2 hours 25 minutes, and the longest lasting 5 hours 25 minutes. Each interview was spread over 3 to 5 visits to best accommodate the schedules of the subject and researcher. Five of the interviews took place at the participants' homes with the exception of one participant who chose to meet at the researcher's home. All interviews were recorded on tape and were transcribed to written form. Each tape and

transcript was identified by code to ensure confidentiality of the participants.

Procedure for Data Analysis

Data were synthesized by the researcher by reading transcriptions and listening to tape recordings several times. Comments and ideas made by the participants that pertained to the research questions were written on index cards by the researcher. One hundred and twelve cards were collected and organized according to common themes that emerged. Several direct quotes from the participants have been included in this study to support evidence of the themes that recurred throughout the interviews.

CHAPTER 4

DATA

The data were collected through in-depth interviews at the homes of the participants with the exception of one participant who chose to meet at the researcher's home. The interviews took place between June 5 and July 24, 1990. There were a total of 13 interview sessions, the longest session lasting one hour and 43 minutes and the shortest session lasting 36 minutes. The number of interview sessions ranged from one to four, the average number of sessions was 2.6. The average length of total interview time for each participant was 4 hours and 20 minutes, with the longest lasting 5 hours and 25 minutes and the shortest total interview time lasting 2 hours and 25 minutes.

The Instrument

The interview guideline was divided into seven sections including disease process, medical intervention, family life/home environment, relationships, functional activities, occupational therapy intervention, and quality of life. (See Appendix F).

Participants

The six participants who participated in this study were women who have been diagnosed with rheumatoid arthritis by their doctor and who have been seen by a registered occupational therapist for at least five visits for the treatment of rheumatoid arthritis. Five of these women are Caucasian, one is Japanese. The participants ranged in age from 27 years to 80 years. The average age of onset was 41.5 years. The minimum number of years of living with the disease was 12 years, the maximum was 28 years, with the average at 18 years. Four of the women were married, one divorced, and one was single. Standards of living ranged from middle to upper middle income.

All six participants were able to share meaningful experiences of what it is like to live with rheumatoid arthritis, although some chose to expand and elaborate about their lives more than others. All participant's live in the community either alone or with family or friends.

Participant number one is 64 years old. She was diagnosed with the disease 18 years ago when she was 46 years old. She lives alone in Magalia, California with her two dogs in a two story home but only uses the first floor because of difficulty climbing stairs. She is retired and has been widowed a number of years. Although she has no children, she helped raise her niece and described her as "like a daughter." Much of her free time is spent with friends and family as well as

traveling in her motor home. For the most part she leads a functionally independent life except on days when her symptoms are exacerbated or after surgery. She then depends on her niece or neighbor for assistance.

The participant's rheumatoid arthritis affects most joints in her body especially both knees, wrists, hands, and feet. She has undergone seven surgeries, including bilateral hand metacarpal phalangeal (MP) arthroplasty (her right hand operated on twice), open left knee surgery for cartilage removal, left knee and foot arthroscopy, and left foot bunionectomy. She anticipates a right foot bunionectomy within the next year. She has difficulty bending, stooping, climbing stairs and walking for distances longer than 1/4 mile. She also has limited function in both hands making it difficult to accomplish activities that require fine motor control and strength. She is currently able to drive a car and a motor home and is able to accomplish light household chores and self-care activities. She does not have any outside assistance other than family and friends.

Participant two is 69 years old and was diagnosed 17 years ago at the age of 52. She lives with her husband, who is retired, in San Jose, California in a three-bedroom single story home. The couple spends most of their time in and around their house, visiting neighbors and tending their garden. They enjoy spending time with their two children and three grandchildren who live close by. At the time of the interview, the participant was independent in self-care activities such as bathing

and dressing and was able to carry out light household activities. She relies on her husband for transportation, meal preparation, and most household chores. A woman comes in twice a month for heavy household cleaning.

Arthritis for this participant involves most of the bilateral joints in her body including her neck and jaw. She does not have back involvement. Early in the course of the disease, she was afflicted with severe coughing, which lasted 5-6 weeks along with bilateral lung problems which have been attributed to the arthritis. She has had two surgeries on the right wrist. She underwent a tendon transfer in 1988 and a tendon repair from a bone spur in 1990. According to the participant, both surgeries have increased hand movement and function. The specific joints that are currently most affected are those in her wrists, hands, elbows, ankles and feet. She has difficulty with fine motor activities like knitting, crocheting and writing. She describes her ambulation as limited to 1/2 mile and has problems descending stairs.

The third participant is 72 years old. She has had the disease for 28 years since age 44. She lives with her husband in a three-bedroom single story home in San Jose. Both are retired and the participant described their life as quiet with the exception of occasional visits with their two sons and grandchildren. They spend most of their time at home. The participant is independent in self-care activities but occasionally requires assistance from her husband when symptoms in her

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right shoulder increase. She takes responsibility for most household chores except yard work. Her husband has multiple health problems including osteoarthritis in his spine.

This participant's arthritis affects both hands and wrists, shoulders, hips, knees, ankles, feet, and neck. Presently, her left hand and right shoulder are exacerbated. In 1990 she had MP joint arthroplasty in her right hand which increased the function in that hand significantly. The participant would like to have the same surgery on her left hand in the near future. She is able to drive a car but has difficulty turning the keys. She does not use an adaptive key device and was unaware that one existed. She describes her mobility as limited to about three blocks. She has problems descending stairs, stooping, and reaching with her right arm. She also has problems using her hands for activities such as knitting.

Participant number four is 45 years old. She has had rheumatoid arthritis for 13 years since age 32. She lives with her husband and two of their four teenage children in a single story home in Morgan Hill, California. She describes her life as very active and family-oriented. They are involved in church and school activities, along with traveling to sporting events in which the children are involved. She characterizes her household as busy with friends and neighbors visiting frequently. Most often she is independent with self-care activities except after surgery when she relies on her family for assistance.

The participant's arthritis is quite severe involving most bilateral joints including the neck, jaw and soft tissue. She has undergone a total of 24 surgeries including numerous synovectomies in the knees, hands, wrists, and jaw in an attempt to prevent joint destruction and to delay joint replacement because of her young age. Her first joint replacement was in 1985, on the right knee. Since then she has had seven hand surgeries for MP arthroplasty, fusions and tendon repairs. She has had joint replacements in both knees, the right hip, right shoulder and right wrist. Secondary complications include cataracts and glaucoma in both eyes which have been corrected by surgery. On two occasions she has gone into adrenalin insufficiency, a life-threatening condition, from a lack of cortisone in the body.

Despite the severity of her disease, the participant completes selected household activities such as the family laundry, cooking, grocery shopping, and light household cleaning chores. She is currently able to drive a car and her walking is limited to 1/4 mile. Descending stairs, stooping, and bending are difficult and on some days impossible. Her teenage children contribute to the cooking, yard work and household chores. Her husband works full time and helps with yard work and cooking. They employ a woman twice monthly for heavy household cleaning tasks.

The fifth participant is 80 years old and has had the disease for 20 years since age 60. She lives with her husband in a single story two-bedroom home in San Jose. She portrays her life with her husband as

calm and routine. She spends the majority of her time in her home, rarely going outside. She prefers to wear a simple buttoned dress at home because of the ease of donning and removing. She is independent with personal hygiene and eating. A female attendant comes in three times a week to assist with her seated showers and to care for her hair.

This participant's arthritis affects her feet, knees, lower back and tailbone, shoulders, elbows, hands, and neck. She had one surgery 18 years ago for the removal of a nodule on the right hand. She reports that since this surgery she has not had pain in that area. Although the participant presented with severe bilateral hand deformities and functional hand limitations, she has not undergone surgery for these problems. The participant describes difficulties with tasks such as writing, turning the stove dial, and opening packages. She attributes lungs problems and shortness of breath to the arthritis. Her mobility is limited to about 50 feet and she prefers to remain at home but will occasionally visit her daughter and two grandchildren. Her husband completes the shopping, cooking, and most household activities. They have cleaning assistance twice a week.

Participant number six is 27 years old and has had rheumatoid arthritis for 12 years since age 15. During the time of the interview she had just returned from a six month teaching assignment in Guatemala. Her plans are to move back to her home state, Colorado, find a female roommate and return to school. Participant six describes her life as full and challenging. She has been employed as a school teacher for the

past three years but anticipates having to change careers because of the difficulty keeping up with the physical demands that teaching imposes. She has lived with various female roommates whom she describes as compassionate and helpful. She is independent with all self-care activities except at the time of surgeries when she has relied on family and roommates.

The participant's arthritis affects her right shoulder, both hips, knees, feet, elbows, wrists, hands, jaw and neck. She has had a right total hip replacement and a synovectomy and shaving of the carpal bones in the right wrist. She anticipates a total right shoulder replacement but reports that she is waiting for improvements in shoulder prostheses. In her past living situations, the participant has taken responsibility for grocery shopping, some meal preparation, and light household chores. Her roommates have taken care of heavier household tasks. Her walking is limited to about three blocks. Climbing stairs, bending, and reaching with her right arm are extremely difficult. She drives a car and uses an adapted key ring. Writing can be a problem, depending on the day, and she has found this to be a major obstacle in her teaching responsibilities.

Results

Disease Process

Participants described the disease, the diagnosis, and their initial reactions. They also related the level of pain within which they usually function along with how loss of function has affected their lives. Finally, the participants were queried regarding the factors which they think may have contributed to the diagnosis of arthritis and if they feel there is hope for a cure for the disease.

Beginning of Disease Process

Ages for the initial onset of symptoms varied from ages 15 to 60. Four of the six participants described the onset of the disease process as fairly rapid. One woman, whose onset began at age 52, described symptoms alternating from one hand to another beginning in the month of March. By May she described the arthritis as being in almost every joint in the body. At this time she went to her family doctor who ran a series of blood tests and diagnosed the RA two weeks later. A second participant described her symptoms as occurring quickly in a matter of a few days when she was 46. She was painting her house and discovered that she was unable to get up from a kneeling position. A neighbor took her to her family doctor. She said when he saw her knees he told her, "you've got rheumatoid arthritis," leaving her in shock and disbelief.

She recounts a number of blood tests and in a few days the confirmation of RA was made.

Another participant said her first symptoms began in January when she was 32, gradually getting worse until April. She described her problems as becoming progressively worse, with loss of control over her everyday tasks occurring. At the time she was working part-time and had three children between the ages of three and seven. She remembers that the arthritis affected her hands early on, specifically her ability to comb her daughter's hair.

Her initial tests were negative yet her doctor sent her to a rheumatologist at Northwestern University in Illinois. She recalled receiving a battery of x-rays and laboratory tests and being diagnosed with RA. She described a short period of remission lasting about two and a half weeks but by September of that year she was hospitalized and her condition became increasingly worse and responded very little to the medications. Over the course of the next 13 years she would undergo 24 surgeries for rheumatoid arthritis. A fourth respondent also described a rapid onset, in the course of a few months, with symptoms becoming increasingly worse throughout her body.

The remaining two participants recounted gradual onset over a period of years. One woman was able to continue a job as a nursing assistant for seven years after diagnosis until she began to develop symptoms in her hands which made it difficult to perform such tasks as wringing out a washcloth. Participant number six who began to develop symptoms at

age 15, described a gradual onset over a three year period. Active in sports at school, she repeatedly dislocated her right shoulder and had increasing pain and stiffness in that joint. Initially, she attributed it to overuse and a possible sports injury. After the initial three year period, her symptoms would appear suddenly requiring her to remain in bed for many days because the pain and fatigue were severe throughout most of her body. Soon thereafter she was diagnosed with RA.

Three of the women said they were not prone to go to doctors and tended to avoid seeking health care whenever possible. One woman remembers trying to endure the symptoms and not pay too much attention to them, hoping they would just go away. After nine months, she finally conceded and went to see a doctor. Another participant said she finally went to see a doctor when she reached the point of requiring two hours to get dressed.

All six of the participants said they were initially shocked by a diagnosis of rheumatoid arthritis and had no idea how their lives would be impacted. One woman expressed gratitude regarding the rheumatologist's handling of giving her the news. He sat down with her and her family and explained how their lives would be altered, anticipating knee surgery within five years. She recounts that initially she was angry and did not believe him. Looking back she stated that he was one of the few doctors who was frank and honest with her, and said this eventually helped her to accept and cope with her situation. Two women said they were not aware of rheumatoid arthritis

at the time of the diagnosis and were given very little information about their disease and how it might influence their lives. They expressed feelings of intimidation and fear of asking questions of medical personnel.

The two participants with the youngest onset, ages 15 and 32, expressed a feeling of isolation because of their inability to find other persons of the same ages with the disease that they could relate to. Both recalled that early on in the disease process they felt a strong state of denial and determination to "beat the disease." One of these participants remembers being referred to a large rehabilitation center that included a class entitled, "Learning how to live with rheumatoid arthritis." She reports that one of the most difficult things for her was being younger than anyone else in the class by about 30 years. She recounts saying, "I'm too young to have the disease, I know I won't have it more than a few months. I'm not like anyone in this class anyway." In thirteen years of living with the disease, she has known of few persons her age with RA. The other participant, now 27, cherishes a close friendship established later in her disease process. She describes this person as special because he not only had rheumatoid arthritis but also shared her young age. She also said that she has met few persons her age with RA.

Description of Symptoms

The description of symptoms was very similar in all six cases. All participants reported varying degrees of continuous pain. Only on rare

occasions could any one of the participants say they were pain free. Joint symptoms were described as sharp, achy, stiff, swollen, and hot. Two of the women have had symptoms in their jaw, making mastication and jaw opening difficult. One woman related being able only to place a straw through her lips because opening her jaw was so painful. She also reported difficulty swallowing because a joint involving swallowing was inflamed. One participant described the pain as "like a wave starting in my shoulder and moving down my arm." Another described the pain "like a toothache, like something had attacked the nerves. My shoulder feels like a bundle of nerves that are on fire and shoot up my neck. At times it hits so hard and so sharp, it's like needles." Three described hip pain as the worst, seeming to encompass the whole trunk and being the most excruciating.

Fatigue was mentioned by all participants as a major symptom affecting their lives. One woman stated she had never realized how fatiguing pain could be. Some described fatigue as a sort of malaise, flu-like feeling, where there is little energy to do even simple tasks and an overwhelming need for rest. Participant's described fatigue as a major intrusion of their lives primarily because they were unable to predict the exhaustion and could not plan ahead. One woman said her daughter called to tell about a birthday party for her grandson in the coming weeks. She said she could not let her know if she could attend until the last minute. She said, "I just don't think she understands how quickly I can go downhill." Another participant said that usually

after a shower she is "wiped out" and must rest 1-2 hours until she is able to function again. She said, "some days just the physical act of getting dressed or taking a shower can leave you exhausted."

A common pattern described by five women was symptoms beginning in a joint on one side of the body and consequently moving to the same joint on the opposite side in a matter of days or weeks. A strikingly similar experience held by five women was the increase in symptoms with a change in barometric pressure. As one woman explained, "it doesn't seem to be a certain type of weather that bothers me, like cold or heat, but a change in the pressure itself." Most commented that they could always feel a storm coming on or a change in the weather pattern.

The participant's were questioned about what they did to relieve their symptoms. The responses were varied. Four women named rest as the activity in which they were most often engaged when their symptoms are escalated. One participant shared her doctor's explanation of rest.

My doctor told me that when he meant rest he didn't mean reading a book or watching TV but instead he meant flat on my back in total relaxation. He said I needed about 10 minutes an hour of this total relaxation, but in this day and age that's hard to do, life is just so busy to try to slow down like that.

Later she commented that through the years of living with the disease, she has had to learn to take time for rest every day to be able to function most optimally. Taking medications was another important factor in relieving symptoms for the participants. Warm showers or

baths, light massage and reduction of stress were included. Two women said they routinely wear night resting hand splints and one occasionally wears a small plate in her mouth when her jaw is inflamed that was fabricated by her dentist. Two participants commented that focusing their faith on God was an important part of alleviating symptoms. As one woman explained,

If I begin to focus on myself I get worse and feel depressed. I look at the hope and look at my faith and know that there is more to life than this body.

Two participants reported that the pain routinely affected their sleep and their activity the following day. The remaining four participants reported some sleep disturbance ranging from one to three nights a week. Many commented that it was beneficial to get up at least once or twice a night to prevent increased morning stiffness. All six participants reported an increased need for sleep since the onset of the disease, an average increase of about 2-3 hours a night along with routine naps during the day.

The participants were asked to rate the level of pain with which they usually function on a scale of 1-10 with "10" requiring bedrest. Five responded with "7", and one with "9." All commented that their pain limited them but to varying degrees. Two reported that pain at "7" required rest and keeping activities to a minimum, usually seated activities. They reported relying on their spouses or significant others to complete necessary tasks. Three women said they felt that

they needed to rest with pain at "7" but could not because of obligations. They expressed feelings of frustration and pressure of having to accomplish tasks out of necessity even though they knew rest would be the best alternative. Yet they said they were forced to learn through these experiences to learn how to simplify tasks such as spreading out laundry over a period of days or rearranging kitchen and closet spaces to make items easily accessible.

Loss of function in the hands and limitations in walking were reported by all participants as significantly limiting their ability to function optimally. One participant reported that she does not want to go anywhere anymore because of a lack of strength and energy. She said she also hesitates being around others because she feels misunderstood. One woman recalls giving up sports as a teenager was one of the more trying aspects of the disease with which she has had to cope. She commented on how difficult it was for her to watch others enjoying themselves in sports because she had to give it all up. She said that watching them made her focus on what she could not do rather than on what she could do.

Four women said that loss of function has been more limiting than pain. One woman commented that the two aspects that bothered her most were her inability to keep up the yard and the housework. One participant said she has learned to adjust to the loss of function by learning to adapt her environment and lifestyle. She reasoned that it was hard for her to separate pain and loss of function. Another

participant related the same idea by saying that pain and loss of function are very interconnected. For her pain limited her in her functional mobility and she shared that psychologically they are both hard to cope with.

Factors Related to Disease Onset

One woman declared a feeling of anger and hostility toward people in her life and literature she has read that have suggested that she may be responsible for her disease. She related that there seems to be an attitude in society that says that people with arthritis can bring on their disease because of faulty coping mechanisms for stress or tragedy. She stated,

I used to feel really guilty and think that it was my own fault that I had the disease. All the people that gave me those books made me feel even worse and more guilty. I want to know how to cure it, not how I caused it!

When questioned about a hope for a cure for the disease, five responses were favorable in hope that a cure could be found. Yet they expressed skepticism, frustration, and anger from the lack of attention to research and the attitudes about the disease. One woman expressed,

Arthritis is one of the oldest diseases and they still haven't found the cause or cure. The funding for RA is not as much as for other diseases because of the way the world looks at it. People just think that older people get it and that it is just a normal part of aging. But what they don't understand is that it is

something that kids and young people get and that it is a devastating disease. If we are going to see more research we need to educate the public and we need to expose those who are younger and let them see just how much pain people with arthritis are in and what they have to go through.

Other participants expressed opinions of frustration for the lack of research because arthritis is not a life threatening disease like cancer or AIDS. One woman said, "they always say it isn't life threatening but it gets you eventually and causes other things to happen and it kills you."

Medical Intervention

The next section of the interview provided responses regarding medical intervention including experiences with doctors, medication, and surgery.

Experience with Physicians

Five participants stated that they have been under the care of a rheumatologist for all or part of their disease process. Two women regularly see their rheumatologist about every month to 6 weeks. The participant who was recently out of the country just prior to the interview claimed that she tries to be in touch with a specialist or rheumatologist. Two women have seen rheumatologists in the past but are

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currently under the care of their family doctors, both specializing in internal medicine. The sixth participant has been under the care of a hand surgeon and a family doctor.

Responses varied regarding perceptions of relationships with doctors. Five women said they experienced good relationships with a number of doctors during their disease process. There were two common factors that marked a favorable relationship. One factor found in all five cases was described as "feeling like the doctor was listening to me and caring about how the disease was affecting my life." One participant said that the most helpful inquiry made by her doctor was about her well-being and how she was getting along in her everyday activities. Another woman shared,

I appreciate the doctors who are patient with me and take my problem seriously. I have one doctor who gives me a really big hug and wants to know how I'm doing. It's nice to see compassion and concern.

Another common factor that the participants described as beneficial in their relationships with their doctors was receiving an explanation of how the disease affects their bodies physically. One woman stated that she appreciated the doctors and nurses explaining in detail what is going on through drawings, diagrams, models, and pamphlets. One participant said that she is appreciative of the rapport that her doctor has with her husband and the time he has taken to explain what is going on especially before surgery. She also said that she is thankful for

the doctors who have been honest and realistic about the impact of the disease on her life. She said the doctor who initially treated her, referred her to a rehabilitation center which put her in touch with a number of resources including physical and occupational therapy. She stated that having those resources early in her disease helped her to learn how to adjust and cope with the disease.

All but one of the participants said they have had at least one negative experience with doctors and other medical workers. A frequent complaint participants shared during encounters with doctors was a feeling of being rushed and not listened to. Four women said they have been to doctors who seemed to just push medications on them and did not take much time to talk to them. One participant remembered one doctor would hardly say hello to her. She said he would just rush into the room and examine her, yet not ask how she was doing that day. Looking back, another participant expressed annoyance at the lack of information she received and said she felt intimidated around doctors and was afraid to ask questions especially when they acted like they were in a hurry. She said she was not told what she could and could not do such as which exercises to do and when to stop. She went on to say that she did not think many doctors instruct patients on how to take care of themselves and feels there needs to be more education regarding what one can do for oneself. Another woman also expressed feeling intimidated and afraid to ask questions. She described herself as being a quiet and shy person and felt that her doctors were too busy for her. Because she felt she

was slowed down in her life she clashed with her doctors because she felt they operated on "two different wavelengths." She went on to say that her doctor would get very angry and frustrated with her when she tried to play volleyball or softball.

I think he forgot how young I was and what things were important to me. All his lectures only made me feel worse. I just wanted to be a normal kid.

In reflection she said she wished her doctor would have referred her to more organizations that could have dealt with the psychological impact of the disease.

Medication

All six participants have been prescribed numerous medications for the treatment of the disease. The pattern and course of medicines prescribed have been similar in all cases. Generally, conservative medications such as aspirin were given initially followed by a progression to stronger, less safe drugs. In all six cases, stronger medications were administered as the disease progressed. These drugs included gold shots, anti-inflammatory drugs, pain medications, and steroids. One participant commented that the drugs that were given were by trial and error and with many negative side effects. Of the five women who were given gold injections, four claimed a period of significant relief lasting anywhere from one year to five and a half years. Yet they were removed from the medication because of toxic

effects. One woman remembered having an episode of severe coughing lasting 5-6 weeks from the gold.

What made me so mad about the whole thing was that they (the doctors) didn't even believe that I had problems with my lungs at first. The doctor told my husband that he thought I was just trying to get attention. He gave me some cough syrup and told me to go home. He was just insensitive about the whole thing and thought I was just a complainer.

Later, X-rays of her lungs revealed them to be completely dark and a sputum test lead her doctor to diagnose lung cancer, giving her five years to live. She said that she lived with that news for over a month. Her doctor finally called her one afternoon and told her she did not have cancer but instead had a reaction to the medication.

Surgical Intervention

Surgical intervention varied from one relatively minor surgery for one participant to 24 surgeries for another participant. All participants described the surgical intervention as beneficial in restoring function and relieving pain. Three women anticipate future surgery with reservations only in regard to expense. One participant has had only one surgery for the removal of a nodule on the right hand 18 years ago. She was pleased with the results and reported that pain has not returned to that area. Currently, however, bilateral hand function is moderately to severely limited secondary to joint deformity in her fingers, thumbs and wrists. When questioned about the

possibilities of surgery to increase hand function, she said she was not aware that surgery could help and was not given that option by her doctor. She commented that she thought her age of 80 years would hinder this probability.

Five women have had surgery on the wrists or hands, for either joint replacements, tendon transfers, or shaving of the carpal bones. Two participants described synovectomies on the wrists and MP joints to delay joint replacement because of their young ages. Eventually these joints were replaced with positive results. In all cases, participants expressed being thankful for the surgeries because of increased hand function and long term pain relief. One participant had bilateral knee replacements and claimed that these surgeries have increased her ability to walk. Another participant has had an open knee surgical procedure on the left and closed arthroscopy on the right. She said that before her surgeries she could hardly bend down because of pain and swelling. She reported that her strength is still limited but her functional independence has improved. Two participants have experienced a total hip replacement. Both described that prior to surgery they had extreme pain and difficulty with all of their ADL including sitting and walking. Both credit these surgeries as instrumental in their ability to ambulate. One woman stated that although she has lost some muscular control in the replaced hip, she does not have the intense pain that she felt since the onset of the disease. She said that although she is slow, she can walk.

One participant had a total of 24 surgeries, including 7 hand surgeries, five knee surgeries, a total hip replacement and a total shoulder replacement. Other surgeries have been synovectomies on the knees, hands, and jaw in an attempt to delay joint replacement surgery and to relieve pain. She also experienced lens implants in both eyes after developing cataracts and glaucoma from taking steroids. She affirmed that she would most likely be bedridden if she had not had all the surgeries.

All of the participants reported that they would go through the surgery again if they had a choice and have been pleased with the results. Five said that the hardest aspect with which to cope after surgery was not pain but having to depend on family and friends to complete necessary tasks. One woman said that it was hard to depend on her husband after the surgery. She said the first thing she wanted to know after surgery was when she could start driving again. Although she is limited in walking, her ability to drive provides her the functional independence she desires.

Family Life/Home Environment

In this section of the interview participants were asked questions regarding their family life and home environment. Participants were queried about the prevalence of the disease among family members and their feelings and perceptions of the family members who have had the

disease. Participants were also asked about their home life, with whom they live, and how their family has responded to the arthritis, both past and present.

Prevalence of the Disease Among Family Members

Five participants could not recall any family members who were diagnosed with rheumatoid arthritis; however, three could name at least one family member who complained of occasional joint achiness or back pain associated with older age. Only one woman remembers both grandmothers and one aunt specifically having rheumatoid arthritis. She said their ages of onset were later in life, between age 40 and 60, unlike her early age of onset at 15. She commented on her relationship with one of her grandmothers.

My one grandmother lived long enough to see me have the disease and it was great because we could talk to one another and really identify with each other about what the pain felt like. We really knew what the other one was going through and I knew I was a special person to her.

Perceived Response of Family Members

Two women described their families as "not the type to dwell on the subject of illness or problems." One said she felt supported by her family and felt they understood her illness but was appreciative of the fact that they did not focus on her disease or dwell on her problems. She did say though that there were times when her family seemed unaware of her pain and need for help. She shared that because she does not

talk about it too much she tends to forget that her family may be unaware of her limitations. She is single now and has been married two times. She described her first marriage as ending in divorce and said that her first husband did not really understand what she was going through with arthritis and was not very sympathetic. Her second husband was described as very kind and understanding. The marriage lasted many years but ended with his death.

Another participant shared that her family never talks about health problems. She said that she feels that her family just does not respond to her arthritis and rarely ask her how she is feeling. She said she feels bothered and saddened by the apparent apathy of her family. She went on to say that she did not want to burden her daughter with her problems but has wished her daughter would approach her more to ask how she is doing. She alluded that maybe her daughter thought she was putting on an act.

Most participants recalled positive experiences with their family members. One woman said that her husband always looks for ways to make things easier for her around the house especially after her surgeries. She commented that her family does not seem to be embarrassed when she must wear platform crutches or splints on her hands. Because her children were young when the disease started, she said they do not see her limitations as anything abnormal.

One participant said that her family has been very understanding of her disease. She explained that because her family knew her before the

onset of the disease they did not see her as indolent. However, she feels that many acquaintances who met her after the onset of the disease think that she is lazy and "putting on an act," leaving her feeling frustrated and misunderstood.

Another woman said that her family has been very sympathetic and helpful with household duties. She explained how much it has meant to her that, during times when she has been in a lot of pain and has been irritable, her family has responded with patience and love. She added that she felt badly for her husband knowing how much he would like to travel but cannot because of her limitations with walking. She also said that it was very difficult for her to have her husband see her in so much pain.

Another participant shared that because of her early age of onset, she saw her parents and siblings as overprotective. She recalled feeling frustrated because of the difficulty of trying to establish her independence during adolescence. She said that in the last 10 years her family has let go of their over-protectiveness and have respected her need for independence.

Home Life

Most participants said they felt satisfied with their home lives and those with whom they live. One woman who is currently living alone stated that she would like to remarry someday and expressed some apprehension about the possible increased need for physical assistance in the future. She commented that she depended on her best girlfriend

for emotional consolation and physical help. She described her life as active, spending time traveling in her motor home or visiting neighbors and friends.

Another participant was in the process of looking for a roommate and a place to live at the time of the interview. She shared some of her past situations with other roommates. She said that every time she has lived with someone she had to alert them to the severity of the disease. She recalled during the times when she required hospitalization because of the disease, her roommates would realize how bad the disease was. At the age of 27, she was planning to return to graduate school in hope of finding a new career that will accommodate her physical limitations.

Three participants live with their spouse and are retired. All three women expressed gratitude for the assistance their husbands gave them and stated that they felt their spouses understand their limitations and need for rest. They describe a quiet life with a majority of time spent at home or visiting family and friends.

One participant lives with her spouse and two teenage children. She said she has tried not to let the disease interfere with her family life and their many activities. She says she tries not to dwell on the severity of the disease. She described her husband and children as very helpful and compassionate and believes that her children have learned a lot from the arthritis and seem to sense when other people are hurting and need help. She said that her goal has been to keep her house open

to people, especially to the children's friends and feels blessed to have her family.

Relationships

Participants described experiences with various relationships including friends, co-workers, and groups that are enjoyed in daily life. Participants reported their feelings about themselves with others and about looking to others for help and assistance.

Friendships

All six participants shared common experiences with friendships. Most said they had only one or two close friends with whom they could share their difficulties of living with arthritis. Yet they said they were not the ones to initiate a conversation of talking about the disease and did not want their friends to pity them. One woman said that her best friends were the ones who made her feel like a normal human being and helped her to focus on what she could do rather than on what she could not do. Two participants said they choose to surround themselves with positive people and those that understand them but do not try to fix them. Three women commented that one of the hardest things encountered with friends was when they have tried to be too helpful. Two recalled instances where friends have tried to pull them out of a car or hold their hand while walking. One woman said, "not

only does it cause pain but it makes me feel like they think I'm helpless."

Work Related Activities and Relationships with Co-workers

Three participants said they felt misunderstood because of their co-workers lack of knowledge about the disease and how arthritis can affect the body. The youngest participant at age 27 described her experience working as a 6th grade teacher for the past three years. She said,

It was always a dream of mine to teach kids and to try to give them a good self-esteem and sense of well being and let them know who God really is. I see my arthritis limiting that dream. I can't do the things I used to like writing on the chalkboard and being on my feet all day. I just don't have the energy required to do the job anymore. I need to prepare myself mentally for the changes that are about to come.

When asked about her relationship with her co-workers she said,

My co-workers have run both extremes. For the most part they treat me as normal until I can't do something. I don't think they understand the daily pain. On the other hand the kids understood what I was going through because they would see me all day. My co-workers only saw me periodically and were less understanding. It's not that they weren't compassionate, they just didn't know.

One participant said she had to quit work as a real estate agent one month after being diagnosed with the disease. She said she would work for four hours and literally be in bed for a day or two from exhaustion.

She felt her co-workers felt bad but they did not seem to know what was going on. She commented that they just stayed away and thought that if they got too close it would happen to them. Another participant said that during the last few months of working she felt co-workers expected too much and reacted to her in a negative way. She said,

I don't think they understood me on the days I had to call in sick, I just don't think the public is educated enough about the disease. My co-workers just expected me to meet a certain quota and when I couldn't they didn't make allowances for me, they just got upset. They didn't know what my life was like at all.

One participant was able to continue working as a nursing assistant for seven years after the onset of the disease. She shared that she felt her co-workers understood her and that they always worked together as a team. One might speculate that persons working in the medical field may be more educated about the rheumatoid arthritis and how it can impact a person's life, therefore making allowances for a co-worker with the disease. Two participants said that they have not worked outside the home since a number of years before the onset of the disease.

Groups and Social Interactions

Two women said they are currently involved in activities outside the home. One woman said she is very active in her children's school related functions along with church activities. She said she has had positive experiences with others in these groups and has had a chance to minister to those who are going through difficulties in life. She

shared that having a disease like rheumatoid arthritis has helped her to be sympathetic to the struggles others face. She said that the disease has also been a source of frustration with other social events especially husband's social engagements through work or skiing trips with the family. She said she is forced to stay in the lodge and that is emotionally hard for her.

Another participant said she is also active in her church. She reported that her relationships with others at church have been positive and that many people have told her that it is refreshing to talk to her because she is not in a hurry. She commented that people have told her that they feel calm and peaceful when they talk to her. She also stated that having the disease has taught her to slow down and listen to people.

All participants said that having arthritis has impacted their relationships in some way. One woman said that family bonds have been strengthened and the family has pulled together to help especially during and after surgery. Another woman said that she feels closer to her children and grandchildren because of their willingness to help.

One respondent commented on what she is still able to bring to her relationships,

I think my relationships are more special to me. I have always been one who did for other people before the disease started and I really treasure being able to do that now. Maybe I can't do things

physically but I can be caring and considerate by a phone call or a prayer. I am not limited in being able to give of myself.

Three women said that they felt arthritis has influenced their relationships in a more negative way. One woman said she feels people have avoided her since the onset of the disease and consequently she has been less sociable. Another woman said she feels like she has to conform and keep up with her friends and has difficulty because of her limitations. She expressed feeling inadequate around others and has tended to avoid social engagements and entertaining at home. One participant expressed her disappointment and a feeling of being robbed by the disease. She shared that all her life she worked on two jobs so that she would be able to rest and enjoy her relationships when she got older. She said now she feels she is too tired and in too much pain to enjoy her relationships the way she had hoped.

Experience with Arthritis Support Groups

Three participants recounted experiences with arthritis support and education groups. One woman was recommended to a seminar class by her doctor. The class met once per week for five weeks. She remembered that the class, led by an occupational therapist, focused on exploring and sharing ideas that were helpful in adapting the environment and simplifying tasks. She remembered the class being helpful from a practical standpoint but it did not help her with the emotional aspects of the disease.

Interestingly, two participants stated that they helped start a water exercise class for persons with arthritis. One participant shared some of the benefits of the group.

It was the first time in a long time that I felt I was doing something for somebody else as well as myself. We did a lot of laughing and joked about what one could do one week and couldn't do the next. It was nice to interact with others who had the disease but we weren't there to pity one another but simply to know we weren't alone.

The other participant shared similar feelings. She said she felt a camaraderie with the other participants in the group, but stressed that the purpose of getting together was not to pity one another but to encourage and support one another. She shared that it was a fun time to laugh and socialize in a pain-free environment.

In addition to the exercise group one participant also met with a class entitled, "Learning how to live with arthritis." She recalled that she felt isolated at times because everyone was much older than she but she still pushed herself to go every week although her pain level made it difficult to sit through the sessions. She said that the group was instrumental in helping her to cope with the disease and the positive attitude of the leader made a lasting impression. She said the more she went to the group the more she seemed to accept the disease.

One participant was encouraged to contact a group of people with arthritis after her hip replacement. She remembered that a woman from

the Arthritis Foundation came to visit her in the hospital and suggested the group. She said she did not like the group because the participants were so much older than she and she felt their lifestyles were too different. She said that she has benefitted from one on one interactions rather than groups and found talking to her friends has helped her the most in coping with the disease.

Two participants said they were never interested in support groups and chose to avoid them.

Self-Perception when Encountering Others

Five participants stated that they have some difficulties when encountering others. One woman said she feels "low" when she sees others around her going places and doing things of which that she is not capable. Another participant said she feels self-conscious when she cannot do the things she did previously. A third participant said she felt ashamed of the way she looked. She said,

I was kind of a vain person I guess and I used to like to dress up and have my hair look nice. I can't look the way I used to so in some ways I feel kind of embarrassed but I think I'm beginning to get over that. When I first had the disease I wouldn't tell people or admit it, I would just pretend things were better than they were.

One participant said that she felt fine around others and did not see herself as "sick." But she expressed concern over how the reactions

of others has affected her children. She recalled a particularly painful incident with her daughter.

I remember my daughter and I were out shopping on a cold rainy day and I was hurting quite a bit. We parked in a handicapped spot and my daughter was helping me out of the car with the umbrella. A man drove by and screamed, 'some limitation you have!' and drove off. It bothered my daughter that people don't realize what I go through. The hardest thing for me is not what I think of what others think but how it affects my family and that they have to see me go through this.

She went on to say that the public does not see the limitations like they would for another disease because arthritis is not as visible. Another participant expressed similar feelings of the difficulty of seeing those she loves watching her go through the pain. She stated,

I don't like people to see me hurting so much because I know it is painful for them to watch. It makes them feel very helpless because there is nothing they can do except be there. I wish they could help and make the pain go away because I know it would make them feel better.

All six participants stressed the difficulty of asking others for help. Most described themselves as independent and active before the onset of the disease. Four women related the burden of receiving needed help but being able to return the favor. As one woman expressed, "you feel humbled and helpless." Most of the participants said that over

time their families have learned to anticipate their need for assistance without them having to ask but that their burden still remains. One participant said that because her family and friends know her and understand her limitations it is not as hard to ask for help from them as it is to ask for assistance from strangers. She recalled a situation of sitting down in a low chair in a department store to rest. She commented,

I knew I couldn't get up by myself so I asked this young woman to help me and explained that I had artificial knees. She kind of looked at me funny, helped me up and just smiled without saying a word. I could tell she really didn't understand my situation because it was not visible and I looked relatively normal.

Functional Activities

Participants described a typical 24 hour day and depicted how rheumatoid arthritis affects self-care activities, homemaking activities, fine motor tasks, functional mobility, and child care activities. The women were asked to recall adaptive equipment they have used in the past or are currently using and how that equipment has affected their functional independence. Participants were also questioned about how arthritis has influenced their ability to work outside the home and how they have been affected financially because of

the disease. Finally participants were queried regarding the impact of rheumatoid arthritis on retirement plans, hobbies and leisure interests.

Description of a Typical 24 Hour Day

The two youngest participants described their days as active and full. This was not because the disease process did not affect them as severely, as both women have had numerous surgeries and problems associated with the disease. Both participants attributed their active lifestyles as necessary to either earn a living or maintain a busy family and home.

One participant said the hardest part of the day was having to walk outside her home, leaving her safe haven to face the world. She recalled the difficulty of realizing how slow she would have to walk in comparison with others around her. She said she had to mentally prepare herself to be in the classroom, where she taught sixth grade, and to try to be normal and that was very painful. She said for the first three class periods she would stay in the proximity of the classroom because there was something safe about staying there for the first part of the day. She shared that venturing out to other areas on the school grounds was intimidating because she wasn't sure if she could handle walking the distance. By the afternoon, she said her activities were a little easier physically because of movement throughout the morning.

She shared that one of the frustrations she faced in arthritis groups she has encountered has been the difference in lifestyles. She said that most of the people she has met with rheumatoid arthritis have

been able to stay at home and "move at their own pace." She stated that she has had to work and support herself along with coping with the disease and its limitations. She said it has been hard because she hasn't found many people she can relate to who are in her situation of having to work and deal with the disease.

Another participant said breakfast and self-care activities including a shower are estimated at taking about two hours. Before noon, she is involved in neighborhood Bible studies or errands in the car. She says she tries to slow down in the afternoon and rest and take an hour nap so by dinnertime she can prepare the meal and involve herself in activities with the family. Although she does not have to work outside the home, she says she feels it is crucial for her to stay active both for herself and also out of responsibility for her family, especially her children.

Two participants say they rely mainly on their spouses for household chores and meal preparation. One woman said that although it is difficult for her to complete household activities, she is unable to rely on her husband because of his physical limitations and health problems. She said that in the morning and afternoon she will rest and try to complete chores later in the day. All three women said they spend a good deal of time watching TV and reading, and occasionally participating in activities such as gardening, knitting, and caring for pets. Daily afternoon naps are part of the routine, lasting about one hour.

Self-care Activities

All six women stated that they have problems with self-care activities with limitations varying depending on the severity of the symptoms. Currently all participants are independent with personal and oral hygiene as well as eating. Participants who have had hand surgery and were required to wear a splint managed these tasks with the other hand. All six participants said that they are no longer able to take baths because of difficulty getting in and out of the tub. Two women use bath benches for seated showers, the other four participants stand during showers. Three participants have had grab bars installed in their showers, and four participants said they use raised toilet seats. One woman said she employs an attendant to assist her three times a week with seated showers and caring for her hair. She said she usually wears a front buttoning housecoat with slip-on shoes during the day that she is able to manage independently. On the few occasions when she goes out, her daughter or husband assists her with dressing and grooming. She commented that she does not like to use any adaptive aids such as a button hook or a dressing stick for self-care tasks because she has found them to be too cumbersome and time consuming.

All participants said they have had to adapt their clothing in some way to maintain independence with dressing. Loose unrestrictive clothing, elastic waistbands, and slip-on shoes have been common options. Front opening blouses have proved easier than over head or back opening blouses especially for those with shoulder limitations.

All of the women said they could manage larger buttons fairly well but tended to choose clothing with few buttons. Two women occasionally said they use a button hook on days when their hands are stiff and painful.

Only one participant said she uses a variety of adaptive aids for self-care activities, including a dressing stick, a sock aid, a reacher, and built up handles on her comb and toothbrush. She commented that she does not always need these items but feels secure in knowing they are there when the need may arise. She said she learned of these aids from an occupational therapist. She reported that through the years she has also learned how to adapt things on her own.

Only one participant says she occasionally uses a built-up handle for her eating utensils when her hands are painful and her coordination is impaired. Another participant says she solves this problem by eating only finger foods on days when her hands are bothering her.

Homemaking Activities

The description of homemaking tasks that proved to be most difficult was shared by all participants. Generally, heavy homemaking chores such as washing windows, cleaning floors, and vacuuming have been deferred to other household members or outside help. Three women employ cleaning services twice a month for heavy chores. Most participants are able to manage laundry especially if it is spread out over a period of days. One participant says she has difficulty with laundry because she needs to carry her load to the laundry facilities in her apartment complex.

Modifications to kitchen tasks has been required by four participants who continue to take part in meal preparation and clean up. Lighter dishes and utensils such as Teflon and Tupperware have replaced heavy iron skillets and glass bowls. One woman says she regularly uses paper plates instead of dishes because of the ease of handling and clean up. Electric appliances have been used mainly in place of manual ones. Three women said that even with adapted knives, foods such as carrots and celery are difficult to cut and these textures have been avoided. Two participants said they learned of various modifications to the kitchen from suggestions from occupational therapists. The others said they have learned to adapt and figure out modifications on their own.

Fine Motor Tasks

All participants have had problems and limitations with one or both hands. All six women say they are able to write but not for long periods of time. Three have tried built up handles which have proved helpful especially after hand surgery. Currently only one woman occasionally used built up material for writing. All participants have opted for slip on shoes to avoid tying shoe laces. Of the four women who are currently driving a car, two stated that they use an adapted key ring to aid with turning keys. The other two participants said they struggle with turning keys but were unaware adapted key rings were available. This was also true for three women who have difficulty turning stove dials. Because they were unaware of adapted aids they

have either had to ask for assistance or struggled using two hands, sometimes causing pain. Most participants said that opening jars has usually been solved with a rubber grip and banging the jar to release the pressure before hand.

A participant said she was given to a number of devices for activities such as writing and turning knobs and keys while she was in the hospital. However she said she didn't want this equipment and would rather have her husband or daughter help her instead. She adamantly said that it is not that important to her to be able to do it all herself. Another participant expressed similar thoughts. She said when she was in the hospital for a total hip replacement, she was issued dressing stick and other pieces of equipment to help her maintain independence with dressing and other self-care activities. Yet she said that for the six weeks she would need to adhere to her hip precautions it was not that important to her to be fully independent. She said,

I had so many problems in my hands that it was hard to manipulate the equipment and I wasn't patient enough to want to learn. It was more frustrating than helpful for me. If I couldn't put on my socks, I just didn't wear them. If I couldn't put on my pants, I had someone else help me.

Functional Mobility

All participants are currently ambulatory. One participant has a wheelchair for long distances and two women said they occasionally use a cane for walking. All respondents said their ability to walk has been

greatly affected since the onset of the disease. Tolerable walking distances ranged from a maximum of 50 feet for one participant to about one half mile for another participant. Managing stairs was mentioned by all women as a problem especially descending stairs. Elevators, escalators, and ramps were reported as being most helpful for community mobility. Large heavy doors such as those in banks, restaurants and other public places was indicated as one of the most prevalent community barriers.

One participant shared,

Arthritis is not a disease where you see a lot of physical handicaps. It's funny but when I use my cane I get a lot more sympathy and assistance from the public. I guess the cane is a marker that you have a disability. If I am just limping people will ask me what I did to my leg like I was in an accident or something. I have found that people will help me if they think I am handicapped rather than if they think I was in an accident.

She commented that she did not have a handicapped placard for fear someone would think she wasn't handicapped. Three other women said that they have had problems getting the assistance they need in public such as help with heavy doors because they feel people do not see their limitations and need for help. Two participants mentioned that some handicapped bathrooms have been obstacles.

At one time or another, either after surgery or when symptoms have been exacerbated, four women said they have had to give up driving

temporarily. One woman explained that when she could not drive for a period of time she felt "trapped like a prisoner in her own home." All four said they cherish the ability to drive and the feeling of independence driving offers. Two participants rely on their husbands to drive them around. None of the women said they utilize public transportation.

Bending, stooping, lifting and getting up and down from the floor were indicated as problems by all women mainly due to back and lower extremity pain and stiffness. Many said they have rearranged closets and cupboards to keep items within easy reach. One participant mentioned that when she grocery shops, she takes a friend along if she knows she will be purchasing heavier or difficult to reach items. She said she does not feel comfortable asking other shoppers or store clerks for help because she does not think they understand her need for help.

Discovery and Use of Adaptive Equipment

All participants said they use some type of adaptive equipment in their daily lives. Some of the most common pieces of equipment used are raised toilet seats, grab bars, kitchen aids such as adapted knives and electrical appliances, built-up handles and reachers. Most of the participants said they did not prefer items such as dressing sticks and buttons hooks because they were too cumbersome and difficult to use especially when hand symptoms increased. Two participants said they learned of adaptive devices through occupational therapists and problem solving on their own. Two other women said they found out about

equipment through catalogs published by the Arthritis Foundation. One woman said she learned about the raised toilet seat from her doctor. Family members were also noted for sending gifts such as an adapted knife and a large push button telephone. Participants agreed that their equipment has improved their functional independence and ease in their daily activities, although prevalence of use of equipment and number of devices used for each person, varied significantly among respondents.

Childcare Activities

Of the four participants who have had children, all began to develop symptoms after the birth of their last child. The one participant who developed symptoms when her children were young commented that her youngest child was three and a half when she first had symptoms felt lucky that they were all out of diapers by that time. She recalls difficulty lifting her children and helping them with their self-care tasks such as bathing and dressing. She said,

There were times when I could hardly care for myself and they just had to learn to get along on their own. At first I had a fear that I might loose them if I couldn't care for them but looking back I see there was a blessing in what happened because my kids learned how to be responsible and take care of themselves.

The other participants who had children said they began to develop symptoms when their children were old enough to care for themselves. However they stated that now that they are grandmothers they have difficulty. All have said they are unable to change diapers and pick up

their grandchildren. One woman commented that her grandson wants her to get down on the floor and play with him and he doesn't understand why she is in pain and can't participate with him.

Financial Costs

All participants stated that arthritis has affected their ability to work. As mentioned earlier, four participants were working outside the home at the onset of the disease. Two participants had to quit work in a matter of months and one was able to continue working for seven years. The other participant at age 27 is in the midst of changing careers because of arthritis. She said that rheumatoid arthritis is limiting her career choices. She says she chose teaching because she thought it was something she could handle but never realized how much energy it took. She is apprehensive about the future and the limited choice of job possibilities and the financial burden of further education. She expressed some apprehension about the future of seeking employment and going through interviews for a position. She said,

I used to be able to hide my disease but I can't really anymore because of my limitations with walking and with my hands. It would be awful to be discriminated against because of arthritis. I don't know how much to tell them regarding the severity of the disease. In the past I've just down played it a lot.

Four participants said their insurance coverage has been adequate to cover surgeries and hospital expenses. Secondary insurance other than Medicare have proved extremely helpful to cover additional costs such as

therapies and medications. A considerable expense for the majority of participants has been adaptive devices, most of which are not covered by insurance companies. Two of the participants said their secondary insurance coverage has been poor leaving them with large medical bills. Both stated that they desire surgery within the next year but said they did not think they could afford the costs. One of the main complaints from participants was the inconvenience and stress of filing and keeping track of insurance claims. One participant described her ordeal of handling insurance claims,

It is so stressful to have to keep track of what the insurance companies do along with the doctor and hospital bills. You think you have everything straightened out and you get a statement saying you need to pay another bill. I finally got tired of fighting the system and all the red tape because it wasn't helping my arthritis at all. I ended up hiring someone to handle it for me and she is even having trouble!

Four women said they feel their retirement plans have been affected both financially and physically. The biggest disappointment shared by all is the limitation on their ability to travel and handle walking for distances longer than about a half a mile. One participant said,

That adage of doing things while you're young is really true. You don't realize that bang there you are and you're not able to do what you want to do. It can happen all of a sudden. I was always in good health. One thing I've noticed about people I've met with

arthritis is that they were more active than the average person before the onset of the disease. It's so hard to have to give all of that up.

Leisure Interests

Loss of the ability to take part in various leisure skills and interests has permeated the lives of all six individuals. Three women said they were active in sports such as water skiing, tennis, and softball but because of the stress on their joints and decreased strength and endurance, these activities have been abandoned. One woman said she was extremely active in horseback riding and continues to ride with discretion, although she feels this activity has been detrimental to her condition. She said,

I love riding and the thought of having to give it up is so hard. I just try to slow down. My horse knows me and I know her, we're both old and we get along great. I can't care for her like I want to such as cinching up the saddle and brushing her and that hurts because I enjoyed that as much as riding. My doctor was furious when he found out I was still riding. But it means so much to me.

Three women said that they have had to either give up or modify activities such as knitting, crocheting and sewing. Generally activity time has had to be shortened because of fatigue and pain. Difficulty with gardening and keeping up with household tasks was mentioned as a major source of frustration and a feeling of inadequacy. One woman shared her disappointment by saying,

Arthritis just cuts you down to nothing. I guess that's why I feel so inferior, I just don't feel accomplished anymore. You can't do the things that you did all of your life.

Walking and decreased endurance was indicated as restricting both family and leisure endeavors. One participant said she frequently declined invitations to family outings for fear she would hold the group up.

When asked if there was anticipation of having to give up leisure interests because of arthritis, participants responded by saying that they do not really think about what they may lose but simply try to take one day at a time. However, two commented that they hoped the disease would not progress to a point where they would have to give up the ability to walk.

Occupational Therapy Intervention

Respondents recalled their experiences with occupational therapy including how they first came into contact with OT, how long they received therapy, and for what specific reasons they obtained services. Participants were asked about receiving occupational therapy for post surgical rehabilitation and how that intervention may have affected their functional ability or their pain. In addition, the respondents were asked to explain the information or therapeutic techniques which they learned from the therapist including what was most helpful and what

was least helpful. Finally, participants were asked if they felt they could have benefitted from OT earlier in life.

Factors Leading to Contact with Occupational Therapy

Three participants said they came into contact with an occupational therapist before they were referred to therapy from their doctor. All three women attended community classes that were presented by OT's. One woman remembers going to a fashion show put on by occupational therapists and other health care professionals who demonstrated adapted clothing for disabled persons. The therapists also demonstrated adaptations that could be made in the kitchen and other areas of the home. The classes were presented on a university campus and focused on a variety of disabilities. The participant said she also recalled skits that were presented dealing with the issue of self esteem.

A lot of what they (OT's and other health care professionals) did was to try to improve self esteem. They didn't call us handicapped but handicapable. They did a lot of skits on the issue of self esteem and that helped me to know that there were other people suffering from a low self image. Not a lot of people have dealt with how a disease could affect my self esteem and I appreciated the OT's taking that role.

Another participant attended a class at a university entitled, "Learning how to live with rheumatoid arthritis" that was presented by occupational therapists. The class met for an hour and a half for 6-8 sessions. She recalls learning about adaptive equipment, and joint

protection and energy conservation principles. She said that she found the information helpful and useful but didn't apply it right away because she said she denied that she would have the disease for more than a few months. She said that through the years of living with the disease, she has used a lot of the information she learned.

The third participant who encountered occupational therapy before a physician referral, said she attended a community seminar once a week for five weeks that was presented by occupational therapists. She recalls the therapists instructing the class on "different ways to do everyday things." She said she learned how to do things without putting unneeded stress on her joints. She commented that she also learned a lot about different devices to "make life easier".

Five participants said they were referred to occupational therapy after surgery by their physicians. For two of these women, it was the first time they became aware of occupational therapy. The sixth participant was referred to an inpatient rehabilitation center after being admitted to the hospital for pulmonary problems. She received both occupational and physical therapy everyday for a total of nine days for endurance problems as well as rheumatoid arthritis. She was 80 years old when she first received OT services and showed marked hand deformities and loss of function. Although she reports she has had hand limitations and pain for a number of years, she said her doctor has not suggested surgery as an option. She said that when she received occupational therapy she felt she was to the point where she did not

want a lot of changes and did not feel there was anything anyone could do. She said she was shown built up handles, long handled bath brushes and clothing adaptations but felt she was too old to want to learn and would rather have her husband help her with her activities. She commented that if she would have been younger and didn't have her husband to help her, she probably would have benefitted more from the suggestions.

Post Surgical Rehabilitation

As stated earlier, five women said they were referred to occupational therapy after surgery. One woman said she was referred to occupational therapy after MP arthroplasty on her right hand. She recalls her occupational therapy treatment focusing on splinting and functional activities. She commented on her experience saying that she felt the splint was the most helpful thing because it was instrumental in keeping her joints in a functional position. However, she reported that she did not see the purpose behind the functional activities she was given in therapy because she was already using her hand functionally at home. She said that she did not feel pain after the surgery and did not attribute therapy to this absence of pain but to the surgery itself.

Another individual remembers being referred to an occupational therapist on two different occasions after MP arthroplasty on each hand. She commented that the occupational therapists have helped her tremendously during the rehabilitation on her hands. She said,

I didn't go to a therapist as long as I should have with this left hand and I still can't make a good fist. I went to an OT a lot longer for my right hand and there is a big difference in the right hand, I have more use and movement and I think it is because I went to therapy longer. I saw the first about one month and the second therapist about three months. It hurt at first when the therapists pulled on my joints but it was good for me to know how far I could push my joints without damaging them. As long as I had therapy I was getting more flexibility with those joints and it didn't hurt in the long run. The joints that hurt now are the ones that don't have the flexibility.

Another woman was also referred to OT after wrist surgery. She attributed the therapy to helping her to regain function and strength. She said she did not think the therapy helped her pain level.

The participant who attended the classes with the fashion shows and skits that was mentioned earlier, received OT after her hip replacement years later. She commented that she was already familiar with the dressing equipment that was shown to her in the hospital but did not want to use it because of the difficulty she had manipulating it with her hands. She also said that she did not think that the therapy was instrumental in helping her pain after surgery. Later, she did receive night resting splints fabricated by a physical therapist after one of her wrists surgeries that proved helpful for easing pain and keeping her hands in a position of function.

The fifth participant said she has had occupational therapy for multiple joint replacements including seven hand surgeries. She saw an occupational therapist after each joint replacement and for all the hand surgeries. She says she was instructed on use of adaptive equipment as well as how to adapt her environment and daily schedule. She also received various splints after hand surgeries. She said,

The OT would make me splints and help me to regain strength and function back in my hands. The night splints really helped the pain. After my hip replacement I was shown how to dress and take care of myself without dislocating. I was told about the importance of rest. At various times in my life different types of information have helped me. It was nice to know from an OT that I was overdoing my exercise program and to learn how to judge when I had done too much and how to remedy it. I always thought the more the better. I think the therapy after surgery is just as important as the surgery itself.

Perceptions of Occupational Therapy

Three participants said that one of the most helpful aspects of occupational therapy was the education they received. As one respondent stated, "I needed to not only know what to do and how much, but also what not to do." She commented that she found out much later in the course of the disease that she was putting unnecessary stress on her joints and over doing her activity. Another participant said that she appreciated her occupational therapist showing her how to move her

joints. She was also given a booklet about "the do's and don't's of living with arthritis" that she said proved helpful. She commented, "If I would have received that booklet a long time ago, I wouldn't have tormented my joints as much as I did."

One participant said the most important aspect of her experience with occupational therapy was the attitude of the therapist and the encouragement and patience she received. She said she felt included in her program and felt like she was treated "like a person." She said,

The OT dealt with every aspect of my life. She helped me reorganize my time and adjust my environment to fit my needs. She listened to me and cared about my life and my ability to do the things I wanted to do. The information I received was great and I would rate it at the top of the scale in helping me to function independently.

She went on to say that when she was in the hospital she had a variety of different therapists involved in her treatment program and this left her feeling fragmented. She said that each time a new therapist would come in to treat her she would have to explain her situation all over again and felt like she was starting back at square one each time. She also said that once she was out of the hospital and was attending out-patient occupational therapy, she preferred going to a clinic for treatment rather than a hospital because it gave her more of a sense of wellness and healing rather than a focus on sickness.

Many respondents said that they felt more in control and more a part of their program and recovery when they understood why a particular treatment was being given. One woman said that when she had her program and treatment explained to her by her therapist, she followed through with the instructions more consistently. One participant recalled working with a therapist that did not explain the treatment to her. She said because he did not explain anything he was doing, she did not feel like the treatment was doing any good.

Four respondents said they felt the splints they received in occupational therapy after surgery were essential to their recovery and hand function. Three participants said they have received night resting splints. All three reported a decrease in pain and stiffness especially upon waking.

As mentioned earlier, two women said they first learned of adaptive equipment through an occupational therapist. Others said they found out about equipment through the Arthritis Foundation, their doctor, family or friends. All participants attributed adaptive equipment to increasing their functional independence. One participant expressed some frustration when she was first introduced to this equipment from an occupational therapist at her university. She stated what she did not like about the OT's was that they would present the adaptive equipment but didn't tell her how she could make it on her own. She said as a college student she could have saved a lot of money if she would have been taught to use her own resources at home.

Four respondents said they felt they could have benefitted from occupational therapy earlier in their lives. One woman said that getting the "do's" and "don'ts" ahead of time would have made a big difference in her functional ability as well as her pain. Another woman said that she could have benefitted from education regarding ways she could have done more things independently. At eighty years old, she says she now feels a resignation to rely on her husband and feels it is too late to want to learn to be more independent. Two other participants also said they could have used suggestions and ideas to make their lives more independent. One woman said she feels she probably struggled through a lot of things she could have avoided if she would have received OT earlier in her life.

One participant said she benefitted from occupational therapy immediately after her diagnosis and was thankful for this early intervention. One respondent said she did not see occupational therapy as a necessary profession for her particular needs. She stated,

All I've seen from OT's is the use of adaptive equipment and that has helped me some but I could have found that in a catalog. I did like the skits that dealt with the issue of self-esteem though. That was very helpful.

Quality of Life

In the final section of the interview, respondents described those things in their lives which bring the most meaning and sense of well-being. In addition, they reported the most difficult aspects of living with rheumatoid arthritis and the variables that have affected the quality of their lives. Participants described what has helped them the most in their ability to function independently as well as what has helped the most in coping emotionally. Respondents stated any changes they would like to make in their lives and what has been their biggest fear. Finally, participants related the kind of person they considered themselves to be prior to the onset of the disease and the ways in which arthritis has changed their philosophy or outlook on life.

Meaningful Life Experiences and Sense of Well-being

When asked what brings the most meaning and sense of well-being, two women responded with their relationship to God. One woman shared that although her family and husband are extremely important in her life, her most important relationship is with the Lord. She said,

God has made it very clear that he will never leave me nor forsake me. I believe in the Bible completely as the truth from beginning to end. God is everything to me, He knew of the disease before I had it and He will know of the outcome so who could ask for more? He has provided me with the best doctors, therapists, hospitals and the latest medication.

Another participant said,

The only thing that really gives me a sense of well-being is my faith. The disease sure affected my self-esteem especially having the disease as a teenager. Knowing that there is something better than this body, knowing that God is guiding me through this by building my character and teaching me to help other people, is what gets me through each day. There are times when I still ask, 'why me, why so bad?', but I know God has a purpose for it. I don't see my life as wasted. I've been forced to go different paths and I have seen myself influencing people that will last their lifetime and it is because of the disease. God is working through the disease and I don't say that out of pride, God has caused that good to happen.

Family relationships were described by two participants as instrumental to their sense of well-being. One respondent commented that knowing that her children love her and care for her gives her a sense of purpose. She shared that as long as she can enjoy things like nature and her family she does not feel like she is losing everything and still has some control over her life.

Another participant said that getting together with her family gives her the most meaning and sense of well-being. She said that she grew up with a sense of closeness in her family and it has been very important for her to enable that to continue.

One participant said she felt very content with her life and that contentment gives her a deep sense of peace. However she said this has not always been the case. She said,

I tried to fight it, I even tried to ignore it but none of those things did any good. Now I'm content with the way things are. I know I have limitations but I have accepted them. I don't fight it and I try not to get depressed over it. I just go ahead and live my life and I think I've lived my life normally for a long time now.

The sixth participant said that being involved in activities such as travelling, visiting friends and family, and keeping up a household have give her a sense of well-being along with a sense of purpose. She expressed feeling frustrated and defeated,

I used to work all the time and for awhile I worked two jobs. I was always on the go. Now I can't even keep my house clean. I just can't do the things I want to anymore and I wish I could. Sometimes I just feel beaten down.

Perceptions of Difficult Aspects of Living with Arthritis

Regarding the most difficult aspects of living with rheumatoid arthritis, four respondents said that the attitudes of others are one of the hardest things to deal with. One woman said,

People think I'm lazy. I look like a big strong healthy person and people wonder why I can't do something. My husband knows I hurt though and he doesn't think I'm lazy, he knows how hard I've worked

all my life. I don't think people know when someone with rheumatoid arthritis is in pain, they just think you're putting them on.

Another respondent shared similar feelings by saying,

People always think of arthritis as an old person's disease and I'm not sure if people really understand what we go through. Unless you have arthritis it is hard to know what it feels like. It seems like people who have had family members who have arthritis are more sympathetic to what we go through. People can't really tell that I have arthritis just by looking at me unless they see me walking or they look closely at my hands.

A third participant said that it was hard for her to be around people who are healthy and see the contrast between others and herself. She said she feels others can be unsympathetic when they complain to her about being out of shape. Because of her early onset at age 15, she said that dealing with the disease has been more challenging psychologically than physically. She shared,

If I would have gotten the disease when I was older I would have expected it more because you expect things to not work as well when you're older. It's hard when you have the disease when you're young because people my age are concerned more about the physical. It's a challenge to face that I am not normal. Physically I can adapt to anything, mentally it's another story.

A fourth participant also said that the attitudes of others have been a major obstacle in her life. She said that she feels people

associate those with limitations as being poorly dressed and groomed and living in a shack. She recalls parking in handicapped parking spaces on numerous occasions and being questioned for parking there. She commented,

People just say things without thinking. I think education in the area of arthritis is really lacking. I think our society is so busy and everyone is self-centered and concerned with themselves.

Compassion is not at the top of the list of our human side. I finally began to accept that I had rheumatoid arthritis about a year after I was diagnosed. I've had the disease a long time but I usually don't like to bring it up because I don't think others really understand.

Three women said that they have struggled with feelings of inadequacy because they have had difficulty engaging in activities such as homemaking tasks and working outside the home. Asking for help and relying on others was reported as a major obstacle in adjusting to and dealing with the disease. Another commonly reported problem was the difficulty in planning ahead and keeping a schedule. This problem has caused particular frustration when trying to organize and plan family activities. As one participant stated that when she goes to bed at night, she never knows how she going to feel the next morning and that problem makes planning ahead and being organized difficult. She described "feeling so fragmented at times".

Two participants shared the pain of seeing those they love watch them struggle with the disease. One participant shared that when a close friend started to weep from seeing her in so much pain, she felt awkward and helpless.

One respondent currently lives alone and said she worries about something happening to her and not being able to get help. She said she is apprehensive about the future and her well-being. She said she is concerned about her ability to continue to care for herself in the coming years.

Other Variables Affecting Quality of Life

There were three variables reported by all six participants that affect quality of life: fatigue and lack of endurance, pain, and loss of strength. One woman said that the fatigue can come regardless of previous activity level, leaving her feeling confused and defeated. Many commented on how fatiguing pain can be and noticed an increase in fatigue with an increase in pain. One woman stated, "no matter what I do I'm worn out, it just seems like everything is an effort." The participant who is changing her career because of arthritis, attributes the problems in her profession as related more to fatigue than to any other variable.

All participants said they struggle with pain almost constantly. All reported that the pain varies, and rarely is pain absent. One woman reported,

When I'm in a lot of pain my temper is shorter. There are times when the pain is so bad that I am crying by the time I get dressed. I remember when my son graduated I was in so much pain that I could barely get dressed let alone drive there. Sitting through the ceremony was absolute agony but I knew I had to be there for him.

As stated above, many said that it was difficult to separate pain and fatigue, when one is present, the other is usually there also.

Loss of strength is also a major problem reported by all participants. Although surgery has been beneficial in regard to pain and range of motion, participants reported that loss of strength is something that surgery can't correct especially in the hands. Two women said that the hardest aspect that they face with loss of strength is the lack of confidence they have during activities, especially those that require lifting. They said that often they run into hazards when they start an activity and realize midway through it that they cannot complete the task, which leaves them at risk for injury or increased pain. As stated earlier most of the participants reported difficulty opening heavy doors in public and two women said they sometimes lack the strength to open refrigerator doors. One participant stated that she frequently forgets how limited her strength is until she sees her own children handle an activity with relative ease. However, she says she tries to focus on the strength she has left and not the strength she has lost.

Three participants said they had been greatly affected in their daily ability to be functionally independent. All have said that one of the most difficult aspects of losing functional independence is having to ask others for help. One woman says her husband takes over tasks she once did and that bothers her some because she feels she could still accomplish many of these things but is too slow, consequently her husband believes it is easier for him to just do them for her. Many of the participants expressed feelings of despondency and inadequacy because they are unable to complete tasks that once helped them to feel accomplished and productive. Most reported problems with manual dexterity and having to curtail certain leisure interests such as knitting, crocheting, and gardening. All respondents said they felt grateful for their continued ability to care for their personal needs independently. Times of greatest difficulty in this area has been during an acute exacerbation or after surgery.

Three women said that although they cannot accomplish tasks which they could achieve prior to the onset of the disease, they feel satisfied with what they are currently able to do on their own, such as lighter homemaking activities and participation in social gatherings.

Four participants reported bouts with depression and despair. Most have said what keeps them going and helps to lift their spirits is the love and concern of family and friends. One woman said she needs someone who will keep her from feeling depressed because she feels like the world is against her. Another participant commented,

Anyone going through trials will feel depressed at times. I think everyone has problems with depression whether or not they have a disabling condition. I have a choice, I can let the disease consume me or I can chose to have a balance in life. I have no choice over the disease but I can choose the way I deal with it. I do struggle from time to time when fear and loss of hope sets in. That's when I have to trust that God will get me through.

One woman commented that she struggles with depression often because of the lack of ability to do the things she wants to do. She said that when ordinary things are an effort she "feels worthless."

Two participants said that their lives are regularly upset by abnormal sleep patterns because of pain, causing fatigue and problems functioning the following day. All participants said they require more sleep since the onset of the disease, thus shortening their waking hours and time available to accomplish necessary tasks.

Only one participant said that she is bothered by physical deformities especially in her hands. She said she always hated the physical deformities because she prided herself in the way she looked, but has reached the point where she tries not to fight it anymore. One participant said that her surgical scars and the cosmetic appearance of her hands does not bother her; however, she believes it has affected her family. She said that she has seen her family get angry when strangers inquire about her hands or her problems with walking. Ironically, most of the respondents commented that they felt misunderstood because they

do not "appear" to have any physical barriers. Many comments throughout the interviews have proposed the idea that people with arthritis do not have the hallmark signs that let the public know that they have limitations, such as wheelchairs, walkers, or problems with communication.

Isolation was also identified in many of the participants' responses as affecting the quality of their lives. One participant said she frequently felt alone and isolated especially when she underwent surgery. She shared, "no one can go through that with you even if they wanted to. It's just you and God." Many other participants shared similar feelings of isolation. One respondent said,

It is so hard to explain the pain to people. It's like no other pain you've ever had and only those with the disease can really identify. You feel alone at times and you feel different. It's hard to face you are not normal, that's a real challenge.

Aspects That Have Helped Most With Functional Independence

Two participants said that taking their medications has helped them significantly in their ability to function independently. As one woman shared, "if I don't take my pills, I won't be able to do a thing, it's as simple as that." One respondent said that MP arthroplasty on her right hand has helped the most. She said that before her surgery, her hands were to a point where the physical deformity and pain would not allow her to complete simple tasks. She has been pleased with the outcome on her right hand and desires surgery on her left.

Adapted equipment was mentioned by one woman as the most helpful aspect in her ability to complete certain tasks independently. The equipment she mentioned helped her most in her self-care tasks and functional mobility.

Two participants said that their attitudes and faith in God have been the most beneficial aspect in their functional ability.

Aspects That Have helped Most in Coping Emotionally

Attitude was mentioned by three respondents as the most important factor that has helped them to cope with the disease. One participant stated,

Pain is not the enemy, it is the fear of it. My attitude is something I can choose and have control over. I think it is real important in to have things in my life that I can look forward to especially after the surgeries. Of course, my faith in God has been tremendous and that is something I have chosen.

Another woman said,

I think what has helped me the most is just being bull headed! I just keep trying to keep going and I give myself a good talking to when I get real depressed.

Two respondents said that the companionship and love from family and friends have helped them the most to cope emotionally. One woman expressed the struggle she faces living alone. She said there are times when she feels alone and that she cannot overcome the disease. She said

that when she is depressed she has a hard time reaching out to people because she does not want to bring them down. She said,

My best girlfriend calls me everyday and I don't know where I'd be without her. She knows when I'm getting to my breaking point and how much I can take. When I get to that point, she takes me out and reminds me of what I can still do. Her husband will pick me up and carry me all the way up the stairs even in public. It makes me feel good that there are no limitations with them. They treat me like I'm not a burden and find one way or another to break down barriers.

One participant said that knowing other people are out there struggling along with her has helped her to carry on. She expressed mixed feeling towards her encounters with medical personnel. She said,

The therapist and doctors in the hospital were very caring and that helped me a lot emotionally. But part of me feels like suing the doctors because of the lack of research and treatment for rheumatoid arthritis. This disease has already ruined 20 years of my life.

Participants were asked what changes they would want to make to improve the quality of their lives. Most respondents first said they would like to get rid of the disease. Two women said that for the most part they are satisfied with the quality of their lives now. They shared that they are content with their living situation and felt they are able to cope with the difficulties that the disease poses. One of these women, who has had 24 surgeries at a relatively young age said,

I try to live one day at a time. I don't look back and I only look ahead to set goals. I like the quality of my life, I have been blessed in so many ways. That is what I focus on.

Two participants said that they would choose financial stability to improve the quality of their lives. One woman said that being a young and single woman is hard especially now that the disease is forcing her to make new career choices. Another participant said she has had success with MP arthroplasty on her right hand and would like to have the same operation on her left hand to improve her functional independence. She commented that her ability to work independently at home is very important to her. She is concerned about adequate insurance coverage and her ability to pay any difference.

One respondent said that she would like to change her attitude about the disease. She said,

Keeping a good attitude is the best thing to do. I would like to change mine because it isn't that good. I need to keep more of a bright and cheerful outlook and try not to think of depressing things.

The last respondent said she wished she could change her ability to participate in more social events and travel more with her husband.

All respondents said that living with the uncertainty of the disease process was one of the most difficult aspects to cope with. Most said that it was difficult to plan their daily lives. One respondent reported that the biggest game arthritis plays on people is the day to

day uncertainty. For her, this uncertainty is a big source of her insecurity and low self-esteem. Long term it affects her in planning for the future and whether to marry and have children. Another woman shared that dealing with the uncertainty of the disease was not something she had anticipated. She said the one thing she wished she could have had in the beginning was someone who would have talked to her about the emotional aspects of living with the disease and someone to help her prepare for the uncertainty about the disease process. She said it would have been nice for someone to say, "you have a choice with your attitude and how you're going to let the disease affect you."

Biggest Fear

Five participants said they feared most being totally dependent on others for their care. Two of these women mentioned that they feared being in a wheelchair and the stigma of being "crippled." Most relayed experiences and periods of their disease when they had to depend on someone else for their self-care needs and described the difficulty of losing their independence. One participant said,

When I first had my arthritis I didn't want to live it was so bad. I couldn't get up by myself, I couldn't cook, I couldn't even get dressed. I had to be wiped up after a shower and I felt very helpless. The thought of that does scare me.

One woman said her greatest fear is falling down the stairs. She reported a total of five falls since the onset of the disease but never

down the stairs. She said she feared the pain of falling and not knowing how to turn to make the fall less painful.

Additional fears were described as well as loosing the ability to care for one self and the fear of falling. One woman said that because she has had surgery for cataracts and glaucoma in both eyes at a young age, she fears the possibility of loosing her eyesight. She shared that throughout the disease her fears have changed. She said,

In the beginning I think my two greatest fears were losing my children and thinking that the disease would hold them back from being active and leading a normal life. Neither one of those things happened and I think that the things I fear the most never come to pass. However, I don't look forward to being in a wheelchair and the thought of loosing my eyesight does scare me.

Another participant said that she fears not being able to pay her bills for surgery and medications. The participant who lives alone said she fears getting to the point where she could not move and get help such as in a fall situation. She said that she fears not being able to feed her dogs if she could not get help.

Outlook on Life

Each participant reported the kind of person she considered herself to be prior to the onset of arthritis and in what ways, if any, the disease had changed her philosophy or outlook on life. One woman described herself as friendly and outgoing before the onset of the disease and said that she does not feel she has changed too much since

then. She said that she may feel depressed more than she used to as a result of the disease but her outlook on life is largely the same. She said, "as long as I can still eat and talk I am okay."

One respondent said that before the onset of the disease she considered herself to be easy going, fun-loving, and enjoyed staying active in her work. She says that having arthritis has made her a more critical person especially of the government and doctors because she feels that arthritis has been ignored in regard to treatment and research.

Another respondent described herself as easy going and sociable before the onset of the disease but feels that her personality has changed somewhat. She says she feels she is more hateful when she hurts and is more irritable towards others, especially those close to her.

Three respondents said that they considered themselves extremely active and outgoing especially in sports prior to the onset of the disease. Similarly these women said that they believe God has worked through the disease to help them to slow their lives down in a positive way. As one participant explained,

I think it has been good to have had to slow down because God has taught me to listen to people and take my time with people and not be in such a rush like the rest of the world. I see a real benefit of having this disease, I have received a great gift in learning to take life slowly.

Another respondent shared, "I believe in God and I think that probably God allowed this to happen to get me to slow down."

Besides helping her to slow down, another woman said that she has seen how her arthritis has had positive effects on her children. She said,

I can see how much more compassionate they are with other people. At first I didn't think anything good could come from it. I thought my children wouldn't turn out okay because I physically couldn't take care of them. Now, I can see a lot of blessings. My children are a lot more self-sufficient and have learned to do a lot of things for themselves. I think their quality of life has probably been better because if I didn't have the disease I may have prevented them from growing.

When participants were asked if they talk often to others about their disease process, all six said they avoid talking to others mainly because they said they feel misunderstood and do not want to focus on the disease. One woman said,

People don't see the limitations as much because they are mostly inside. Because I get up and get going people just think it's no big deal. It's hard to explain my situation to others and I don't like to dwell on it.

Other participants said they do not feel comfortable sharing their experiences with the disease because they are afraid they will turn people off. One woman said,

I don't like to talk about it because I feel people will think I'm complaining or something. When I was an Ambassador for the Arthritis Foundation I would go and talk to other people but not in a sense that was complaining but in a sense that they needed to know that they are not the only ones who are hurting and that there are things that they can do about it. That would be the only way I would talk about arthritis with other people. I usually don't initiate the conversation.

The participants said they felt good about discussing their experiences with rheumatoid arthritis in this study and feel a need to clarify misconceptions and misunderstandings that the public may hold. All said they were anxious to hear what the other respondents had to share.

CHAPTER 5

DISCUSSION OF COMMON THEMES

In this chapter, the common themes that were apparent in the data reported in chapter 4, are identified and discussed. Literature that supports or refutes these themes will be presented along with a discussion of the relationship of the common themes to the theoretical framework of The Model of Human Occupation.

Nine themes were identified. These themes were: similarity of disease process and medical intervention, rheumatoid arthritis as a hidden and misunderstood disease, experience of isolation, importance of self-identity, varied definition of independence, feelings of inadequacy and need for purposeful activity, loss of control versus adjustment to disability, attitude as a sense of control, and ability to rely on oneself.

In chapter 6, the identified themes will serve to answer the research questions and determine the implications for the profession.

Similarity of Disease Process and Medical Intervention

All six participants described similar physical symptoms such as those described by Pedretti (1985). These include joint inflammation, edema, pain, and loss of joint range of motion and functional ability.

All six participants said that the symptoms initially started on one side of the body and eventually moved to the other side. Although four women described a rapid onset and the remaining two a more gradual onset, the progression of symptoms and medical treatment was strikingly similar.

The process of medical intervention began with conservative medical treatment and medication in all six cases and progressed to stronger, less safe drugs and in most cases, surgery. The general opinion regarding medications from the participants was to be conservative especially with pain medication. Yet most women agreed that medication has been one of the most helpful means available for coping with both physical and emotional aspects of the disease. Liang et al (1984) also reported that patients described medication as one of the most important aspects in helping persons to cope with the disease.

Loss of hand function and ability to walk long distances were the two most common complaints regarding loss of function by all respondents. Surgery for the treatment of rheumatoid arthritis was portrayed positively by all six women and instrumental particularly in regaining hand function and the ability to walk. Occupational therapy for post surgical rehabilitation, especially for those who had hand surgery, was deemed necessary and important for optimal surgical and functional outcome.

Melvin (1982) reported that genetic factors may be attributed to the onset of the disease yet only one respondent said that she recalled both

grandmothers specifically having rheumatoid arthritis. Three others said that they remember one or two family members having occasional joint achiness. Liang et al (1984) reported stress as one of the main reasons given for contributing to the onset of the disease. Five respondents in this study reported a major stressful life event prior to the onset of the disease. However, most women gave multiple reasons as to possible causes for the disease onset supporting the multicausal hypothesis described by Zeitlin (1977). Of the four women who have had children, all four developed symptoms after the birth of their last child possibly suggesting a hormonal link. The fact that three-fourths of persons with RA are women, may also give credence to this theory. Other commonalities described by all participants were the increased need for sleep after the onset of the disease, an average of two hours a night, and an increase in symptoms with a change in barometric pressure.

Earlier literature of the 1950's and 1960's described the "arthritis personality" in which individuals brought about a rage against their body and may be responsible for their disease (Moos, Solomon, & Lieberman, 1965). The respondents who were familiar with this theory expressed anger and resentment at the suggestion, from other people or literature, that they brought on or caused their disease. They reported that they did not agree with this theory and stated that its implications have been damaging both physically and psychologically, producing increased guilt, stress, and apathy over control of their lives.

All six respondents said that they described themselves as more active than average before the onset of the disease and were initially shocked by the diagnosis. Many described a denial period early in the course of the disease and a determination to "beat the disease." This determination was found to be correlated with a younger age of onset. Although the respondents expressed annoyance regarding the lack of research, the younger participants seemed more hopeful for a cure for the disease. This finding was consistent with that of Edwards, Calabro, & Wied (1964).

Thompson (1988) and Cornelissen, Kasker, & Valkenburg (1988) reported that coping with loss of function was more difficult to deal with than pain. Five out of six respondents supported these conclusions and said that loss of function was harder to live with than the chronic pain. The sixth participant said that it was difficult for her to separate the two variables because she feels they are very interconnected. However, she did state that she has found it harder to adapt mentally than physically.

The four main variables that were identified as most difficult to live with were loss of function, fatigue, decreased strength, and pain. Interestingly, when asked what level of pain was most typical in daily life on a scale of 1-10 with 10 requiring bedrest, five women said "7" and one said "9." All respondents reported pain as almost constant. Another variable that was described to pose problems in daily living were the secondary symptoms caused by either the disease itself or from

side effects to the medications. These included problems with the eyes, autoimmune system, skin, lungs and cardiovascular system.

Rheumatoid Arthritis: A Hidden and Misunderstood Disease

Throughout the interview process, the participants expressed their strong sense of feeling misunderstood. Reportedly, one of the most frustrating and difficult aspects with which to cope psychologically and emotionally, was being looked upon as lazy or as "putting on an act." One participant stated that she worked hard all of her life and presently accomplishes as much as she can within her limitations. Yet she says that those who have not known her long or do not know her well have implied that she is lazy, leaving her feeling frustrated and discouraged.

Liang et al (1984) found that most patients felt that their family and friends understood their illness. Similarly most participants said that they were satisfied with their home life and with their close personal relationships and felt that those closest to them have understood the difficulties they face. Respondents stated that they have felt misunderstood by those who were not as close to them such as distant friends, acquaintances, and the public rather than close friends and family. However, participants said that they were reluctant to discuss their disease even with those close to them and rarely initiated conversations about the disease.

Fatigue and pain do not manifest themselves outwardly which complicates the problem of lack of public awareness and understanding. Kielhofner (1985) said that joint pain and other symptoms of arthritis, are not visible to others, particularly in the early stages of the disease and stated that these particular symptoms may be interpreted by friends, family and co-workers as signs of laziness or malingering.

One respondent said that friends and co-workers have made comments such as, "you look good, you must be feeling good." She said that the problem is that the symptoms of arthritis for the most part are hidden. Only until later in the disease process do more outward signs appear such as hand deformities or problems with walking. Even then, these signs can be subtle and not readily noticed. One woman said that although she has visible hand deformities, it is evident that many do not notice or understand her pain because when they shake her hand they squeeze too hard.

Many respondents said that the hardest aspect that they confront in coping with the disease is dealing with the attitudes of others, especially the public. Two participants recalled being angrily questioned for parking in a handicapped parking stall even though they possessed a handicapped placard. One young woman said she would rather walk for a distance, even though it is difficult and painful, instead of parking in a handicapped space for fear she will be misunderstood and questioned. She said that having arthritis at a young age is especially hard because the public views arthritis as "an older person's disease."

She said that she is uncomfortable asking for help in public because, "people look at me like I'm crazy because I look normal." She commented that on the occasions when she uses her cane, an outward sign of a limitation, others jump at the chance to open a door for her or help her with a heavy item. Another respondent said that when she dresses up she receives less assistance in public. She commented that she feels the world thinks that if someone is limited or disabled, they have to be poor or shabbily dressed.

All respondents expressed annoyance and disappointment with lack of funding and research for rheumatoid arthritis as well as the lack of public education regarding the scope and severity of the disease. Something that may add to misunderstanding about what it is like to live with RA, is the person's hesitancy in discussing the disease for fear it may turn people away and compromise relationships as mentioned earlier. The respondents said that they do not want to be seen as complainers or ones to dwell on the disease. Some said they have noticed that physicians who do not know them well, will not take time to listen to them if they think that they are chronic complainers.

Most felt that public education should not necessarily come from those who have the disease but rather from the medical establishment and the media. Participants themselves expressed a need to want to learn more about the disease process. Edwards, Calabro, & Wied (1964) also concluded that those with RA desired to learn more about their disease. Even more importantly, there exists a strong desire from the

participants to feel that others, especially the general public, understand their lives and concerns.

Experience of Isolation

Although respondents commented that they felt supported by those close to them, feelings of isolation frequently emerged. The hesitancy to talk about the disease for fear of turning others "off" or dwelling too much on problems, has left many respondents feeling isolated and alone. One woman said that the pain associated with rheumatoid arthritis is like no other pain she has ever felt and no one can really understand what she goes through unless they have the disease also. Another participant said she feels most alone and isolated right before surgery. She said, "no one can go through that with you even if they wanted to. You are alone."

Strong feelings of isolation were related to a young age of onset mainly due to the inability to find other persons of the same age with the disease with whom to relate. For the younger women with the disease, arthritis support groups produced further feelings of isolation primarily because of a difference in lifestyle. One participant said that because she worked full-time while others in the group were able to remain at home, she found it difficult to discuss coping strategies because of different perspectives. While others were advocating rest and slowing the pace of activities, she said she felt frustrated that

she could not take advantage of these options. Conversely, she reported having problems keeping up with those her own age and has felt left out of many activities especially those involving sports. In college, she remembered frequently walking alone to class because of the inability to keep up with classmates.

Another participant with an early age of onset recalled the struggle of raising small children. She said she met only one other woman with RA who was a young mother as well. She said their relationship was extremely important in helping her to cope with her circumstance but the relationship drifted apart when she moved to another city. Since then, she said she has not found another woman of her age with RA.

Four women said they do not participate in social events as much as they did previous to the diagnosis. One woman said that she fears holding others back especially if an activity requires walking so consequently she declines many social invitations. Another participant said that since she has had arthritis, she feels some of her friends have avoided her. In addition, much of her previous social activity involved dancing, and because her arthritis has limited this activity, her opportunity for social contact has diminished. Another woman said that her limitations have forced her to spend most of her time at home which have increased her feelings of separation and isolation.

Many respondents expressed a feeling of fear of isolation such as being caught in a situation rendering them helpless. Many said they avoid venturing out too far from home or work for fear of not being able

to get back because of fatigue, pain, or lack of strength. One respondent recalled sitting down in a low chair in a store and not being able to get back up. She reported feeling helpless and isolated, and had to wait for someone to pass by to help her up. Problems with architectural barriers such as large heavy doors and stairs have discouraged many participants from venturing to places that they desire to go.

Finally, feelings of isolation have resulted from encounters with medical personnel. The most frequent complaint from the participants was the feeling that physicians did not treat the whole person but rather just "looked at the joints." Many reported feeling alone when their doctors seemed to rush them and neglected to inquire about how the disease was affecting their lives or functional activities.

Importance of Self-identity

Liang et al (1984) reported that a common problem recounted by persons with rheumatoid arthritis was the inner conflict about whether to acknowledge symptoms to others and accept the sick role or to conceal the symptoms and try to appear normal. The results of the data for this study indicated that the participants were reluctant to acknowledge symptoms or accept the sick role. Udelman and Udelman (1981), in their work with rheumatologic patients in clinical research and psychotherapy,

identified the importance of self-concept and the way a person views himself or herself as a total person.

Throughout the interview process, respondents frequently commented on the need and desire for a positive self-identity. Participants stressed the importance of wanting to be known for their positive roles and their contributions to their family, friends, and society. These roles include wife, mother, grandmother, friend, co-worker, and community and church member. Respondents resented and avoided the "sick-role" identity and being known as "the lady with arthritis." The possibility of being labeled was one of the primary reasons that the participants said they avoided talking about their disease, even to those close to them. Another reason that participants said that they were reluctant to discuss their disease was to try to spare their families and friends from the pain of watching them suffer. One woman said that she hated to see her children grieve when she was in tremendous pain. She said that she tried to keep the severity of the disease away from her family in order to establish a "normal" home life. She said she did not want her home to be a place of sickness and disease, but rather an atmosphere of optimism and well-being.

One woman said that because of her early age of onset, she had a hard time establishing her independence and self-identity because her parents were too overprotective. She said that she had to move a good distance away from her family to establish her identity and to break her dependency on them.

A "wellness" perspective and approach to life was a goal for which most respondents said they have strived. One woman said she preferred going to an outpatient clinic for her therapy in an attempt to steer away from the hospital environment that tended to center around sickness and disease.

Another important aspect regarding medical intervention was the relationships which the participants shared with their physicians. Respondents said they were offended when they felt they were being treated solely for the "disease" rather than being treated as a whole person in terms of how the disease process was affecting their lives and functional ability. The most favorable and positive interactions with doctors took place when the participants felt that they were being respected as individuals with unique needs and concerns.

Three participants said that arthritis support groups have been beneficial for achieving and maintaining a positive self image. These particular groups were portrayed as environments of laughter, fun, and sense of commonality and camaraderie. Rather than focusing on problems and limitations, these women said they chose to focus on what they could do. Conversation was primarily dominated by their roles and relationships with family and friends and the life events that surrounded them. These women said that although there were times of seriousness and need for sharing difficulties, the main objective for meeting was to try to enjoy their lives and establish friendships.

Two women said that they have experienced occasions when a friend would try to be too helpful by trying to pull them out of a car or holding onto their arm while walking. These women said that although they knew the friend was acting out of good faith, the gestures made them feel helpless and incapable. Most respondents said the friends whom they appreciated most were those who seemed to make them feel "normal" by focusing on abilities rather than disabilities. Many said they try to surround themselves with positive people that understand them but do not try to fix them.

Varied Definition of Independence

Liang et al (1984) reported that patients with rheumatoid arthritis described their greatest fear and worry to be physical disability. These patients said that decreased independence and function were seen as the "biggest problems" caused by their disease. Similarly, participants of this study said they feared loss of independence. The greatest fears described by the participants were not being able to care for one's personal needs, not being able to move, and being confined to a wheelchair. The ability to care for one's personal needs such as bathing, personal hygiene, and eating, were common areas of function that all participants said they would have great difficulty giving up.

Yet the definition for independence beyond personal care activities varied substantially among the respondents. A broader scope of

independent function was positively correlated with younger participants. The younger respondents said that their lives were more active out of necessity for earning a living or raising a family. Older participants seemed more resolved to forego various life tasks such as homemaking activities, and community tasks and errands.

The fear of having to give up driving a car did not correlate with age. The eldest participant said she no longer cared to drive a car and another participant said she never learned. The other four participants, ranging in age from 27-72 said that the ability to drive offered an important element in functional independence and all four said they feared the possibility of being required to give up driving. One woman said that after hand surgery when she temporarily could not drive, she felt like a prisoner in her own home.

The preference and use of adaptive equipment varied greatly among participants and did not seem to correlate with age or severity of the disease. All participants reported using adaptive equipment but the frequency of use of equipment and number of devices used for each person varied significantly. One younger woman said she uses a large variety of adaptive equipment for most of her activities. She said she learned about this equipment from an occupational therapist and from problem solving on her own and has appreciated the increased independence the equipment has offered her.

One participant who was introduced to occupational therapy at age 80, remembered being given a number of devices for dressing, writing,

and homemaking activities. Yet she said that complete independence in these skill areas was not a priority for her and she found the equipment cumbersome and frustrating to use. A younger participant also shared similar feelings when she was given equipment in the hospital to help her maintain independence after hip surgery. She stated that for the six week period of adherence to the total hip precautions, it was not important to her to be fully independent. She said she resented the implication from the therapists that she had to do everything on her own and struggle with the difficulty of manipulating the equipment.

Participants expressed a need to define independence in their own way as it relates to their experiences, preferences and lifestyle. Many said they were offended by others pushing ideas of independence on them without listening to their needs and wishes.

Feelings of Inadequacy and Need For Purposeful Activity

Kielhofner (1985) pointed out that in later stages of chronic disability, an individual may be required to give up or change roles. He added that when a person must take on roles that are seen as less important or less significant, a loss of identity and self-esteem may occur. He also adds that because of a person's inability to perform at their own standards, there may be a loss in the meaning of an activity (Kielhofner, 1985). Geis (1972) discussed the emphasis of American

culture on physical attractiveness and productivity and that feelings of self-worth and self-esteem tend to be all-or-none in nature.

Most of the respondents described frequent feelings of inadequacy and despondency because of the inability to complete tasks that once helped them to feel accomplished and productive. One participant said that a major source of her feelings of inadequacy came from the inability to accomplish simple tasks. Many reported problems with manual dexterity, walking, and the lack of sufficient energy and strength to complete tasks. Inability to engage in homemaking tasks and working outside the home have been reported as main sources of frustration and depression. Another commonly reported problem was the difficulty of planning ahead and keeping and organizing a daily schedule, because of exacerbations of the disease.

One participant said that keeping up with family events and maintaining her home gave her a sense of well-being and a sense of purpose. She also reported a sense of accomplishment from working two jobs at one time. Currently however, she says she frequently feels "beaten down" because she cannot do the things she did previously. Another participant said,

Arthritis just cuts you down to nothing. I guess that's why I feel so inferior, I just don't feel accomplished anymore.

Difficulty with engagement in leisure pursuits has been another source of frustration, especially for those who are retired. Some women

reported feeling bad for their husbands because of problems with travelling and sharing leisure activities.

One young respondent shared the difficulty of having the disease at an early age. She said, "people my age are concerned more about the physical. It's a challenge to face that I am not normal."

Participants described a need for purposeful and meaningful activity to diminish feelings of inadequacy and helplessness. One woman stated that although her physician advised against her horseback riding, she has found tremendous satisfaction and enjoyment from her ability to pursue this hobby. She said she has had to slow her activity level but is still able to derive the psychological benefits that riding has offered her in the past. Similarly, other participants said they have needed to adapt activities such as gardening, sewing or crocheting. Yet despite adaptations or problems with pain and fatigue, many women said they have found that involvement in purposeful activity is strongly related to feelings of well-being and worthiness.

All participants shared the difficulty of asking others for help mainly because it produced feelings of incompetency. Two participants commented that their involvement in water aerobics increased feelings of worthiness and sense of purpose because they were able to give to others. Another participant said that although she may not be able to give to her friends and neighbors physically, she can give in other ways such as encouraging phone calls or writing notes. She said that when she feels like she is giving to others, her feelings of worthiness and

purpose are increased. Another woman stated that it is not only important for her to engage in purposeful activities, but it is important for her children to see her life as fulfilled and complete. She stated that she has a strong need to maintain a "normal" home life that facilitates a sense of well-being.

Loss of Control Versus Adjustment to Disability

Kielhofner (1985) stated:

All persons with physical disabilities face some threat to, or interference with, their ability to continue to function within their occupational roles. Persons experience sudden and permanent change in their physical status and must often reconstruct everyday life and life plans (p. 170).

It was evident throughout the interviews that there was ongoing struggle between feelings and experiences of loss of control and adjustment to disability. Participants recounted the difficulty of maintaining a prior level of function within given occupational roles as the disease progressed. Feelings of frustration and defeat often preceded eventual adaptation to the changes the disease imposed. All participants said they felt shock and disbelief when they were first diagnosed with rheumatoid arthritis. Many reported feelings of loss of control over their lives and fear of the future. Five participants said they suffered greatly because they were not prepared emotionally for the

life changes that were to come. A young participant regretted that she had not been referred to organizations which could have helped her to adjust to the psychological impact of the disease. She said she remembered feeling out of control and lost for many years. One participant, however, expressed thankfulness that her rheumatologist sat down with her and her family and explained how her life would be altered by the course of the disease. She said that this early intervention and counsel was instrumental in helping her to accept and adjust to her situation.

Four women said that getting the "do's" and "don't's" for particular activities would have been beneficial in helping to adjust emotionally as well as to maintain a sense of control. A need for increased education was also listed as important especially in regard to learning how to accomplish tasks more independently and give one more choices in approach to daily life.

All participants described initial feelings of futility and frustration in learning how to adjust daily activities to accommodate the progression of the disease course. Through occupational therapy, assistance from arthritis organizations, and/or problem solving on their own, participants said they have learned how to better manage their daily lives and gain some control in handling the disease.

Many participants said that struggling with financial difficulties and insurance claims has added significant stress to their lives. One woman said she had fought with hospitals and insurance companies for

years, never feeling as if she could gain control over her situation or her finances. She said she finally hired a bookkeeper to take care of this for her and she now chooses not to worry about these problems. She commented, "I'm tired of fighting. If they want all my money, they'll have to put me in jail."

One participant who has had arthritis for 40 years remembered fighting the disease for many years trying to gain control over it. In recent years her perspective has changed and she now finds contentment. She said, "I tried to fight it but it didn't do any good. I know I have limitations but I have accepted them."

The youngest participant recalled after the onset of the disease, she had to slow down in many areas of her life, especially walking. She remembers the frustration of not being able to keep up with her peers and adjusting her daily routine to accommodate her increasing limitations. Yet despite her hindrances, she has found benefits from her restrictions. She commented that having the disease has taught her to slow down and listen to people. She said she does not feel the pressures of needing to hurry through life as she once had.

Liang et al (1984) found that although patients with rheumatoid arthritis reported "lowered spirits" for substantial periods of time, approximately 50% of the group said that their illness had a positive effect on their spirits and this was described as "being thankful for what I've got."

Correspondingly, many respondents said that they try to focus on what they are able to do presently rather than on their limitations. Many have stated that their present limitations have helped them to cherish the functions they still are able to maintain. One woman said, "as long as I can still eat and talk I am okay." Another respondent said that although she cannot travel and walk as she did previously, she is still able to enjoy her family and her beautiful surroundings. The biggest fears described by the participants were situations of increasing loss of control such as being totally dependent on others for all needs including self-care, being wheelchair bound, fearing falling down stairs, and fearing not being able to secure help in an emergency.

Attitude: A Sense of Control

Dr. Victor Frankl, a survivor of the Auschwitz Nazi death camps, wrote,

...everything can be taken from a person but one thing: the last of the human freedoms--to choose one's attitude in any given set of circumstances (Frankl, 1980, p. 104-105).

Throughout the interviews, the researcher was impressed with the participants struggle to gain a sense of control over their lives. Although the respondents expressed past and present fears and frustrations of losing control, one element stood out for most participants in gaining control over their lives. This element was the

ability to still chose one's attitude toward one's life and the disease process. Eventual adjustment to the disease process was strongly linked to attitude. The respondents who seemed to have more difficulties coping with RA, frequently alluded to their feeling of lack of control over their lives. Importance of attitude was rarely mentioned in the course of their conversation.

Kielhofner (1985) described the effects of chronic diseases such as arthritis on the volitional subsystem. He stated,

Since the disease process is progressive and results in irremediable losses of function, ultimate adaptation of the chronically disabled person depends on adaptive volitional changes and choices (p. 176).

Kielhofner's observations and conclusions were restated by many of the respondents during the interviews. One participant said that although she did not chose the disease, she can chose how she responds to the disease. She attributes her attitude, positive or negative, as directly influencing her sense of well-being.

Many respondents commented on the importance of redirecting the focus from themselves to others, especially during times of extreme pain. This conscious choice was mentioned as an important resource for pain management. Many have said that they have chosen to surround themselves with positive people as well as focusing on those activities which they were still able to accomplish.

Three women said that their faith in God was instrumental in coping with the disease and helping their attitudes. One woman said that focusing on her faith helps her to see beyond today's suffering. She said what is important to her is not her physical body which she says is temporal, but rather her choice in attitude. She says she has tried to focus on the positive and look for the blessings the disease has brought her such as learning how to slow her life and listen to others. Another participant mentioned similar feelings by stating that she has also tried to focus on the positive aspects of the disease. She commented that her children have benefitted from her having arthritis because she feels they have a better understanding of disability and seem to have a strong sense of compassion and empathy for others in similar situations. One respondent said that her belief that God is in control of her life and her future has brought her tremendous peace and resolution. She feels God will not give her more than she can handle and this helps her to face the future without overwhelming fear.

Ability to Rely on Oneself

Early in the disease process, respondents said they tended to rely mainly on medical treatment to alleviate symptoms and exacerbations of the disease, as well as to help them cope with the devastating effects of the disease process. Many respondents also recalled trying many

various methods to either cure or relieve symptoms such as fish oil diets and copper earrings and bracelets.

Years of coping with rheumatoid arthritis has taught most respondents to rely more on themselves than on medical science. Although medications and surgery have proven beneficial, participants said they realized that current medical intervention cannot completely arrest the pain nor stop the disease process. Initially most participants said they frequently called upon physicians when symptoms increased. Now, many of the women said there no longer exists a pressing need to immediately see a doctor. One woman said that making it through bad periods of the disease has taught her that she can rely on herself to get through once again. She says that she looks ahead knowing that she can face anything and her fear of the future has diminished as she has survived difficult periods.

Another participant remembered visiting Guatemala and the amazement of her friends when she did not go to see a doctor when her pain increased. She recalled saying that she already had the medication she needed and the rest was up to her. She stated that she has dealt with the pain before and she can deal with it again. She said she will rely on her inner resources when she changes careers to accommodate her limitations.

The search and need for information regarding what one can do for oneself has also increased as participants have become more aware of limitations of medical science. Respondents said they had difficulty

accepting suggestions for maintaining independence early in the disease process. Denial and a stronger reliance on medicine for cure curtailed ambitions to depend on inner resources. Time and experience has helped participants to realize that one of the most important resources for coping with and handling the disease of rheumatoid arthritis has been the ability to rely on oneself.

CHAPTER 6

RESULTS, RECOMMENDATIONS, SUGGESTIONS, AND SUMMARY

This chapter answers the research questions for this study and discusses how the findings relate to occupational therapy theory and practice. Suggestions for further research are discussed and a summary of the study is presented.

Research Questions

Question 1: What are the variables which persons with rheumatoid arthritis identify as valued for their quality of life?

There were a number of variables identified as common themes by the participants in this study that affected the quality of their lives. These common themes were: the similarity of disease process and medical intervention, rheumatoid arthritis as a hidden and misunderstood disease, the experience of isolation, the importance of self-identity, the varied definition of independence, feelings of inadequacy and need for purposeful activity, loss of control versus adjustment to disability, attitude as a sense of control, and the ability to rely on oneself.

All participants stated that the medical intervention they received greatly improved the quality of their lives. This included medication

to reduce inflammation and pain as well as medication to slow the process of the disease. Surgery followed by therapeutic intervention was also mentioned by five participants as an important aspect to preserve function and reduce pain thus improving the quality of their lives.

One of the strongest themes that emerged from the interview process was the expressed need to feel understood. Participants stated that an important factor in coping emotionally with the effects of the disease is to feel that others understand the difficulties they face. Coping with uninformed public attitudes was described as particularly discouraging and frustrating. For all participants, this has been an ongoing struggle throughout their disease process.

Feelings of isolation affected the lives of all participants. Many said that they would feel less isolated if they felt they could share their experiences with others without the fear of possibly turning them "off." The women who were diagnosed with the disease at a younger age said that they would have felt less alone and isolated if they had known other persons of their age and circumstance with whom to relate.

Another important variable affecting the quality of their lives was the desire of the participants to be identified as a unique person with strengths and assets to offer their family, friends, and society. Respondents expressed resentment at the notion of being labeled as "sick" or as "the lady with arthritis." Most women commented that they did not want to dwell on the disease and chose to live their lives as

normally as possible. Respondents expressed gratitude to those friends and family members who "helped make them feel normal and not disabled."

Independence in personal care was mentioned by all participants as an important part of their daily lives, including independence in bathing, personal hygiene, and eating. All respondents said that giving up independence in these areas would greatly affect the quality of their lives. Many stated that periods such as after surgery or during an exacerbation of the disease has forced them to rely on others for their personal care, leaving them feeling helpless and overly dependent on others.

Although all respondents reported frustration with limitations in their activity level, all women described a need for purposeful activity and found that involvement in purposeful activity is strongly related to feelings of well-being and worthiness. The ability to continue to pursue leisure interests was particularly important to those women who are retired or are no longer raising a family.

Having a sense of control over one's life was strongly linked to a high quality of living. All participants said they have struggled with trying to control the disease process but to little avail. Many said they have struggled for years with feelings of loss of control, depression and despair. Respondents said that through years of living with the disease, problem solving on their own, and receiving professional help, they have learned ways to gain control over areas of their lives that were once in turmoil. These areas include adapting the

environment to accommodate limitations, using adaptive aids, adjusting one's daily regime, and becoming more educated on how to handle the effects of rheumatoid arthritis. Many participants expressed increased control and satisfaction with their lives by participation in leisure interests or arthritis support groups.

Perhaps one of the most important variables identified by the participants that produces a sense of control is the ability to choose one's attitude. As many expressed, one may not have the ability to control the disease process but one does have the ability to control one's own attitude. Participants stated that a positive or negative attitude can directly impact the quality of their lives and their sense of well-being.

Finally, respondents said that the quality of their lives improved greatly when they had learned how to rely on themselves. Through years of living with rheumatoid arthritis, participants said they have learned to tap inner resources for coping with the disease, giving them a stronger sense of self and of well-being.

Question 2: What are the variables which persons with rheumatoid arthritis identify as essential to their ability to function independently?

What became apparent throughout the interviews, is that the meaning of "functional independence" can vary greatly among persons with rheumatoid arthritis. Age, lifestage, living environment, knowledge and

use of adaptive equipment, and adjustment to the disease process are just a few variables that can influence how one sees oneself in regard to being independent or desiring independence.

Although many aspects regarding functional independence vary among the participants, there are two areas of commonality that recurred throughout the interviews. These areas include the ability to use one's hands and the ability to walk. These areas are mentioned more frequently than any other areas regarding functional independence.

All participants said that the disease had greatly affected the use of their hands which has made many activities difficult or impossible. For many, surgical intervention has proved extremely beneficial to preserve or increase hand function. Similarly, post surgical therapy and education was also deemed crucial to increase functional use of the hands. Adaptive aids for some have increased hand function such as adapted key rings, built-up handles, and a variety of devices making kitchen and other household activities easier. Yet for others, adaptive equipment such as dressing sticks, reachers, and sock aids have been reported to be extremely cumbersome to use when the hands have been significantly affected by the disease.

The ability to walk was mentioned as an important aspect of functional independence and all participants said they feared confinement to a wheelchair. The respondents shared common problems with walking such as community barriers, lack of sufficient energy and strength and joint limitations. Again, surgical intervention for the

hips, knees and feet has been helpful for many to maintain ambulation. Learning to structure time and conserve energy were mentioned as important aspects in maximizing the ability to walk given distances.

Surgical intervention was favored by all participants and four of the six women attributed surgery as directly benefitting their ability to function optimally. Post surgical rehabilitation was credited as an important aspect of optimal surgical outcome especially for those who have had hand surgery. Splinting and patient education were listed as some of the most therapeutically beneficial treatment techniques.

For many, financial independence and stability or lack thereof, have influenced functional independence. At the time of the interviews, one participant said she desired MP arthroplasty on her left hand after experiencing the positive outcome of this surgery on her right hand but she did not think her insurance would cover an additional surgery. She said that her financial situation has not permitted her such advantages as cleaning services for heavy household chores, in order to allow her more time and energy for activities she enjoys. This same complaint was mentioned by two other women who have struggled with the burden of having to keep up with difficult activities in order to maintain a household or earn a living.

Question 3: Are there common variables among a sample of persons with
rheumatoid arthritis?

Throughout the interview process, the researcher was impressed

with the similarities among the participants. Given the variances among age (27-80), socioeconomic status, lifestage, roles, and living environment, the themes that emerged throughout the interview process confirmed that there are numerous common variables held by a sample of persons with rheumatoid arthritis.

Nine common themes were identified. These themes were: similarity of disease process and medical intervention, rheumatoid arthritis as a hidden and misunderstood disease, experience of isolation, importance of self-identity, varied definition of independence, feelings of inadequacy and need for purposeful activity, loss of control versus adjustment to disability, attitude as a sense of control, and ability to rely on oneself.

Although there were variances in some areas such as in the definition of functional independence or the expressed need for independence in certain activities, there emerged more commonalities than discrepancies among the sample of women in this study.

Question 4: What is the perception of persons with rheumatoid arthritis of the role of occupational therapy intervention to influence quality of life and ability to function independently?

Most of the respondents expressed the perception that a main role for occupational therapy is patient education. This education includes joint protection, work simplification and energy conservation

principles, environmental adaptations, and learning about the anatomical and physiological aspects of the disease process. Three participants claimed that education was one of the most helpful aspects of the occupational therapy they received. Four of the six subjects said that they could have benefitted from occupational therapy earlier in their lives, especially in relation to patient education. These women said that the education they received has made a difference in functional ability as well as dealing with pain. Two women said that if they had received the education earlier, they may not have put unnecessary stress on their joints. Along with patient education, respondents said they felt that it was the therapist's role to inform them regarding the reasons why a treatment was being given in order to increase motivation and follow-through.

One participant who has had extensive therapy because of numerous surgeries and severity of the disease, referred to her intervention as holistic, and she said that she felt included in her program and treated "like a person." She commented that her therapist helped her with many facets of her daily life and helped her to continue to do the things that were important to her. She felt her program was very personalized and tailored to help with her emotional and physical needs.

Pre and post surgical splint fabrication was mentioned as another important role of OT by five participants. Splinting was mentioned as the most important aspect for optimal recovery and functional outcome

following hand surgery. Three participants said night resting splints significantly reduced pain and stiffness.

Only two participants said they first learned of adaptive equipment through an occupational therapist. This is most likely due to the introduction of OT services later in the course of the disease for most of the participants. Others learned about adaptive equipment through the Arthritis Foundation and other community resources, as well as from family and friends.

One participant did not see OT as necessary for her particular needs. Her experience with the profession has mainly been suggestions for use of adaptive equipment which she stated has been of some benefit but something she had been aware of before her encounter with an occupational therapist.

Recommendations for the Profession

One of the objectives of the profession of occupational therapy is to give priority to preventive activities in an effort to reduce the incidence and severity of disease and also to reduce the cost of disease (Jaffe, 1986). It is important for occupational therapists to become involved early in the course of the disease to help persons adjust both physically and emotionally as well as to mediate and prevent dysfunction.

Although patient education was viewed by the participants as one of the main roles of occupational therapy for the treatment of rheumatoid arthritis, many of the respondents reported that they received information regarding their disease too late in the disease process. Increasing physicians' awareness of the role that occupational therapy could assume in the treatment and rehabilitation of persons with rheumatoid arthritis could benefit a person's adjustment to the disease process. Increasing community awareness of occupational therapy is another important avenue to help persons receive early intervention. Expansion of occupational therapy involvement to teaching classes through resources such as local arthritis support groups, outpatient clinics, and the Arthritis Foundation could increase public awareness and help provide timely OT services.

As a profession, it is important to monitor and evaluate the effectiveness of treatment. Along with the use of objective tests and measures, feedback from patients regarding their opinions of occupational therapy services provided as treatment is crucial. The themes that emerged in this study identified some of the complex feelings and difficulties that persons with rheumatoid arthritis face in their daily lives. Occupational therapists can help persons with RA identify difficult feelings and refer to other appropriate resources. Therapists can assist persons with RA to gain a sense of control over their lives by helping them to identify their personal needs and adapt their environment and lifestyle to improve function and quality of life.

Therapists can be sensitive to the financial resources available to each individual and teach ways to create adaptive equipment to accommodate limited assets. Each person with rheumatoid arthritis has different needs. Actively listening to these needs without making assumptions, will help a therapist to determine how best to assist the individual, especially when recommending adaptive equipment.

Treatment for RA in other than hospital settings may be beneficial in assisting emotional adjustment to the disease by fostering a wellness perspective. It is important for only one therapist to treat each person to ensure consistency and quality of care. Participants in this study stated that familiarity and trust between themselves and the therapist were important components of service excellence. It is the therapist's responsibility to include the client in the treatment program and never assume the therapy does not require explanation. Participants have stated feeling uncomfortable about asking questions; therapists should be sensitive to this possibility. Including the family in treatment and education may be helpful to minimize the client's feelings of isolation and misunderstanding and to provide necessary information and support to family members.

Finally, an important role for the profession is that of advocacy for persons with rheumatoid arthritis. Occupational therapists are educated and trained to understand and treat the effects of disability in relation to function and quality of life. Providing this information

to the public as well as to the political arenas can help dispel the myths surrounding the disease and secure needed financial assistance.

Suggestions For Further Research

As indicated in the literature review, there have been few studies that have explored the perceptions of persons who live with rheumatoid arthritis. This study of a small sample of persons who have rheumatoid arthritis cannot be generalized to a larger population. Replication of this study would be appropriate for comparison and for expanding the existing data. Increasing understanding of the daily life experiences of persons with rheumatoid arthritis will help health care professionals to serve this population more effectively and compassionately. Equally important is the need for public education to increase awareness and understanding of the effects of rheumatoid arthritis.

A study that may provide valuable insight regarding the effectiveness of occupational therapy for persons with rheumatoid arthritis would be a comparison study of persons who have received occupational therapy services to those who have not. Many aspects can be explored including knowledge of the physiological effects of the disease, knowledge of joint protection and energy conservation principles, awareness and use of adaptive equipment, and awareness of community resources.

Similar studies involving men would be valuable to identify contrasts or similarities among men and women. Cross-cultural studies of persons with rheumatoid arthritis would be of value since cultural influences may effect definition of and need for functional independence. Studies conducted in various geographical locations, such as urban and rural areas, may provide interesting insights regarding perceptions and experiences of persons with rheumatoid arthritis.

Further research involving physicians who treat rheumatoid arthritis regarding their knowledge and use of occupational therapy services would provide pertinent information for their profession. This information may lead to an understanding of what steps the medical profession can take in an attempt to increase physician awareness of the benefits of occupational therapy services.

Finally, research that examines how family members, including children, are affected by the disease would be beneficial. Research could address their needs and concerns, and kinds of services needed to help family members cope with the effects of the disease. Research should also examine how the profession of occupational therapy can incorporate the family's needs into treatment.

Summary

This study explored the variables affecting quality of life for persons with rheumatoid arthritis. The researcher reviewed literature that explored the impact of disease on a person's life, the theoretical framework for the study and its relationship to the field of occupational therapy, the measurements of functional ability in clinical practice, the psychosocial and emotional issues surrounding the disease, and finally the few but extremely important articles regarding the attitudes and knowledge from the perspective of persons with RA.

The researcher conducted in-depth interviews with six women who have been diagnosed with rheumatoid arthritis and who have received occupational therapy services. The interview included seven sections; disease process, medical intervention, family life/home environment, relationships, functional activities, occupational therapy intervention, and quality of life.

After synthesizing over 200 pages of data, the researcher identified nine themes. These themes are identified as follows; similarity of disease process and medical intervention, rheumatoid arthritis as a hidden and misunderstood disease, experience of isolation, importance of self-identity, varied definition of independence, feelings of inadequacy and need for purposeful activity, loss of control versus adjustment to disability, attitude as a sense of control, and ability to rely on oneself.

The researcher identified and discussed the variables that affect quality of life and functional independence. The perception of persons with rheumatoid arthritis of the role of occupational therapy intervention was also explored and discussed.

Recommendations for the profession of occupational therapy were drawn from the results of this study. One of the main roles identified for occupational therapists is that of educator, to both patient and family. An equally important role for therapists is to function as an advocate for the patient in an effort to increase public awareness and understanding of the effects of the disease and to dispel the common myths that surround rheumatoid arthritis.

There remains a vast amount of information yet to be explored and delineated regarding the impact of rheumatoid arthritis on those who live with the disease as well as the impact on the family. Further research in this area, especially research utilizing the phenomenological approach, is crucial to best understand and serve the needs of those who live with rheumatoid arthritis.

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APPENDICES

APPENDIX A

SUBJECT CONSENT FORM

SUBJECT CONSENT FORM

I have been asked to participate in a study of variables that affect the quality of life for persons with rheumatoid arthritis. I understand the researcher hopes to discover any similarities or differences in factors that affect for persons who live with rheumatoid arthritis. I also understand that the aim of this study and its findings will attempt to better prepare occupational therapists and other health care professionals to provide services for persons with rheumatoid arthritis and to better understand what is important in their daily lives.

I have been selected as a participant for this study because I have rheumatoid arthritis and am willing and able to communicate my past and present experiences.

If I decide to participate, I will meet the researcher at a time and place that is convenient and comfortable for me. I understand that my responses regarding my experience with rheumatoid arthritis and will be tape recorded using an interview guideline prepared by the researcher. I understand that the entire interview should take between 4-6 hours which can be spread over a period of time to best accommodate the schedules of both myself and the researcher.

I have been informed that after all of the interviews have been completed from the subjects involved, the researcher will listen to the tape recordings and analyze and interpret the results for the final portion of the thesis.

I understand this study will be presented to the Department of Occupational Therapy at San Jose State University, and will be submitted for publication in a national, professional journal.

If I decide to participate and give my permission by signing this document, I will be allowing the researcher to use information I have given her regarding my experiences with rheumatoid arthritis and what factors I see as valuable pertaining to my quality of life. My signature also indicates my permission to allow the researcher to send a letter to my doctor to confirm a diagnosis of rheumatoid arthritis. My signature further indicates my permission to allow a letter to be sent to the occupational therapist who treated me to confirm the number of visits and type of treatment rendered.

I am aware that my name will not be used in any way in this study and all measures will be taken to ensure absolute confidentiality.

School of Applied Arts and Sciences • Department of Occupational Therapy
One Washington Square • San José, California 95192-0059 • Main Office: 408/924-3070 • Fieldwork Office: 408/924-3078

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The benefits I may receive from participating in this study are simply knowing that my shared experiences can help health care providers better understand what it is like to live with rheumatoid arthritis. I will not receive payment for my participation, however there will be no cost to me. The anticipated risks for my participation in this study could be the emotional distress of recalling experiences that may have been upsetting to me.

If I do decide to participate in this study I may withdraw at any time without prejudice to my relations with the researcher, San Jose State University, or San Jose Medical Center.

Any questions about my participation in this study will be answered by Jeanette Davis, OTR (researcher) at (408)279-1809. Complaints about the procedures may be presented to Gordon Burton, Ph.D, OTR, (advisor for graduate students) at (408)924-3074. For questions or complaints about research subject's rights, or in the event of research-related injury, contact Serena Stanford, Ph.D. (Associate Academic Vice President for Graduate Studies) at (408) 924-2480. I have received a copy of this form for my records.

BY SIGNING THIS FORM I AM GIVING MY VOLUNTARY CONSENT TO PARTICIPATE IN THIS STUDY AND HAVE READ AND UNDERSTAND THE INFORMATION ABOVE.

Date

Signature of Participant

Date

Signature of Researcher

APPENDIX B

LETTER TO PHYSICIAN

Jeanette Davis, O.T.R.
1505 De Rose Way #5
San Jose, CA 95126
Date

Physician's Name
Address

Regarding: Participant's Name

Dear Dr. ,

I am a registered occupational therapist currently practicing at San Jose Medical Center. I am enrolled at San Jose State University as a graduate student in the Department of Occupational Therapy. In partial fulfillment of the requirements for the Master of Science Degree, I am conducting a study entitled, "An Exploratory Study of Variables Affecting Quality of Life for Persons with Rheumatoid Arthritis".

This study will attempt to give insights, to occupational therapists and other health care professionals, into understanding what life is like from the perspective of persons who live with rheumatoid arthritis and draw pertinent information from their unique experiences of coping with and handling the disease. Your patient, _____, has agreed to be a participant in my research. Please see (his/her) signature on the attached form.

The validity of the findings of my research will be increased with your confirmation of the diagnosis of rheumatoid arthritis for _____. If you agree with this diagnosis, please sign and date the attached form and return it to me in the envelope provided. Thank you for your reply.

Any questions about your participation in this study will be answered by Jeanette Davis, OTR (researcher) at (408)279-1809. Complaints about the procedures may be presented to Gordon Burton, Ph.D, OTR, (advisor for graduate students) at (408)924-3074. For questions or complaints about research subject's rights, or in the event of research-related injury, contact Serena Stanford, Ph.D. (Associate Academic Vice President for Graduate Studies) at (408) 924-2480.

Sincerely,

Jeanette Davis, O.T.R.
Registered Occupational Therapist

APPENDIX C

PHYSICIAN'S CONFIRMATION OF DIAGNOSIS

PHYSICIAN'S CONFIRMATION OF DIAGNOSIS*

Participant's Signature:

I have read the material provided by Jeanette Davis, O.T.R., regarding her research, and have agreed to be a subject.

_____
Signature

_____
Date

_____
_____
Physician's Signature:

I have read the attached letter regarding the research to be conducted by Jeanette Davis, O.T.R.; and the above signature of the agreement of my patient, _____, to be a subject in that research. My signature states my agreement that this patient has rheumatoid arthritis.

_____
Signature

_____
Date

*Adapted from Kibele, (1986). Reprinted by permission.

APPENDIX D

LETTER TO OCCUPATIONAL THERAPIST

Jeanette Davis, O.T.R.
1505 De Rose Way #5
San Jose, CA 95126

Date

Name of O.T.R.
Address

Re: Participant's Name

Dear ,

I am a registered occupational therapist currently practicing at San Jose Medical Center. I am enrolled at San Jose State University as a graduate student in the Department of Occupational Therapy. In partial fulfillment of the requirements for the Master of Science Degree, I am conducting a study entitled, "An Exploratory Study of Variables Affecting Quality of Life for Persons with Rheumatoid Arthritis".

This study will attempt to give insights, to occupational therapists and other health care professionals, into understanding what life is like from the perspective of persons who live with rheumatoid arthritis and draw pertinent information from their unique experiences of coping with and handling the disease. Your patient, _____, has agreed to be a participant in my research. Please see (his/her) signature on the attached form.

This study is also aimed at discovering the subject's information and opinion of occupational therapy services. To meet the criteria of this study, each subject has to have seen an O.T.R. for at least five visits for the treatment of rheumatoid arthritis. If _____ was seen by your for at least five visits for the treatment of rheumatoid arthritis, please sign the attached form in the space provided and comment briefly on the type of treatment that was rendered.

Your name and the organization with which you are affiliated will not be used in any way in this study. Your confirmation only is needed to increase the validity of the findings.

Thank you for your reply. Any questions about your participation in this study will be answered by Jeanette Davis, OTR (researcher) at (408)279-1809. Complaints about the procedures may be presented to Gordon Burton, Ph.D, OTR, (advisor for graduate students) at (408)924-3074. For questions or complaints about research subject's rights, or

in the event of research-related injury, contact Serena Stanford, Ph.D.
(Associate Academic Vice President for Graduate Studies) at (408) 924-
2480.

Sincerely,

Jeanette Davis, O.T.R.
Registered Occupational Therapist

APPENDIX E

CONFIRMATION OF SERVICES RENDERED BY A
REGISTERED OCCUPATIONAL THERAPIST (O.T.R.)

CONFIRMATION OF SERVICES RENDERED BY AN O.T.R.*

Participants Signature:

I have read the material provided by Jeanette Davis, O.T.R., regarding her research, and have agreed to be a subject.

Signature

Date

O.T.R.'s Signature:

I have read the attached letter regarding the research to be conducted by Jeanette Davis, O.T.R.; and the above signature of the agreement of _____, to be a subject in that research. My signature indicates that this individual was seen at least five times in occupational therapy for the treatment of rheumatoid arthritis.

Brief description of type of services rendered.

Signature

Date

*Adapted from Kibele, (1986). Reprinted by permission.

APPENDIX F

GUIDELINE FOR INTERVIEW

Guideline for Interview

Thank you for taking the time to meet with me. Please answer the following questions, taking as much time as you need. You may stop the interview at any time and continue at a later date.

Disease Process

Tell me about your arthritis. When did it begin? Was the onset gradual or rapid? How many years have you had it? What were the symptoms first like? What factors lead you to see a doctor or rheumatologist? How long did it take until you were diagnosed with rheumatoid arthritis by a physician? What tests were done (that you can remember) that lead to your diagnosis?

What specific joints are affected by arthritis?

Talk about the symptoms you experience. Do the symptoms come and go? If so, what is the pattern like?

Can you tell ahead of time if your symptoms will increase? What factors do you feel may lead to making the symptoms worse? Do you feel certain foods increase or decrease your symptoms? If so, in what way?

What do you do for yourself to help relieve the symptoms brought on by arthritis?

What do you do for yourself to help relieve the symptoms brought on by arthritis?

Tell me about the physical pain you feel. What is it like? Does the pain interfere with your ability to do the things you want to do? Has your tolerance to pain increased over the years?

Does the pain you feel affect you at night and disturb your sleep? If so, how often? How does this affect your daily routine? How much sleep did you need before the onset of arthritis? How much do you need now?

If you had to label your pain on a scale of 1-10 ("10 requiring bedrest"), what level of pain do you usually function in?

When you have pain at a "7", what do you do to accomplish tasks around the house?

Tell me about any loss of function you may have had and how that's affected you. What do you feel limits you more, pain or loss of function?

What factor or factors do you think may have caused or brought on your arthritis?

Do you feel you had any stressful life event or emotional disturbance before the onset of the arthritis?

Do you feel there is hope for a cure for your arthritis? Please explain.

Medical Intervention

Are you currently seeing a rheumatologist?

Have you been prescribed medications for arthritis? Which types? Please describe the advantages and disadvantages you have experienced with these medications.

Have you had surgical intervention for your arthritis such as arthroplasty, joint replacement or any other type of surgery? Please

describe. Has the surgery been helpful to you? Just after surgery did you experience less pain in the areas where pain was prevalent before surgery? (Not including the night of surgery). How long was the relief?

Please describe your relationship with your doctor. What was most helpful? What was least helpful? What would you want to change?

Has anyone explained the anatomy and physiology of the involved areas?

Family Life/ Home Environment

Does arthritis run in your family? If so, please talk a little bit about the family members who had arthritis. How did you feel about your parents having arthritis, if applicable.

Describe how your family has responded to your arthritis both past and present.

What is your home life like now? With whom do you live?

Do you feel your family or those you live with understand your arthritis? Do you feel supported by those with whom you live when things may be difficult for you?

Relationships

Please talk a little bit about your friendships and how they have influenced your life.

If you are married and/or a parent, please talk a little about your relationship with your spouse and your children.

In what ways, if any, have your relationships been influenced by you having arthritis?

Do you work outside the home or are you involved in any outside activities or organizations? Please describe your relationships with your co-workers. Do you feel your co-workers are understanding and supportive of you with your disease? If so, how? If not, why not?

Have you ever been involved in an arthritis support group? If so, what did you think of it? What was good about it? What would you like to change? Did this group help you cope with some of the difficulties you face?

Please describe the types of groups or social interactions you enjoy and your relationships with others in these groups.

Is there anything you would like to change or wish was different in any of your relationships?

How do you feel about yourself when encountering others? How do you feel about looking to others for help and assistance?

Functional Activities

Tell me about a typical 24 hour day. (i.e. 6am-10am: 10am-2pm: 2pm-6pm: 6pm-10pm). What time do you usually go to sleep? When do you usually arise to start your day? Do you take naps during the day? If so, how long?

Does arthritis limit you in any way with your self-care activities such as bathing, dressing, hygiene, grooming, and eating? If so, how?

Please describe what your physical home environment is like. Does arthritis limit you in carrying out homemaking activities such as cooking, cleaning, laundry or other household chores?

Do you have any difficulties with things like writing, buttoning clothes, turning a key, tying shoes, using the telephone or opening a jar? Please explain.

Are you limited in any way with mobility such as walking, climbing stairs, bending, lifting or stooping?

How do you get around in the community? Do you need assistance?

If you are a parent, have you been limited at all in caring for your children? In what ways?

What is your physical work environment like? Does arthritis affect your ability to carry out any work related tasks? Please describe.

Do you have uncovered financial costs or loss of job time because of arthritis?

Do you need someone to help you with any of the tasks mentioned above? Are you able to get the help you need? If you have assistance, how did you find out about it?

Do you use or need adaptive equipment for any of the activities previously mentioned? If so, please describe. How did you find out about this equipment? Has this equipment improved your level of independence?

Has arthritis affected your earning capacity or ability to work?
Has RA affected your retirement plans?

What are your hobbies and interests? Has arthritis limited you from doing the things that you enjoy? Have you had to give up any leisure interests because of arthritis?

Do you anticipate having to give up any leisure interests because of arthritis?

Occupational Therapy Intervention

What factors led you to see an occupational therapist?

How long did you receive occupational therapy?

For what specific reasons did you see an OT?

Have you ever had occupational therapy for post surgical rehabilitation? If so, how has this intervention affected your functional ability or your pain?

Tell me about information or therapeutic techniques you learned from an occupational therapist. What was most helpful to you and why?

Do you feel you could have benefitted from OT earlier in your life? If so, how?

Quality of Life

Please describe the things in your life that bring you the most meaning and sense of well-being.

What are the most difficult aspects about living with rheumatoid arthritis?

In regard to your quality of life, please talk a little bit about the following variables and how they have affected you:

-Physical deformities:

-Fatigue and endurance:

-Pain:

-Sleep:

-Strength:

-Functional independence:

-Depression:

-Other:

What has helped you the most in your ability to function independently? What has helped you the most in coping emotionally?

What changes, if any, would you want to make to improve the quality of your life?

What is your biggest fear?

What kind of person did you consider yourself prior to the onset of RA? (i.e. shy, outgoing, serious, etc.).

In what ways has arthritis changed your philosophy or outlook on life?

Do you talk often to others about what it is like to live with arthritis? Has it helped talking to me?

Is the uncertainty of the disease process difficult to live with?

Thank you for your assistance.