THE UNIVERSITY OF CALGARY

Determinants of Participation in an Arthritis Self Management Program

by

James A. Rankin

A DISSERTATION
SUBMITTED TO THE FACULTY OF GRADUATE STUDIES
IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE
DEGREE OF DOCTOR OF PHILOSOPHY

DEPARTMENT OF COMMUNITY HEALTH SCIENCES

CALGARY, ALBERTA
August, 1998

0-612-34696-X

Abstract

Rheumatoid arthritis (RA) is a chronic inflammatory disease of connective tissue. The disease trajectory is characterized by periods of exacerbation and remission (Rasker & Cosh, 1987; Schumacher, 1988). At the present time RA cannot be cured and it is not amenable to primary prevention. As with all chronic diseases it is important for patients to take an active role in the management of their condition.

One way that patients may learn coping behaviours and achieve effective self-management is through participation in arthritis education courses. The Arthritis Self Management Program (ASMP) was developed with the major aim of empowering participants to improve their coping skills and become better managers of their condition.

Studies have been conducted (Lorig, Lubeck & Holman, 1982; Lorig & Gallagher, 1984) to examine the effectiveness of ASMPs on improving the health status of participants. One interesting finding has been that an increase in health status is not associated with a change in health behaviours but rather with changes in the psychological construct of self-efficacy (SE) (Bandura, 1986; Lorig, Chastain, Ung, Shoor & Holman, 1989).

Self-efficacy is related to the confidence and beliefs individuals have with respect to them performing particular behaviours (Perry, Baranowski & Parcel, 1990). Self-efficacy is regarded as one of the most important prerequisites for behaviour change (Bandura, Adams & Beyer, 1977).

One of the major reasons for RA patients reporting an increase in health status following participation in an ASMP may be due to an increase in self-efficacy. On the other hand, the increase in health status may be because those patients with an increased SE are more motivated to take the ASMP. If the latter is true then one might expect that those RA patients who do *not* want to take the ASMP would have a lower SE for certain behaviours. Nothing is known about those patent who do not want to take the ASMP with respect to their SE and overall health status.

In the present study, the health status and SE levels of those RA patients not interested in taking an ASMP (the controls, n = 74) were described and compared with those RA patients who did want to take an ASMP (the cases, n =

72). The patients were compared on several variables including SE, knowledge, social support, depression, health status and social desirability. In addition, data were collected on their current medications, pain and swelling in their joints and comorbid conditions associated with RA.

The results showed that, with the exception of social desirability, the cases and controls were remarkably similar on each of the variables measured. The evidence suggests that there was no difference in mean SE scores between those patients who wished to take part in an ASMP and those who did not. Issues relating to SE theory, secular trend and implications for future research are also discussed.

Acknowledgements

It is the convention in the "acknowledgements" section to thank many people without whom the completion of a dissertation would not be possible. It also seems that the spouse and family members are always mentioned last.

I would like to break with the latter convention and start by expressing my utmost gratitude to the one closest to me, my Miggie. I truly would never have completed this project without your loving support, your caring and wonderful words during this arduous journey – I love you and thank you with all my heart, as Van Morrison says, "We've got to get back to the feeling" – We will.

I must also say a heartfelt thank-you to our two beautiful daughters, Julie and Clair. Your patience and words of encouragement have kept me going. I can get back to being a proper Dad now. You know that I love you both and I promise to say so more often.

As for colleagues, mentors, and teachers – where does one begin? I would like to start by acknowledging Jan Mailer a former nurse tutor of mine from many moons ago, her unbridled enthusiasm for teaching in general, and teaching nursing in particular, sparked my initial sojourn into research. Jan was the embodiment of caring inquiry before the phrase was even invented. Sadly, as is so true of all good people, she was taken too soon but I carry her around with me in my heart – a very pleasant burden.

I would like to thank Faculty of Nursing colleagues who took the time to ask "How is it going?". In particular I would like to express my appreciation to Professor Karen Then and Dr. Marlene Reimer for their kind words of encouragement and belief in me.

My appreciation is extended to the members of my supervisory committee, Dr. Ed Love for his realism and sound advice, and Dr. Rollin Brant for his good humour and careful counsel – I promise I will never use pinhead plots ever. My gratitude goes to Dr. Paul Davis and Dr. Faye Weisenberg for graciously agreeing to be external examiners on my committee – I thank you both for taking the time to read and reflect.

I have very much appreciated the encouragement of my supervisor, Dr. Steven Edworthy, his probing questions and considered opinions have caused me to stop and reflect along the way – I thank you.

I must acknowledge the contributions of Debbie Murphy, Shannon Taylor, Rhonda Kennedee, Rosario Talavera, Rafael Talavera and Peggy Watson who assisted at various times during the course of this project.

Funding for the project was received from the Alberta Foundation for Nursing Research (AFNR), sadly the Foundation is no longer with us, another victim of the cuts. I would like to thank the members of the AFNR board who saw fit to fund the research.

I am indebted to the rheumatologists for graciously allowing me access to their day lists and their secretarial staff for being so helpful and informative as I attempted to navigate the system.

The research could not have been done were it not for a very special group of people, namely the patients who live each day with rheumatoid arthritis. I am deeply indebted to them for allowing me into their homes and giving me the data through the sharing of their experiences with RA. I learned not just about self-efficacy from them but also about life. I was gratified and humbled to be with them.

In closing, I want to thank my parents, Aileen and James (two more good people) for being with me through all of it. I felt your presence. Words cannot express the debt I owe to you. I love you both. *Pax vobiscum...*

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

LIST OF ABBREVIATIONS

AIMS2	Arthritis Impact Measurement Scale Version 2
ASMP	Arthritis Self-Management Program
CES-D	Center for Epidemiological Studies Depression Scale
IIRS	Illness Intrusiveness Ratings Scale
MBSS	Miller Behavioral Style Scale
M-CS	Marlowe-Crowne Social Desirability Scale
OA	Osteoarthritis
QSSS	Quality of Social Support Scale
RA	Rheumatoid Arthritis
SCT	Social Cognitive Theory
SE	Self-Efficacy

CHAPTER 1

THE RESEARCH PROBLEM

INTRODUCTION AND PURPOSE OF THE STUDY

Rheumatoid arthritis (RA) is a chronic inflammatory disease of connective tissue that causes articular inflammation as well as systemic manifestations (Zvaifler, 1989). The trajectory of RA is characterized by periods of exacerbation and remission of disease activity (Rasker & Cosh, 1987; Schumacher, 1988). While the use of Disease Modifying Antirheumatic Drugs (DMARDs) has met with some success, their toxicity profiles are such that discontinuation is likely in the short to medium term. For example, Wolfe, Hawley & Cathey (1990) found in a 14 year prospective evaluation of over 1,000 patients that the median time to discontinuation of parenteral gold, auranofin, hydroxychloroquine or penicillamine was two years or less.

More recently Bendix & Bjelle (1996) found that in a retrospective cohort study of 376 patients the discontinuity rates of parenteral gold were 42%, 55%, 74% and 92% after 1, 2, 5 and 10 years respectively. Furthermore it has been demonstrated that morbidity is increased in people experiencing rheumatoid arthritis (RA) over the long term (Pincus, 1988; Pincus, Callahan, Sale, Brooks, Payne, & Vaughan, 1984). In addition to the impact of RA on the individual's physical functioning, psychological and social well being are also affected (Taal, Rasker, Seydel & Wiegman, 1993).

Unfortunately, at present rheumatoid arthritis cannot be cured nor is it amenable to primary prevention. The major goals of treatment are:

- reduction of inflammation and relief of pain
- prevention of joint deformity
- preservation of joint function
- improvement of overall functioning

As mentioned above, the therapeutic regimen can be particularly taxing on patients which leads to difficulty in adhering to demanding treatment and arduous lifestyle changes. Depending on the type of therapy, adherence estimates range from 30% to 92% for medication (Singh, Fries, Williams, Zatarain, Spitz & Bloch, 1991; Bendix & Bjelle, 1996) and 25% to 65% for physiotherapy and home exercises (Bradley, 1989; Feinberg, 1988).

The challenge for health professionals is to minimize pain and disability, and to help individuals manage their condition effectively. As with all chronic conditions, it is important that patients (and their families) take an active role in the management of their condition. Arthritis patient education can help patients make appropriate choices and take decisions about their treatment, as well as facilitate their understanding of, and participation in, self-management behaviours (Lorig, Konkol, & Gonzalez, 1987).

Participating in the appropriate self-management behaviours can lead to improved health status and clinically relevant symptom reduction (Bradley, Young, Anderson, McDaniel, Turner and Agudelo, 1984; Lorig et al, 1987; Lorig & Holman, 1989; Lorig, Mazonson & Holman 1993; Mullen, Laville, Biddle & Lorig 1987). Thus, another major goal of RA therapy should be participation in arthritis patient education. Patient education has the potential to make a major contribution as a therapeutic intervention which helps individuals cope with the experience of RA throughout their lifespan (Lorig, Konkol, & Gonzalez, 1987).

With the advent of early discharge from hospital and shorter lengths of stay the opportunity for in-patient education has become severely limited. It is, therefore, logical and not surprising that community based arthritis education programs have gained in popularity (Lorig & Holman, 1993) with patients who have different types of arthritis.

One program of interest to health professionals working with individuals who have chronic musculoskeletal problems is the Arthritis Self-Management

Program (ASMP). The program was originally developed nearly 18 years ago by Lorig (1980) at the Stanford Arthritis Centre. The ASMP has since been imported to Canada under the auspices of the Canadian Arthritis Society and is currently offered throughout the country (Pring, 1993).

The ASMP is a community-based patient education course that is taught by trained volunteers known as Arthritis Leaders. Usually two leaders conjointly teach the course by providing a two hour session every week for a total of six weeks. Individuals who take the course are known as "participants" rather than "patients" or "arthritics". Most of the participants have osteoarthritis, some have rheumatoid arthritis and a few may have arthritic symptoms from diseases such as systemic lupus erythematosus (Lorig & Holman, 1993; Rankin, 1992).

A major aim of the ASMP is to empower participants to cope with their arthritic condition and thereby become better managers of their arthritis with the result that they will have fewer flares, less pain and adopt healthy behaviours (Lorig & Fries, 1990). Clinically relevant symptom reduction has been demonstrated in certain ASMP participants (Lorig & Holman, 1989; Lorig, Mazonson, & Holman, 1993). From a theoretical perspective, improvement in health status is linked to the health belief model (Rosenstock, 1974; Rosenstock, 1990; Rosenstock, Strecher, & Becker, 1988), social cognitive theory (Bandura, 1977) and in particular to self-efficacy theory (Bandura, 1986; Lorig, Chastain, Ung, Shoor, & Holman, 1989; Perry, Baranowski & Parcel, 1990).

An underlying assumption of patient education is that an increase in knowledge will change health behaviours for the better, and that a change in these behaviours will necessarily lead to improvement in health status (Lorig, Seleznick, Lubeck, Ung, Chastain & Holman 1989). This conventional wisdom has been challenged and, in fact, it has been demonstrated that there is a lack of association between changes in health behaviours and improved health status among patients with arthritis who completed an arthritis self-management course (Lorig, Lubeck & Holman, 1982; Lenker, Lorig & Gallagher, 1984). There appeared to be another factor influencing improvement in health status measures. The factor was suspected to be the psychological construct of self-efficacy. Lorig & Holman (1993) have reported that changes in self-efficacy are more strongly associated (and the association is statistically significant) with changes in health status than changes in health behaviour.

Self-efficacy enhancing behaviours tend to be reinforcing. If individuals have increased self-efficacy for pain management, physical functioning and other activities associated with arthritis management; such individuals are then more likely to be drawn to learning about similar but more complicated behaviours in order to increase their self-efficacy even more.

Those who choose to take part in an ASMP constitute only a small proportion of people with arthritic problems and not everyone who has the opportunity to participate in the program wishes to do so (Edworthy, 1993). There is some evidence to suggest that ASMP participants differ from non-participants to the extent that participants *begin* the course with a relatively high level of self-efficacy (Lorig & Holman, 1993; Taal et al, 1993a). On the other hand, little is known about those individuals who choose *not* to take an ASMP or the determinants of participation in such a program.

Therefore the reason that individuals report an increase in health status following a self-management course may be due in part to an increase in SE while taking the course. It may also be due to the fact that those with an increased SE are more motivated to take the course in the first instance. If this is the case then those who do not wish to take the course should have a lower SE. Nothing is known about those who do not wish to take the course with respect to their SE or overall health status. It is, therefore, important to examine and compare SE in those who are interested in arthritis education and those who are not.

In addition to measuring SE it is also meaningful to measure other variables which are viewed as the "gold standard" of arthritis research, namely, pain, function and depression (Goeppinger & Lorig, 1997). Pain, function and depression were assessed in the present study using the Arthritis Impact Measurement Scale, version 2 (AIMS2) and the Centre for Epidemiological Studies' Depression Scale (CES-D). Furthermore, it was felt necessary to measure information seeking behaviour, knowledge of arthritis, illness intrusion and social support as these variables may variously impact on the individual's interest in participating or not in an arthritis education program.

In a recent review Goeppinger & Lorig (1997) have called for future research to examine the cultural appropriateness of ASMP as an intervention, to focus on the intervention component that is most responsible for improvements and for researchers to access hard to reach populations. It was the "hard to reach" individuals who were compared with those wishing to take the course in the present study.

It is important to describe the relationship of SE between those patients who wish to take the ASMP and those who do not. In addition describing the other variables which are thought to impact on an individual determining to participate or not would have considerable utility in:

- redefining the target population for the ASMP
- inducing modifications that result in increased effectiveness of the existing program
- providing program developers with suggestions for alternative modes of delivery for arthritis education
- examining implications for model testing and future explanatory studies

If the determinants of participation were more clearly understood the findings would have important implications for professionals who design education programs not only for people with musculoskeletal problems but also for individuals with a variety of chronic conditions (e.g. cardiac rehabilitation and diabetes).

The bulk of the work to date has been conducted on heterogeneous populations (with respect to their arthritic conditions) in the United States. For example, participants with osteoarthritis tend to be in the majority (68% to 75%) and those with RA are in the minority (14% to 15%) (Lorig & Holman, 1993). In addition, it is clear that differences exist between the U.S. and Canada with respect to culture and health care systems.

The present research reported here represents an investigation that is pertinent and applicable to a homogeneous group of individuals experiencing rheumatoid arthritis in the context of the Canadian health care system. In addition, the study is timely in the light of current changes to the health care system with respect to the emphasis on early discharge from hospital and community care in conjunction with secondary and tertiary prevention.

From the perspective of program development and modification, it is important to identify, describe and compare the two groups that constitute ASMP cases and ASMP controls. The cases comprise those individuals with RA who wish to take the course. The controls are those individuals with RA who do not wish to take the course.

1.1 Purpose

The primary purpose of the study, therefore, is to identify and describe the determinants of participation in an Arthritis Self-Management Program by comparing two groups of individuals with RA; the cases are those who *wish* to avail themselves of the ASMP and the controls are those who *do not* wish to do so. It is important to emphasize that the cases are those individuals who *wish* to but have not *actually* participated in the program.

1.2 Research question

The research questions relate to variables which may be potential determinants of participation

The primary research question is: What are the differences between cases and controls with respect to self-efficacy? A secondary question relates to what differences exist between cases and controls with respect to: information seeking behaviour, knowledge, social support, health status, illness intrusion and depression.

1.3 Hypotheses

Based on the literature and the investigator's experience the following five research hypotheses were generated.

Cognitive, behavioural and social hypotheses:

1. Those patients wishing to participate in the ASMP (i.e. the cases) will have higher self-efficacy scores than those not wishing to participate (the controls).
2. Those patients wishing to participate in the ASMP will demonstrate more information seeking behaviour than those not wishing to participate.
3. Those patients wishing to participate in the ASMP will demonstrate more knowledge about RA than those not wishing to participate.
4. Those patients wishing to participate in the ASMP will have greater social support than those not wishing to participate.

Health status hypothesis

5. Those patients wishing to participate in the ASMP will perceive and report their health status to be "better" than those not wishing to participate as measured by: the Arthritis Impact Measurement Scale 2 (AIMS2), the Illness Intrusiveness Scale (IIRS) and the Centre for Epidemiological Studies Depression Scale (CES-D).

1.4 Summary

In summary, there is an identified need for research in community arthritis education in Canada that, has a strong theoretical foundation and which deals with homogeneous groups of patients with RA. In addition there is a need to describe the determinants of participation in a community arthritis education program by comparing those patients who wish to participate with those who do not wish to participate on a number of variables related to participation.

CHAPTER 2

LITERATURE REVIEW

The volume of research in arthritis patient education has substantially increased since the 1980's (Daltroy & Liang, 1991; Daltroy & Liang, 1993; Goeppinger & Lorig, 1997). Initially arthritis education programs were concerned with increasing participants' knowledge. The focus has shifted to changing client behaviour and most recently to measuring health outcomes following participation in an education program.

There is no published literature concerning *determinants* of participation in arthritis education programs, that is, what are the determining factors in deciding to participate in an ASMP? Researchers have measured self-efficacy as a dependent variable following participation in an education program, however the effect that self-efficacy might have in *contributing to patient participation* has not been investigated.

An overview will be given of self-efficacy theory which was used both as an organizing conceptual framework and as the central variable of interest in the study. In addition, the literature review will consider major areas of arthritis education research and identify relevant findings with respect to determinants of program participation.

2.1 Conceptual Framework - Self-Efficacy Theory

Many theories and models have been used in health education. For example the health belief model (Rosenstock, 1974; Rosenstock, 1990; Rosenstock, Strecher & Becker, 1988) has been used in a number of studies relating to health promotion/illness prevention (DiFranceisco, Kelly, Sikkema, Somlai, Murphy, & Stevenson, 1998; Hiltabiddle, 1996; Laraque, McLean, Brown-Peterside, Ashton & Diamond, 1997; Wohl & Kane, 1997). Moreover, the concepts associated with the health belief model are incorporated into self-efficacy theory. For example, the concept of "outcome expectations" in self-efficacy theory is analogous to the concept of "perceived benefits" in the health belief model (Rosenstock, 1990). Therefore, in the interests of theoretical parsimony, the present study used only self-efficacy theory for its theoretical underpinning.

Self-efficacy theory proposed by Bandura (1977a) has its beginnings in Social Learning Theory (SLT) which in turn has its early roots in behaviourism (Miller & Dollard, 1941). Behaviourism has utility in demonstrating the importance of reinforcement and punishment in affecting and altering performance in learning situations (Skinner, 1953; Rotter, 1966) but behaviourists have failed to account for any "internal processes" associated with learning (Froman, 1997). In an effort to provide an alternative to the externally focussed behaviourist approach, the social learning theorist Rotter (1954), made speculations about the contribution of cognitive processes to behaviour and learning.

Bandura and his colleagues (Bandura, 1977a; Bandura, 1977b; Bandura, 1986; Bandura, Adams, & Beyer, 1977; Bandura & Walters, 1963) extended the work of Social Learning Theory. Bandura wanted to combine the findings of behaviourists who postulate that behaviour is acquired through both classical and operant conditioning (without the involvement of conscious thought) and the cognitive psychologists who assert that cognitively processing information is key to the acquisition of behaviour.

In order to distinguish his contributions from those of others he labelled his work *Social Cognitive Theory* (SCT). Social Cognitive Theory represents a major shift away from traditional behaviourism to one where cognitive concepts are included in the explanation of behavioural phenomena. According to Bandura, SCT encompasses SLT because the boundaries of the former include self-regulatory processes which extend beyond the phenomena and processes normally associated with learning.

According to SCT, behaviour is not simply a response to a stimulus in the environment but rather there is a dynamic interactive process among individuals, their behaviours and their environments. This interaction is constant and is termed *reciprocal determinism* (Bandura, 1978). The utility of reciprocal determinism for researchers is that they are now cognizant not only of individuals and their behaviours but also of the context in which the behaviours take place.

With respect to stressful life events, Lazarus & Folkman (1984) have asserted that how individuals perceive events (i.e. their appraisal) is crucial to how they interpret and react to them. Primary appraisal involves a subjective evaluation of a situation in which the individual makes a judgement in determining whether an event is likely to be harmful. Secondary appraisal involves a judgement concerning the availability of resources at the individual's disposal and whether the situation is controllable (Carpenter, 1992).

Taylor (1983) has proposed that a major factor in coping with a stressful event through cognitive appraisal is related to the confidence individuals have in mastering or controlling the environment in which the event takes place. This has been extended to health care research in which Lev (1992) has asserted that individuals, who are confident in their ability to master a situation, are more likely to engage in health related behaviours.

Bandura (1986) has made the important distinction between *general* beliefs concerning control (as exemplified by Lazarus & Folkman, 1984) and beliefs that relate to *specific* situations. Bandura (1977a) has encapsulated beliefs as they relate to specific situations by attempting to provide a unifying theory of behaviour change. Bandura has termed this framework self-efficacy theory.

Self-efficacy is related to the confidence an individual has with respect to performing a particular activity (Perry, et al., 1990). Self-efficacy is regarded as one of the most important prerequisites for behaviour change (Bandura, et al., 1977). According to SE theory a behaviour change is a function of certain expectations about the outcome of that behaviour.

Self-efficacy relates to perceptions and beliefs of individuals to the extent that they will be capable of performing a given behaviour which will result in a *particular* outcome (Bandura, 1977a; 1977b; 1978; 1986). Figure 2.1 provides a schematic representation of the difference between efficacy and outcome expectations.

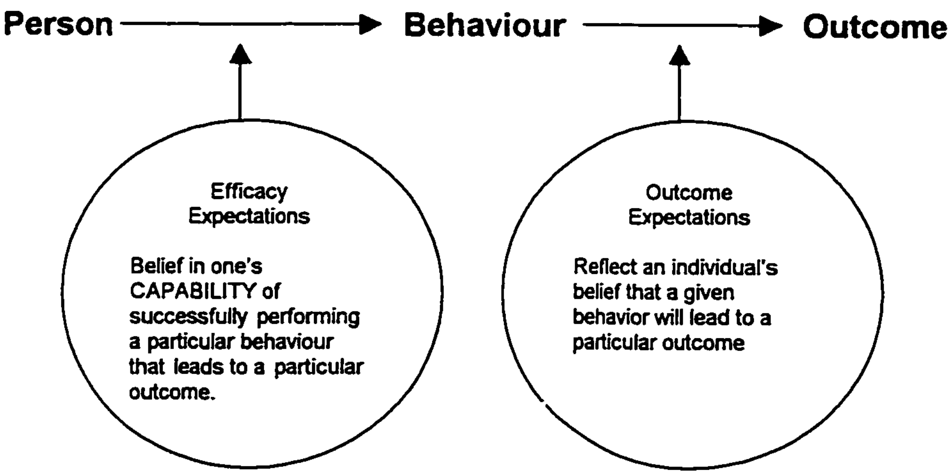


Figure 2.1 Schematic representation of Bandura's efficacy and outcome expectations.

Adapted from: Bandura, A. (1977). Self-efficacy: Toward a unifying theory of behavioral change. Psychological Review. 84(2), p.193

As may be seen from Figure 2.1 there are two types of expectations described by Bandura:

- *Efficacy expectations* reflect individuals' beliefs in their *capability* of performing a behaviour that leads to a particular outcome and,
- *Outcome expectations* reflect individuals' beliefs as to whether a particular behaviour will lead to a particular outcome (Bandura, 1986).

The strength of SE conviction determines whether or not individuals attempt to deal with particular situations (e.g. participate in ASMP). Self-efficacy may be influenced by four major sources. In order of their hypothesized power to influence self-efficacy, the sources are: performance accomplishments, vicarious experience, verbal persuasion, and physiological states.

Performance accomplishments

Performance accomplishments, also known as *enactive attainments* (Bandura, 1982), refer to learning through personal direct experience in which the individual achieves mastery or control over a task which was previously thought to be difficult or threatening in some way. Successful mastery of the behaviours associated with the task will increase an individual's self-efficacy.

Conversely, repeated failures lower SE particularly if they occur early in the program. Occasional failure accompanied by eventual success serves to strengthen self-motivation and persistence (Bandura 1977a). Therefore, failure in and of itself does not necessarily lower SE rather the timing of the failure in the series of events conducted to achieve the task is what is of importance with respect to lowering or increasing an individual's SE.

Vicarious experience

Vicarious experience relates to learning through the observation of others accomplishing a task which might be viewed as threatening or difficult without any adverse consequences. Vicarious experience may also be gained through observing events as well as people. The events and other people are referred to as "models". If human models have a variety of differing characteristics and can succeed at a particular task, this serves to enhance the expectation of the observer in succeeding at the same task (Bandura, 1977a).

However, if the model is similar to the observer (e.g. in age and gender) this will enhance the observer's sense of being able to achieve the same task. In addition it is important that the model is viewed as overcoming the task with determined effort rather than with ease (Strecher, McEvoy, Becker and Rosenstock, 1986). Individuals who are exposed to events and people who have successfully completed certain behaviours can enhance their SE.

Verbal persuasion

Verbal persuasion refers to the efforts of others in discussing, convincing, or coaching people to change their behaviours. Praise and encouragement can enhance SE providing the "persuader" is credible in the eyes of the individual being persuaded. It is also important for the person doing the persuading to arrange the environment in such a way that it is conducive to success (Bandura, 1977a).

Physiological state

The individual's physiological state can enhance or detract from attaining a certain level of SE. Individuals use physiological feedback to interpret their capabilities. For example, high physiological arousal which causes anxiety and visceral agitation may lead to an expectation of failure. Under these circumstances an individual's SE is unlikely to be enhanced (Strecher et al, 1986). Stress management techniques that are employed to reduce anxiety can enhance SE.

Conversely, mild aches and an increase in strength from an exercise program may provide the physiological feedback that an individual is getting fitter and stronger thereby increasing their SE for future activities.

It is emphasized that both outcome and efficacy expectations are concerned with an individual's *beliefs* about behaviour-outcome associations and capabilities. Self-efficacy is behaviour specific (i.e. it is a state not a trait) and it relates to performance behaviours in particular situations (Bandura, 1986).

Having said that, Bandura (1977a) has asserted that once an individual has established an enhanced SE it is possible to generalize and transfer improvements in behavioural functioning to other situations. Bandura indicates further that such transfers need not only be confined to similar situations but it is possible to have application to quite different situations far removed from the activity which enhanced the SE in the first instance.

For example, in their early work on animal phobias Bandura, Blanchard & Ritter (1969) demonstrated that mastery of a phobia for a particular animal could increase coping with fear of other animals and help individuals cope in different social situations. The generalizability of the enhanced SE is predictably related to situations which are most similar to the original encounter in which SE was increased (Bandura at al, 1969).

According to Bandura (1977a; 1986) efficacy expectations can vary along dimensions of magnitude, strength and generality. Each of these dimensions can have implications for performance of a particular task and are now described. Magnitude refers to the grading of tasks by level of difficulty. Individuals who have "low-magnitude" expectations are capable of engaging in the simplest activities in a graded series of tasks. Whereas, those with high magnitude expectations are capable of performing the most difficult tasks in the series (Strecher et al, 1986).

Strength relates to individuals' subjective judgement of how confident they are in their ability to undertake a task successfully. Generality, as alluded to above, relates to the degree to which efficacy expectations concerning a particular situation can be generalized to other (similar or different) situations.

Most recently the notion of generalized self-efficacy has appeared in the literature (Barlow, Williams & Wright, 1996). Generalized SE refers to individuals' global confidence in their ability to cope across a wide range of demanding situations (Barlow et al 1996). A scale has been developed to measure generalized SE (Jerusalem & Schwarzer, 1992).

Measurement of Self-efficacy

Although a generalized SE scale has been developed the majority of research to date has focussed on measuring SE in specific situations. Because SE beliefs tend to be task specific every area of interest requires that a different self-efficacy measure is developed.

For example, an SE scale developed specifically for patients with arthritis necessarily contains items relating to certain tasks associated RA (e.g. How certain are you that you can get out of an armless chair quickly?). Such an item would not be representative of a task associated with an SE scale for measuring efficacy of smoking cessation behaviours. Consequently there are a wide variety of SE scales that have been developed for SE research.

For example, early studies have reported that increased SE is a strong predictor of smoking cessation and maintenance of cessation (Pechachek & Danaher, 1979). Procahska & DiClemente (1984) demonstrated that increased SE was associated with movement from the stage of precontemplation to contemplation or action with respect to smoking cessation.

It was also found that those who wished to join a smoking cessation program have higher SE than non-joiners (Brod & Hall, 1984). With respect to contraceptive behaviour in adolescent teens, Gilchrist & Schinke (1983) demonstrated that an increase in SE was associated with increased use of birth control measures in a sample of 65 male and 42 female high school students.

More recently various authors have reported the development of single item SE scales for measuring behaviours such as breast self examination in n = 402 rural workers (Bastani, Maxwell, Carbonari, Rozelle, Baxter & Vernon, 1994); the use of Faecal Occult Blood tests for colorectal cancer screening (Myers et al, 1994); and self pain management in n = 358 bone marrow transplant patients (Syrjala & Chapko, 1995).

The use of single item scales is questionable with respect to the utility and validity of such measures. Moreover it is not possible to compute an internal consistency coefficient.

Most recently Drummond & Rickwood (1997) have reported on the validation of the Childbirth Self-efficacy Inventory (CBSEI) in an Australian sample of n = 100 pregnant women. The CBSEI was developed by Lowe (1993) to measure maternal confidence in coping with labour. Drummond & Rickwood (1997) did not report any internal consistency coefficients for the CBSEI, however they did report that each of the four subscales in the 60 item inventory were highly correlated indicating that the tool is largely unidimensional and does not discriminate among the four subscales.

In summary, research into self-efficacy has continued since Bandura's original work in the 1960's. A number of areas have been investigated from smoking cessation, contraceptive use, cancer screening to childbirth. Because of the task specific nature of efficacy expectations numerous and diverse SE instruments have been developed with varying degrees of scientific rigor applied to assessment of their reliability and validity.

Within the field of arthritis research one SE scale in particular has received much attention. The Arthritis Self-Efficacy Scale (ASES) was originally developed to measure perceived self-efficacy in people with arthritis (Lorig, Chastain, Ung, Shoor & Holman, 1989). The 20 item ASES has demonstrated concurrent and construct validity and test-retest reliability of 0.85, 0.87 and 0.90 for the physical function, pain and "other" symptom subscales respectively (Lorig et al, 1989). Construct validity, test-retest reliability (0.81-0.91) and internal consistency (0.82-0.91) have been demonstrated in a Swedish version of the ASES (Lomi, 1992; Lomi & Nordholm, 1992).

Several authors have reported using the ASES with RA patients. Buescher et al (1991) found in a sample (n = 72) of male RA patients that those who scored high on the SE subscales of physical function, pain and other symptoms exhibited fewer pain behaviours (e.g. guarding, grimacing). Stenstrom (1994) in her evaluation of a 12 week home exercise program for n = 42 RA patients found that the exercise intervention had a positive impact on SE "other" scores (i.e. symptoms such as mood and fatigue). Parker et al (1995) demonstrated significantly higher SE scores on all subscales in a sample of n = 47 RA patients who received a 10 week stress management training program compared to controls. The differences in SE scores persisted at 3 and 15 month follow-ups.

In an Australian study with patients who had RA, OA and other types of arthritis, the researchers found that there was no difference between the intervention (a community based education program) and control groups with respect to self-efficacy (Simeoni, Bauman, Stenmark & O'Brien, 1995).The reason for the null finding could not be explained by the authors. The use of a heterogeneous group of patients with arthritis and corruption of the standard ASES (only six items were used) may have contributed to the null finding.

Using a Dutch version of the ASES Riemsma et al (1998) found in a sample of n = 229 RA patients that one of the major variables correlating with whether patients needed help with activities of living was SE for coping with RA (overall health status and gender were the two other major variables). The SE instrument used by Riemsma and his colleagues (1998) was modified by having one less item than the standard ASES and the scoring system was changed to a Likert scale (i.e. 1 = totally disagree and 5 = totally agree). The reported internal consistency of the instrument was 0.91.

The ASES has been used in samples of patients who have osteoarthritis without any modification to the instrument. For example, Keefe et al (1996) found that OA patients who were assigned to spouse assisted pain-coping skills group training sessions scored significantly higher on SE and had more frequent use of pain coping strategies than the controls. Keefe and his colleagues (1997b) also demonstrated that in a sample of n = 40 OA patients those who scored high on the SE pain subscale had significantly higher pain thresholds and pain tolerance for a laboratory controlled thermal pain stimulus than those scoring low on the SE pain subscale.

In a third study, Keefe and his colleagues (1997a) examined whether pain coping strategies could be predictive of SE in a group of n = 130 patients with OA. In addition, they assessed the degree to which the patients' SE ratings correlated with the spouses ratings of the patients' SE. Interestingly Keefe et al (1997a) found that the patients' SE ratings were significantly correlated with the spouses' ratings of the patients' SE.

In summary, self-efficacy is considered an important variable to measure among researchers investigating samples of patients with RA, OA and combinations of RA and OA. The standard instrument of choice is the ASES (Lorig et al, 1989). Some researchers have modified the instrument by translating it for use in other countries, while others have altered the method of scoring or simply use only a few of the 20 items that comprise the complete tool.

Making changes to the instrument may alter its psychometric properties, it therefore behooves investigators to either use the "standard" instrument as originally designed, or ensure that they accurately describe the changes made to the instrument and report on the psychometric properties of the revised tool.

The ASES or modified versions of it have been used in research on patients with other musculoskeletal conditions such as:

ankylosing spondylitis (Barlow & Barefoot, 1996);

fibromyalgia syndrome (Buckelew et al, 1994; Buckelew et al, 1996; Burckhardt, Mannerkorpi, Hedenberg & Bjelle, 1994;; Lomi, Burckhardt, Nordholm, Bjelle & Ekdahl, 1995; Mannerkorpi & Ekdahl, 1997);

systemic lupus erythematosus (Peterson, Horton, Engelhard, Lockshin & Abramson, 1993); and

chronic back pain (Anderson, Dowds, Pelletz, Edwards & Peeters-Asdourian, 1995; LeFort, Gray-Donald, Rowat & Jeans, 1998).

From the foregoing it may be seen that research into SE is not only continuing with RA patients but it has been extended considerably to patients with other types of musculoskeletal conditions. It is timely to examine the SE of a sample of RA patients who are *not* participating in a program or receiving any other type of intervention.

It has been asserted that self-efficacy is an important determinant for individuals to be engaged in arthritis self-management behaviours (Taal, Rasker & Wiegman, 1996). Efficacy expectation is deemed to strongly influence the choices and decisions individuals make and it is an important factor in determining the amount of persistence and effort an individual will undertake in self-management activities (Riemsma, Taal, Brus, Rasker & Wiegman, 1997).

However, in order for individuals to learn about self-management behaviours and engage in them, they must make the decision to participate (or not) in the ASMP in the first instance. In this way, taking the steps necessary to enrol in the program may of themselves be viewed as health related behaviours, the outcome of which is successful attendance at the program.

According to SE theory, one would expect that ASMP participants will have greater SE for specific behaviours than those individuals who do not wish to participate in the program. In addition, one would expect differential levels of SE among the ASMP participant group relative to their progression in the program (e.g. those who have completed the ASMP will have higher SE than those currently taking it, who in turn would have higher SE than those about to start, who would have higher SE than true non-participants). In this way one would expect to see a “dose response” effect depending at which stage of participation (or non-participation) individuals are situated.

Self-efficacy may be a major determinant of participation behaviour. The findings of the present study may serve to affirm some of the components of SE theory and it may then be possible to extend the research to intervention studies.

2.2 Knowledge

In a review of the arthritis patient education literature in 1987 Lorig and her colleagues found that in 32 out of 34 studies there was a measurable increase in knowledge by individuals with various forms of arthritis. Unfortunately there was large variation in the studies with respect to scientific rigor and design. One of the earliest examples of arthritis education carried out by a nurse, highlighted the advantages of teaching self-care in a group setting to individuals attending an arthritis clinic (Valentine, 1970). The use of a posttest only design and a small convenience sample limited the generalizability of the study.

Using a pretest-posttest design Vignos, Parker & Thompson (1976) demonstrated that a combination of reading materials and group education could lead to an increase in knowledge about arthritis in a sample of 20 individuals with RA. No comparison group was used and the participants were purposively selected from an arthritis clinic. Interestingly, Vignos et al (1976) reported that the pretest showed that patients were already well informed about arthritis. This observation offers one of the earliest, tentative suggestions that those individuals willing to take part in arthritis education may differ from those not wishing to take part.

In the late seventies Stross and Mikkelsen (1977) demonstrated that it was possible to increase the knowledge of elderly patients with osteoarthritis using a combination of tape/slide presentations and reading materials. However, Moll, Wright, Jeffrey, Goode & Humberstone (1977) failed to demonstrate any difference in knowledge in a randomized posttest only design in 50 patients with gout.

Other researchers have investigated patients/clients in different settings using a variety of methods including, outpatient programs (Kaye & Hammond, 1978; Knudson, Spiegel, & Furst, 1981), inpatient programs (Lorish, Parker, & Brown, 1985; Parker, Singsen, Hewett, Walker, Hazelwood, Hall, et al., 1984; Spiegel, Knutzen, & Spiegel, 1987), computer assisted learning (Wetstone, Sheehan, Votaw, Peterson, & Rothfield, 1985) and self instruction (Oermann, Doyle, Clark, Rivers, & Rose, 1986). All of these studies consistently demonstrate an increase in knowledge among the participating subjects. Lorig et al (1993) and Taal, Riemsma, Brus, Seydel, Rasker, & Wiegman (1993b) have indicated that an increase in knowledge is only one component in the overall aim of more complex arthritis education interventions that are currently available. In a more recent review Taal and his colleagues (1996) have added support to the view that increase in knowledge itself is insufficient to influence health behaviours and health status. Despite this, investigators continue to conduct studies to establish that increased knowledge acquisition is not associated with improved clinical status and increased well being (Maggs, Jubb & Kemm, 1996).

It may be concluded that, to a greater or lesser extent, arthritis education can increase client knowledge. Unfortunately the successful transfer of knowledge *per se* is not sufficient to accomplish changes in behaviour and health outcomes, it is however a fundamental component in client education interventions (Daltroy & Liang, 1993). It is speculated by the investigator that one of the determinants of participation in arthritis education programs is a relatively high level of knowledge of arthritis *prior* to taking the program.

2.3 Behaviour

The behaviours that are thought to affect the health status of individuals with arthritis include, joint protection, exercise, relaxation and adherence to medication regimens (Daltroy & Liang, 1993). In their review Lorig et al (1987) found 48 studies (of varying scientific rigor) that measured behaviour change in patients with arthritis. Of these, 37 (77%) demonstrated a change towards the desired behaviours. This finding is consistent with a meta-analysis of patient education programs for chronic conditions (Mazucca, 1982). Interestingly none of the studies examined by Mazucca (1982) involved arthritis education.

More recently, Lorig and Holman (1993) reported on a series of intervention studies conducted between 1979 and 1985. They demonstrated that, over a four month period, treatment subjects consistently increased their frequency of exercise and relaxation compared with controls. It is important to note that about 70% of the participants in the studies had osteoarthritis (OA) whereas approximately 15% had RA. Separate analyses were not conducted for the OA and RA patients, thus caution should be exercised in generalizing the findings to the population of individuals with RA.

Taking part in an ASMP may be viewed as a secondary or tertiary prevention strategy (Drew, Craig, & Beynon, 1989). Investigators concerned with determinants of adult participation in health promotive and preventative strategies have demonstrated that physical activity in adulthood is associated with skill acquisition and positive experiences during youth (Myers, Weigel, & Holliday, 1989).

Participation by adults at their worksite was related to perceptions about their physical and emotional health (Zavela, Davis, Cotrell, & Smith, 1988). Determinants of participation in exercise by clients with osteo (n = 37) or rheumatoid (n = 63) arthritis was associated with a history of exercising in their youth and perceiving exercise to be of benefit (Neuberger, Kasal, Smith, Hassanein, & DeViney, 1994). The data from both sets of patients were combined for statistical analysis.

In the same study subjects with less formal education, longer duration of arthritis and higher impact of arthritis scores perceived fewer benefits of exercise. One of the variables relating to participation cited above (education level) was measured in the this present study in an attempt to identify some of the determinants of participation and non-participation in the ASMP.

2.4 Health outcomes

Health outcomes that are measured in arthritis education research are pain, depression and disability (Daltroy & Liang, 1993). These major variables are incorporated into the Arthritis Impact Measurement Scale (Meenan, 1982) and have been used to estimate health status in people with arthritic conditions. A meta-analysis by Mullen, Laville, Biddle, & Lorig (1987) of 15 intervention studies concluded that arthritis education contributes to an increase in health status. However, 11 of the 15 intervention studies in the meta-analysis (Mullen, et al., 1987) had sample sizes of less than 30, and a variety of intervention strategies, ranging from one to one counselling (Laborde & Powers, 1983) to group therapy (Shearn & Fireman, 1985) were used. Valid interpretation of the results of a meta-analysis of this nature must be treated with caution due to the variation in sample sizes and methods used in the intervention studies cited by Mullen et al, 1987).

In addition, the effect size estimates cited (Mullen, et al., 1987) for pain, depression and disability were small according to Cohen's (1988) criteria and difficult to interpret in a meaningful way (Brant, 1994). The only study in the meta-analysis with a reasonable sample size (experimental group = 341, control group = 237) was one conducted by Lorig and her colleagues (1985, personal communication to Mullen et al 1987). The only favourable effect size estimate from the study (Lorig et al, 1985) was obtained for the measure of depression (+0.36).

The development of the ASMP by Lorig (1980) was the first example of a comprehensive, systematic program of arthritis education. It has been shown to decrease pain and depression, and increase physical activity (Lorig, Lubeck, Kraines, Seleznick, & Holman, 1985) and reduce health care costs (Lorig, et al., 1993). However, there have been inconsistencies in findings, for example Cohen, van Houten Souter, DeVellis, & DeVellis (1986) found there was no change in measures of pain or depression between experimental and control groups taking part in an ASMP, in which approximately 80% of the participants had osteoarthritis. In a Dutch study of RA patients (Taal, et al., 1993b), knowledge, exercise and self-efficacy increased but pain, depression and disease activity remained unchanged.

Several reasons have been posited for the inconsistencies found in the literature such as variation in education intervention and the selection of a variety of variables and instruments to estimate the effects of the intervention (Goeppinger, Arthur, Baglioni, Brunk, & Brunner, 1989). In addition, the heterogeneity of participants has been poorly addressed. Goeppinger et al (1989) have called for, among other things, research that examines the characteristics of the people taking part in the arthritis education interventions. Determinants of participation would appear to constitute one set of characteristics that may prove worthy of investigation.

2.5 Association between health behaviour and health status

An interesting inconsistency that has been identified in arthritis education is the lack of association between changes in health behaviours (such as walking, exercise and relaxation) and health status (pain, depression and disability) (Lorig, Seleznick, Lubeck, Ung, Chastain, & Holman, 1989). It appears that improvement in health status resulting from participation in the ASMP is associated with an increase in participants' self-efficacy (SE) rather than an increase in their health behaviours (Lenker, Lorig, & Gallagher, 1984; Lorig & Holman, 1993).

In addition, it has been demonstrated that certain ASMP participants (in both intervention groups and control groups) have reasonably high SE at baseline measures (Lorig & Holman, 1993; Taal, et al., 1993b). Given that the patients in the control groups in ASMP studies are delayed participants (i.e. they have prior knowledge of eventual participation in the ASMP) it is possible that a high SE represents a primary determinant in program participation.

In a recent survey of exercise beliefs and exercise habits among people with arthritis (RA 48%, OA 41% and other 11%) Gecht, Connell, Sinacore & Prohaska (1996) found that there was strong association between self-efficacy for exercise and participation in exercise activities. Severity of disease discriminated exercisers from non-exercisers. If individuals with arthritis have high SE for participation in exercise it may also be the case that those with (already) high SE wish to participate in the ASMP. Conversely those with low SE may not wish to participate in the ASMP. It was, therefore, important for SE to be measured in the present study in "true" non-participants (i.e. rather than delayed participants).

Lorig et al (1987) have recommended that investigators attempt to understand the mechanism by which arthritis education operates. The assumption that there is an association between changes in health behaviours and changes in health status has been challenged (Lorig & Holman, 1993; Taal, et al., 1993b). Moreover, researchers tend to generalize study findings to *all* individuals with arthritis even though the underlying determinants of participation in arthritis education have not yet been described.

For example, it is plausible that those individuals who attend education programs constitute a different population of people with arthritis than those who do not attend. Thus any claims with respect to the underlying mechanism of arthritis education should be confined to the former population.

Buckelew et al (1996) assessed 109 subjects with fibromyalgia on a number of measures (disease severity, pain, physical activity and self-efficacy) before and after a six week training intervention. They found that pre-treatment SE was a significant predictor of post-treatment physical activity. A higher SE was associated with a better physical activity outcome. Changes in SE were also significantly related to better outcome measures of disease severity, pain and tender point index.

Buckelew et al's (1996) study provides evidence that pre-intervention SE levels in certain individuals with a chronic condition will predict that they will do better on selected outcome measures. This supports the investigator's contention that people with RA who already have high SE will do well on the ASMP course, not necessarily because of the course but because they have high SE going in to the course. It is important therefore, to measure the SE of those individuals who do not wish to take the ASMP in order to obtain a more meaningful comparison.

It is also worth noting that the majority of studies in arthritis education have been conducted in the States. It is not at all clear that the findings are generalizable to the Canadian context given the differences that exist between the two cultures and health care systems. For example, the publicly funded structure in the Canadian system allows for access to specialist care which is different from the third party payer models in the U.S. (Rachlis & Kushner, 1994) It would therefore be important to identify and describe the determinants of ASMP participation within the Canadian context.

2.6 Information seeking behaviour

Miller (1987) has classified individuals as information seekers (monitors) or information avoiders (distractors) according to the behavioral style they adopt when posed with a threat. A high level of monitoring is associated with anxiety (Miller, 1987) whereas distractors tend to exhibit less stress when posed with a threat (Efran, Chorney, Ascher, & Lukens, 1989). Miller & Mangan (1983) have shown that providing clients with large amounts of information is not always conducive to stress reduction, rather it is important to establish the client's information preferences.

Given these findings one might expect that non-participants would adopt an information avoidance style and participants would prefer a monitoring style of information seeking behaviour. To date information seeking behaviour has not been measured in a population of individuals with RA.

2.7 Quality of Social Support

There has been no clear agreement reached on how to measure the complex construct of social support (Cohen & Syme, 1985; Goodenow, Reisine & Grady, 1990). Two approaches have emerged which either examine the individual's social network or the *quality* of social support within that network (Bowling, 1991).

The assumption underlying the "network" approach is that the individual with many social ties will have greater support than one with a few. The number of people in one's social network is not necessarily a clear indicator of the *quality of* social support received (Sarason, Shearin, Pierce & Sarason, 1987). It has been argued that it is not only important to examine the individual's social network with respect to the number of friends and family but also the quality of support received from the social network (Caplan, 1974; Jacobson, 1986).

Different scales have been developed for measuring social support in the general population and with young adults (Barrera & Ainlay, 1983; Cohen, Mermelstein, Kamarck & Hoberman, 1985; Sarason, Levine, Basham, Sarason, 1983). It has been suggested that individuals who have a chronic disease experience different stressors in coping with the disease from the rest of the "general population" (Cohen & Willis, 1985).

Goodenow, Reisine & Grady, (1990) recognized the need for the development of a tool which addressed a particular population experiencing social stress. Goodenow and her colleagues (1990) developed the Quality of Social Support Scale (QSSS) specifically for use with RA patients. It would appear to be appropriate to use the QSSS to obtain an estimate of the quality of social support in a sample of patients with RA.

In summary, health educators have focussed their attentions on the acquisition of knowledge and skills, and changing behaviour with the intention of improving client health. Investigators are now challenging the assumptions surrounding the mechanism by which health education works. It appears that positive outcomes obtained from education programs occur not simply by knowledge acquisition but rather through increasing individuals' self-efficacy and their skills in managing their condition.

Furthermore, certain participants in ASMPs come to the program with a reasonably high level of knowledge and self-efficacy. The participants in ASMPs constitute a heterogeneous group of people with different forms of arthritis. Most of the research to date has been conducted in the States. Therefore caution must be exercised in making claims for arthritis patient education with respect to its generalizability in the context of the Canadian health care system.

The determinants of program participation are not clearly understood. However, it was decided that variables such as, self-efficacy, health status, illness intrusion, depression, knowledge, social support and information seeking style are worth investigating in a homogeneous group of individuals with RA in Canada.

2.8 Psychometric Instruments

The number of items, scoring and estimated completion time for each instrument is described in Chapter 3. In this section each instrument used in the study will be described with respect to its psychometric properties.

2.8.1 Self-Efficacy

The Arthritis Self-Efficacy Scale (Appendix A) was developed specifically for use with patients who have arthritis (Lorig, Chastain, Shoor & Holman, 1989). The 20 item scale measures the respondents' levels of confidence with three areas as they relate to arthritis management. The three areas are: physical function e.g. getting in and out of a car; pain management e.g. keep arthritis pain from interfering with your sleep, and "other" e.g. control fatigue, dealing with the frustration of arthritis. The instrument has construct and concurrent validity and test-retest reliability of 0.85 – 0.90 (Lorig et al, 1989).

2.8.2 Knowledge Test

Knowledge of arthritis was assessed using a test (Appendix B) specifically developed (Edworthy, personal communication, 1993) for use with patients who have rheumatoid arthritis. Other arthritis knowledge tests have been developed, for example, in the U.K. (Hill, Bird, Hopkins, Lawton & Wright, 1991) and Canada (Lineker, Badley, Hughes & Bell, 1997).

However, the test devised by Edworthy, Devins & Watson (1995) was specifically designed to test knowledge gained through the ASMP. It was decided that it would be appropriate to test the present study's subjects using a test designed for the program in which they either wanted or did not want to participate. The test has face and content validity. The reliability for each of the subsets of the test has had coefficient alphas reported at 0.72 to 0.84 (Edworthy et al, 1995). A subset of 10 items from the knowledge test was used in the present study.

2.8.3 Information Seeking Behaviour

The Miller Behavioral Style Scale (MBSS) (Appendix C) was used to measure information seeking behaviour in the sample of RA patients. The scale was designed to categorize individuals in terms of their preference for information in stressful situations (Miller & Grant, 1979). The MBSS has been used with patients who have acute conditions (Miller & Mangan, 1983) and in patients with chronic conditions who are undergoing a stressful event related to their therapy (e.g. cancer patients having nausea from chemotherapy) (Miller, 1992). The scale had never been used with RA patients in the community. The MBSS has face and content validity and of 0.72 for the monitoring subscale. The blunting subscale had a test-retest reliability of 0.75; blunting refers to the behavioural coping style adopted by certain individuals who prefer not to be given information about their condition (Miller, 1987).

2.8.4 Social Support

Social support was measured by assessing the number of family and friends in the patients' social network. It is important to enumerate an individual's social ties, it is also important to measure the *quality* of social support obtained from the family and friends. The Quality of Social Support Scale (QSSS) was developed by Goodenow, Reisine & Grady (1990) specifically for use in patients with RA (Appendix D). The QSSS has concurrent and discriminant validity (Fifield, Affleck, Reisine, Tennen, Goodenow, & Pfeiffer 1988) and high internal reliability (Cronbach's $\alpha = 0.87$) (Goodenow et al, 1990).

2.8.5 Health Status

An overall estimate of the patients' health status was measured by using the Arthritis Impact Measurement Scale Version 2 (AIMS2, Appendix E), the Illness Intrusiveness Ratings Scale (IIRS) and the Center for Epidemiological Studies Depression Scale (CES-D).

The AIMS and later the second version of the instrument AIMS2 were developed by Meenan, Gertman & Mason (1982) and Meenan (personal communication, 1994) respectively. The instrument was developed specifically for use with patients who have arthritis. It has been used in many studies and has well established convergent and discriminant validity (Decker, 1982; Frank-Stromborg, 1988; Meenan, personal communication,1994; Meenan et al, 1982). Overall test-retest reliability has been reported between 0.87 (Meenan, 1982) to 0.92 (Frank-Stromborg, 1988) with scale coefficients ranging from 0.63 to 0.88 (Meenan et al, 1982).

2.8.6 Illness Intrusion

The Illness Intrusiveness Ratings Scale (IIRS) was used to measure the degree to which illness-induced disruptions impact on lifestyle activities in those with a chronic condition. The IIRS (Appendix F) has content and discriminant validity and an internal reliability coefficient of 0.80 (Devins, Binik, Hutchinson, Hollomby, Barre & Gutmann, 1983).

2.8.9 Depression

Depression was measured with the Center for Epidemiological Studies Depression Scale (CES-D, Appendix G). The CES-D is a well established instrument which was developed specifically for use with the general population (Radloff, 1977). The CES-D has criterion validity and split half reliability of 0.87 to 0.92 (Radloff, 1977). It has been used in arthritis populations and has been deemed to be a valid instrument for use with people who have RA (Blalock, DeVellis, Brown & Wallston, 1989).

2.8.10 Social Desirability

Social desirability in the context of health care research is defined as the potential for the distortion of responses by respondents in such a way that they are placed in a favourable light. The most widely used instrument for measuring social desirability is the Marlowe-Crowne Social Desirability Scale (M-CS)

(Crowne & Marlowe,1960). The MC-S (Appendix H) has a reported internal consistency coefficient of 0.88 and a test-retest reliability coefficient of 0.88 (Crowne & Marlowe, 1960).

2.9 Summary

The volume of research into arthritis patient education has increased substantially since the 1980's. However there is no published literature concerning the *determinants* of participation in arthritis education or the effect of self-efficacy on patient *participation* in arthritis education programs.

An overview of self-efficacy theory was presented in which efficacy and outcome expectations were described. The literature relating to the other variables in the study e.g. knowledge, health status and health behaviours was reviewed. In addition an overview of the psychometric properties of each of the instruments used in the study was provided.

CHAPTER 3

METHODS AND MATERIALS

3.1 Design

It will be recalled that the purpose of the research was to compare the differences between patients who wish to participate in an arthritis education program and those who do not, with respect to: self efficacy, knowledge, information seeking behavior, social support, health status, illness intrusion and depression.

A case-control design was used. The "cases" are those RA patients who expressed an interest in participating in the ASMP (Yes to ASMP) and the "controls" are those RA patients who have no interest in participating in the ASMP (No to ASMP). Data collection was conducted in two phases.

The first phase involved face to face interviews using an interview schedule developed by the investigator (see Appendix I). The interview schedule was used to gather data on demographic variables, arthritis morbidity (including a 28 joint assessment and current medications), social network, assessment of general health (e.g. smoking, drinking and exercise habits) both before and after the diagnosis of RA, and prior knowledge of the Arthritis Society and the ASMP.

The second phase involved completion of a package of eight self-report instruments to collect the relevant data on which to compare the cases with the controls. The package of self-report instruments was left with patients to be completed in their own time and return by mail to the investigator. The package consisted of: a Self Efficacy Scale (SES), a knowledge test, the Miller Behavioral Style Scale (MBSS), the Quality of Social Support Scale (QSSS), the Arthritis Impact Measurement Scale version 2 (AIMS2), the Illness Intrusiveness Ratings Scale (IIS) and the Centre for Epidemiological Studies' Depression Scale (CES-

D). The Marlowe-Crowne Social Desirability Scale (MCS) (Crowne & Marlowe, 1960) was also included in the package and self-administered.

3.2 Sample

The sample was obtained from a target population comprised of individuals with RA who were living in the community in a major urban centre in Canada and had Class I-II involvement (Steinbrocker, Traeger and Batterman, 1949). The classification system proposed by Steinbrocker et al (1949) for assessing functional capacity is essentially a descriptive ordinal scale (see table 3.1). The system remains in widespread use today (Escalante & Beardmore, 1997; Lambert, Hurst, Forbes, Lochhead, Macleod, & Nuki, 1998; Pincus, Larsen, Brooks, Kaye, Nance, & Callahan, 1997; Tlustochowicz, Piotrowicz, Cwetsch, Raczka, Kramarz & Nowak, 1995; Yutani, Koike, Goto & Yamano, 1995). The inclusion criteria for sample selection were: verbal fluency in English, the ability to write in English, 18 years of age or older, Class I-II RA and no prior participation in the ASMP.

Table 3.1 Classification of functional capacity in Rheumatoid Arthritis

Class	Functional Capacity
I	**Complete.** Able to perform all usual duties without handicap
II	**Adequate for normal activities.** Some handicap or discomfort or limited motion of one or more joints.
III	**Limited.** Can do little or none of the duties of usual occupation or activities related to self-care.
IV	**Incapacitated.** Bedfast/chairfast; Can do little or no self-care.

Source: adapted from Steinbrocker, O., Traeger, C.H., & Batterman, R.C. (1949). Therapeutic criteria in rheumatoid arthritis. The Journal of the American Medical Association, 140 (8), 659-662.

3.3 Recruitment

A list of patients with RA was generated from the day lists of five rheumatologists practising in an urban setting. The patients were listed in alphabetical order together with their addresses and the names and phone numbers of their general practitioners (GPs).

Patients who had completed the ASMP, taken part of the ASMP, who were not fluent in English, had Class III-IV RA, and were deceased or had moved out of the city were removed from the list. Some of the remaining patients lived outside of the city or in another province. It was further decided to recruit only those patients who lived within the city limits.

Each GP was called and asked if they had any objections to the patient being contacted and invited to participate in the study. With a few exceptions (e.g. the GP provided additional information such as the patient was currently hospitalized and therefore not able to participate) the investigator was permitted to proceed with contacting the patient.

A standard letter (appendix J) was mailed to the patients from their rheumatologists inviting them to take part in the study. The patients were requested to indicate their willingness to take part by completing and returning a patient reply form (appendix K) in a stamped addressed envelope provided. The completed reply form was returned to the investigator. The patients who did not reply within two weeks of the mailout were followed-up by a phone call (from the investigator or one of his research assistants) requesting their participation. If they decided not to participate at this point no further contact was made.

The patients who returned their forms indicating that they did wish to participate in the study were contacted by telephone. At the point of contact by phone the investigator established whether the patients were cases or controls by asking them: "Are you interested in taking part in an arthritis education program?". If the patients answered in the affirmative they were categorized as "cases", a negative response cataegorized them as "controls". In addition, the investigator confirmed that they had not taken the ASMP before, obtained an informal consent and arranged an appointment for data collection. The patients were given the choice of meeting with the investigator at the university or at their home. The vast majority opted for the latter.

At the pre-arranged appointment the investigator collected information from the patient on the interview schedule and requested that the patient return the completed self-report instruments in the stamped addressed envelope provided within seven days. If the instruments were not returned after seven days a follow-up phone call was made requesting the completed package be mailed to the investigator. If the package was not returned after the follow-up phone call no further contact was made.

3.4 Sample Size

It is emphasized that power calculations are intended to provide "best guess" estimates and of themselves offer no guarantee of sample size accuracy. As previously stated, it is hypothesized that the major difference between the cases and controls will be with respect to their self-efficacy. Therefore the investigator decided to anchor the sample size calculation in the construct of self-efficacy.

Another problem associated with power calculations is in determining what constitutes a meaningful effect size. The problem is further compounded when the population standard deviation (σ) is unknown. Cohen (1988) has suggested, as a rule of thumb, that effect sizes may be nominally categorized as small, medium and large with numerical values of 0.20, 0.50 and 0.80 respectively. Fortunately, unpublished data from a national evaluation study of OA and RA patients who had taken the ASMP were made available to the investigator (Edworthy, 1994). The data indicate a mean baseline score of 47.3 on the SE pain subscale (1 - 100 scale) for an ASMP participant group (n = 346), with a standard deviation of 24.25. The mean and standard deviation from the national data were taken as estimates for the population mean (υ) and standard deviation (σ) respectively.

Taal et al (1993b) have used a five point SE scale, where a score of 1 is interpreted as very low SE and a score of 5 is very high SE. One might arbitrarily consider that a score of 1 to 2.9 is low SE and 3 to 5 is high SE and a change in score of 2 would take any individual from the low to high range. However a change in score of 2 on a 1 - 5 point scale translates into a change in score of 40 on a 1 - 100 scale and, as may be seen from table 3.2, this provides a very small sample size.

Table 3.2 Sample size estimates anchored in differences in Self-Efficacy scores

α	$1 - \beta$ (power)	Effect Size	n	Source
0.05	0.80	1.65	6	Taal et al 1993
0.05	0.80	0.33	144	Lorig & Holman, 1993
0.05	**0.80**	**0.50**	**65**	**Present study**

Lorig and Holman (1993) have reported a change in SE of 0.795 (using a 1 - 10 scale) between baseline and four months, in an ASMP participant group ($n = 77$). The 0.795 change was statistically significant ($p < 0.05$) and translates into a difference of 8 on a 1 - 100 scale, providing an effect size of 0.33 (see table 3.2). It was anticipated in this study that the difference between the cases and controls would be greater than 8 on a 1 - 100 scale and would be at least

12. Given the foregoing discussion, and taking into account availability of participants, the investigator elected to sample 65 individuals from each group. Thus with α set at 0.05, power at 0.80 and β at 0.20, the estimated overall sample size for the study was, n = 130.

Recruitment commenced in January 1995 and was terminated in October 1997 for a total period of 34 months. The data at T1 were collected in a 6 month period from January 1995 to June 1995. The data at T2 were collected from August 1996 to October 1997. The intervening time between T1 and T2 was from July 1996 to July 1996 for a period of 12 months.

In spite of persistent efforts it was extremely difficult to recruit participants into the study, in particular into the control group. It was postulated that those patients who did not wish to participate in the ASMP were also reluctant to participate in the study. However a final effort led to an increase in the control group numbers and the final sample size was, n = 72 for the cases and n = 74 for the controls for a total of n = 146 patients in the study.

3.5 Materials

As previously stated the data were collected in two phases. The first phase involved meeting the RA patients and interviewing them using a structured interview schedule. The second phase involved completion of the package of self-administered instruments and returning them to the investigator.

3.5.1 Phase I - Interview Schedule

The structured interview schedule was developed by the investigator (appendix I) based on his experience, a review of the literature and determining the data of interest to be included in the study. The schedule was examined by two Faculty members and two PhD students with interest in questionnaire development for face and content validity. The schedule was revised based on their evaluations. Finally, the schedule was pilot tested on four patients with RA. Further minor adjustments were made following the pilot test.

The interview schedule was subdivided into five discrete sections as follows: demographic variables, arthritis morbidity (including current medications and a 28 joint assessment), social network, arthritis and health (before and after the diagnosis of RA) and the Arthritis Society and ASMP.

3.5.2 Phase II - Psychometric Instruments

The investigator was cognizant of the fact that individuals with RA might have become fatigued in attempting to complete the instruments. It was important to emphasize to the patients that there was no necessity for them to do any freehand writing, all of the responses required only a check mark or circle to be made around a number. The package of self-administered instruments included: a Self Efficacy Scale, a knowledge test, the Miller Behavioral Style Scale, the Quality of Social Support Scale, the Arthritis Impact Measurement Scale, the Illness Intrusiveness Ratings Scale, the Center for Epidemiological Studies' Depression Scale and the Marlowe-Crowne Social Desirability Scale.

There was no necessity for the instruments to be answered in any particular order. The instruments were randomly assembled for each package. The validity and reliability of each instrument has been previously discussed in chapter 2. Each instrument will now be described with respect to the number of items, length of time for completion and how each one is scored.

3.5.3 Self Efficacy Scale

The Arthritis Self-Efficacy Scale (appendix A) was developed specifically for use with individuals who have various forms of arthritis (Lorig, Chastain, Ung, Shoor & Holman, 1989). The Self-Efficacy Scale is designed to measure the respondent's levels of confidence with certain behaviours (e.g. physical function and pain management).

Twenty behaviours were assessed in total and each behaviour represents a major component of the ASMP course (Edworthy, 1993). The respondents make a circle on a visual analogue scale from 0 to 100 for each item, where 0 is interpreted to mean "very uncertain" and 100 means "very certain". There are three subscales within the instrument for, pain (five items), physical function (nine items) and other symptoms (six items). The entire scale takes approximately 10 minutes to complete. Each subscale may be scored separately by taking the mean of the scores for each subscale. Alternatively, an overall Self-Efficacy score may be determined by taking the overall mean of all 20 items. The minimum score possible is zero, the maximum is 100; the higher the score the greater the level of Self-Efficacy an individual is deemed to have.

3.5.4 Knowledge Test

Knowledge of arthritis was assessed by using a multiple-choice test (appendix B) of 10 items which were developed specifically for an arthritic population (Edworthy, 1993). The test takes approximately 10 minutes to complete. The minimum score possible is zero, the maximum score is 10; the higher the score the greater the knowledge an individual has concerning arthritis.

3.5.6 Miller Behavioral Style Scale

The Miller Behavioral Style Scale was used (appendix C) to measure information-seeking behaviour. Respondents were required to read four stress evoking scenarios in which they imagine that they are taking part e.g., *"Imagine you are afraid of flying and you are on an airplane".*

Each scenario is followed by eight statements that represent different ways of dealing with the situation. Four of the statements characterize information that would be of interest to an information seeker (known as "monitors"), e.g. *"I would read the material provided about safety features of the plane".* The other four statements are of interest to an information avoider (known as "blunters"), e.g., *"I would watch the in-flight movie".*

Two scores are derived from the scale, the total monitor score and the total blunter score, which are arrived at by summing the monitor and blunter options respectively endorsed by the respondents across the four situations. The more monitoring options selected the greater the "information seeker", whereas the more blunting options selected then the individual is characterized as not wishing information (i.e. a blunter) (Efran, 1989; Miller, 1987). The scale has never been used in a population of patients with a chronic condition who are *not* undergoing a stressful event. The completion time is approximately eight minutes.

3.5.7 Quality of Social Support Scale

Social support is a difficult construct to measure with any degree of accuracy. Dimensions of social support in the present study were measured both in the interview and by using the Quality of Social Support Scale (appendix D). As part of the interview social support was measured as follows:

- Social network - respondents were simply asked the number of close friends and relatives they have (i.e. people with whom they feel at ease).
- Emotional social support - respondents were asked to reply to the question: How much *support do* you get in *coping* with your disease from your spouse/children/friends/neighbours/relatives? Each item was rated on a five-point scale with, 1 = very little support and 5 = very much support.
- Instrumental social support - respondents were asked to reply to the question: How much *help* do you get from people close to you? The item is also rated on a five-point scale where, 1 = very little help and 5 = very much help (Taal et al, 1993b).

In addition the Quality of Social Support Scale (Goodenow, Reisine, & Grady, 1990) was self-administered. The scale has 17 items which are rated as follows: never = 1; sometimes = 2; usually = 3; and always = 4. Five of the items (2, 5, 8, 12 and 15) are reversed scored. The minimum score is 17 and the maximum score is 68. The higher the score the greater the degree of social support experienced by the individual. The completion time is approximately eight minutes.

3.5.8 Arthritis Impact Measurement Scale

A general estimate of overall health status was obtained from the Arthritis Impact Measurement Scale, version two (AIMS2, appendix E). The AIMS was specifically developed for use with the arthritic population (Meenan, 1982). A revised and shortened version (the three component model) was used in the present study (Meenan, personal communication, 1994).

There is a total of 57 items on the instrument and nine subscales. Depending on the subscale, the items are variously scored: all days = 1; most days = 2; some days = 3; few days = 4; and no days = 5 or, always = 1; very often = 2; sometimes = 3; almost never = 4; and never = 5. Some items in certain subscales are reversed scored in order to obtain a raw score. A normalization procedure (appendix L) is then applied to each subscale to obtain a normalized score of zero to 10.

In the three component model, six subscales may be combined (mobility, walking and bending, hand and finger function, arm function, self care and household tasks) to provide an overall physical component score ranging from zero to 10. Similarly the affect component may be scored by combining the tension and mood subscales. The symptom component is derived from the score obtained on the pain subscale.

The higher the score the greater the impact that arthritis has on the individual (i.e. the lower the score the "healthier" the respondent). The completion time for the shortened version is approximately 20 minutes.

3.5.9 Illness Intrusiveness Ratings Scale

The Illness Intrusiveness Ratings Scale (IIRS, appendix F) was used to measure the RA patients' broader quality of life. Illness intrusiveness relates to the disruption caused to patients' lifestyles and other activities and interests as a result of the their chronic disease (Devins, Edworthy, Seland, Klein, Paul & Mandin, 1993).

The IIRS consists of 13 items which are rated on a Likert type scale from 1 (not very much) to 7 (very much). The items are summed and an average score is obtained. The higher the score the greater the illness intrusion experienced by the individual. The completion time is less than five minutes.

3.5.10 Centre for Epidemiological Studies Depression Scale

An estimate of the patients' rating of their depression was obtained using the Centre for Epidemiological Studies' Depression Scale (CES-D, appendix G). The CES-D comprises 20 items (Radloff, 1977) scored as follows: rarely = 0; some = 1; occasionally = 2; and, most of the time = 3. Items 4, 8, 12 and 16 are reversed scored. The higher the score the greater the individual is "at risk" for depression. The completion time is less than five minutes.

3.5.11 Marlowe-Crowne Social Desirability Scale

The Marlowe-Crowne Social Desirability Scale (appendix H) was used to obtain an estimate of the degree to which respondents may have responded in a socially desirable way (Crowne & Marlowe, 1960). The scale does not *prevent* patients responding in such a way that they are placed in a favourable light, rather it *detects* social desirability bias of respondents (Nederhof, 1985).

The scale consists of 33 items, 18 are designated "true" and 15 are designated "false". The subject chooses a response by circling "true" or "false" against each item. The designated "true" items are scored: true = 1 and false = 0. The designated "false" items are reversed scored. The higher the score the greater the tendency for responding in a socially desirable way. The completion time is less than five minutes. The total completion time for the entire package was conservatively estimated to be one hour and ten minutes.

3.6 Methods

3.6.1 Data Collection

Two research assistants were involved in collecting interview data as well as the investigator. Research assistant A conducted 27 of the 36 interviews at time 1 and research assistant B conducted nine interviews of 110 at time 2. The majority of the data for time 2 were collected by the investigator. Most of the interviews (95.8%) took place in the patients' own homes. The interviews would take from 30 to 60 minutes to complete. Younger patients tended to complete the interview process faster than the older patients.

3.6.2 Inter-rater Reliability

During the interview process each patient had a 28 joint assessment done to rate their pain and swelling at the time of the interview by the investigator or one of the research assistants. The research assistants were trained by the investigator. Inter-rater reliability was assessed by comparing the investigator totals for pain and swelling with the totals of each of the research assistants (i.e. investigator versus research assistant A and investigator versus research assistant B). Cronbach's coefficient alpha (Shrout & Fleiss, 1979) was used to determine the level of agreement between the investigator and each of the research assistants.

3.7 Data Analysis

3.7.1 Preparation

A total of 96,214 original data points were generated from 146 patient encounters. The data generated from the interviews and the self-administered instruments were entered into a MEDLOG database by two research assistants. It was decided not to double enter the data. This decision was based on research which demonstrated that most errors detected by double entry were of minimal importance to the study outcome when entered by a few individuals (Gibson, Harvey, Everett & Parmar, 1994).

A random selection of 10% of patient files (n = 14) were closely examined for entry errors, this yielded an overall error rate of 9.8 per 10,000 data points. This error rate is lower than the 22 per 10,000 and 15 per 10,000 reported in the cardiac arrhythmia suppression trial (Reynolds-Haertle & McBride, 1992) and the continuous hyper-fractionated accelerated radiotherapy trial (Gibson et al., 1994) respectively.

All errors that were detected were corrected. The data were thoroughly cleaned including careful examination of the raw data and verification of missing data, outliers and apparent discrepancies. The data were analyzed using the statistical software package SPSS® for Windows®. The level of statistical significance was set at < or = 0.05 and 95% confidence intervals were reported.

3.7.2 Preliminary Analysis

The data from the interviews were grouped and analyzed in five discrete categories: demographics, arthritis morbidity, social network and support, arthritis and health, and Arthritis Society and ASMP. The preliminary analysis of the data consisted of exhaustive descriptive analysis to check for data integrity and to describe demographic characteristics of the RA patients using tabulations, boxplots, means and standard deviations.

3.7.3 Primary Analysis

It will be recalled that the research hypotheses are:

1. Those patients wishing to participate in the ASMP (cases) will have higher self-efficacy scores than those not wishing to participate (controls).
2. Those patients wishing to participate in the ASMP will demonstrate more knowledge about RA than those not wishing to participate.

3. Those patients wishing to participate in the ASMP will demonstrate more information-seeking behavior than those not wishing to participate.
4. Those patients wishing to participate in the ASMP will have greater social support than those not wishing to participate.
5. Those patients wishing to participate in the ASMP will perceive and report their health status to be "better" than those not wishing to participate as measured by: the AIMS2, IIRS and CES-D scales.

In the original analysis plan hypotheses one to five were going to be tested by comparing the mean differences between cases and controls for each of the measures of: self-efficacy, information seeking behaviour, knowledge, social support and health status. The comparisons were going to be made by using one way analyses of variance with contrasts.

3.7.4 Secular Trend Analysis

Owing to difficulties with patient recruitment the data were collected over a greater than expected period of time. Data collection took place at two time periods; from January 1995 to June 1995 (T1) and from August 1996 to October 1997 (T2). Given the time periods between the data collection points a secular trend may have occurred and influenced the primary variable of self-efficacy.

A secular trend, in chronic disease conditions, tends to take place over several years to decades (Last, 1988). Factors which influence secular trends include:

- Enhanced diagnostic techniques - increased reporting of the disease.
- Changes in age distribution of the population. This alters crude rates although age specific rates remain constant.
- Improved therapy - causing an increase in survival. Treating patients earlier and earlier detection.

- Actual change to the incidence of the disease - lifestyle and environmental factors may influence incidence rates.
- Changes in enumerating the population at risk - this changes incidence rates but is not a "true" change in actual frequency of disease.

(Hennekens & Buring, 1987)

In order to examine the possibility of a secular trend in SE for the cases and controls at both time periods the data were described separately. That is, the cases and controls at T1 were examined and the cases and controls at T2 were examined. In addition the data were examined by combining the cases at both time periods and comparing them with the controls at both time periods while controlling for potential confounding variables.

3.8 Ethics - Protection of human subjects

Subject confidentiality was maintained at each stage of the research. Only the investigator had access to the research data. No one taking part in the research was identified by name at any point in the study (other than to the investigator and research assistants) nor will be in subsequent publications and presentations.

The data were securely stored in a locked filing cabinet to which only the investigator had access. The interview schedules and questionnaires will be destroyed by shredding when they are no longer required for the study. At the initial point of contact by the investigator the subjects were asked for verbal consent to proceed. Formal written consent was obtained (appendix M) at the time of the interview. Ethical approval to conduct the study was obtained from the Conjoint Medical Ethics Committee of the University of Calgary.

3.9 Summary

In summary, a case-control design was used. Data were collected in two phases. The first phase involved meeting with the RA patients and a structured interview schedule was used for data collection. The second phase required the

RA patients to complete a package of eight self-administered instruments which were returned to the investigator by mail.

The patients were recruited from the day lists of five rheumatologists. All patients lived in the community in a large urban centre. A total of 146 patients were recruited: 72 cases and 74 controls. Owing to certain difficulties in patient recruitment, data were collected on cases and controls at two time periods. It was thought that a secular trend could have influenced the primary outcome variable of interest, self-efficacy, over time.

In addition to the descriptive and comparative analyses of the data, they were also analyzed to determine if a secular trend had occurred. Ethical approval for the study was given by the Conjoint Medical Ethics Committee of the University of Calgary.

CHAPTER 4

RESULTS

The sample characteristics are reported first, followed by the results generated from the analysis of the interview data and the psychometric data. It is emphasized that, according to the original design, it was *not* intended that the data would be collected at two discrete time periods. Given the fact that data were collected at two time periods (T1 and T2) it was decided, for the purposes of clarity (and to assess for a secular trend) to describe the data separately for each time period.

Categorical data were assessed using Chi square tests for cases versus controls at each time period. Comparisons of continuous data were made using a one way analysis of variance and contrasts. Two contrasts were computed, the first one compared the cases and controls at T1 and the second contrast compared the cases and controls at T2 on a number of different psychometric and other variables.

The data obtained from the psychometric instruments were assessed for interaction using a two way (time and group) analysis of variance. Exploratory analysis was also done on the instrument data. The data were examined by comparing the combined cases and controls from both time periods while controlling for potential confounding variables using an analysis of covariance.

Sample Description

The names of patients were extracted from the day lists of five rheumatologists in an urban centre. There was an attempt to contact 586 patients in total for possible recruitment into the study, of these, 146 eventually participated (72 cases and 74 controls). At T1 there were 190 patients contacted and only 36 eventually took part in the study (see Table 4.1).

At T2 a larger group of patients were contacted (n = 396) and of these, data were collected on 110. As may be seen from Table 4.1 the majority of patients who were unable to take part had moved, lived outside of the city limits, no reason was given or it was not possible to contact them. Other reasons for not taking part in the study are listed on Table 4.1.

There were a total of 180 participants initially enrolled in the study, however some of the patient data were incomplete or the questionnaires were not returned. There was a final "usable" dataset from 146 patients.

Table 4.1 Sample recruitment characteristics

Reason for not participating in study	Time 1 - Jan 95 - June '95 Total number of patients contacted n = 190	Time 2 - Aug '96 - Oct '97 Total number of patients contacted n = 396
Moved/Out of town/Unable to contact	44 (23.2%)	72 (18.2%)
No reason	44 (23.2%)	89 (22.4%)
No reply from GP/Unable to contact GP	16 (8.4%)	37 (9.3%)
Taken ASMP	8 (4.2%)	37 (9.3%)
Too sick/personal reasons	10 (5.2%)	27 (6.8%)
GP says "No"	4 (2.1%)	13 (3.2%)
Deceased	2 (1.0%)	6 (1.5%)
Did not meet inclusion criteria	7 (3.7%)	0
Total not participating	135 (71%)	281 (70.9%)
Total participants	55 (29%)	125 (31.5%)
Incomplete files	19	15
Complete files (usable data)	36	110
Number of cases	7	65
Number of controls	29	45

1. Phase I - Interview data

Approximately three-quarters (75.3%) of all the interviews were conducted personally by the investigator. The remaining interviews were carried out by two research assistants (research assistant A, 75% of the interviews at T1; research assistant B, 8.2% of the interviews at T2) who were experienced in conducting personal interviews with individuals who have arthritic conditions. Following the interview the patients were requested to complete the package of self-report instruments and mail the completed instruments to the investigator. The average length of time for return was 12 days.

It will be recalled that part of the interview involved an assessment of pain and swelling in 28 joints. Inter-rater reliability was calculated using Cronbach's α (Shrout & Fleiss, 1979) for fixed raters. The intraclass correlation coefficients (ICC) for the investigator versus research assistant A were, 0.99 (95% CI 0.97 - 0.99) and 0.95 (95% CI 0.69 - 0.99), for the pain and swelling indices respectively. The ICCs for the investigator versus research assistant B were, 0.97 (95% CI 0.90 - 0.99) and 0.96 (95% CI 0.84 - 0.99) for the pain and swelling indices respectively.

1.1 Demographics

The demographic characteristics of the sample are presented on Table 4.2 for the two time periods for each of the case and control groups.

Table 4.2 Demographic characteristics of sample

Demographic Variable	T1 Cases n = 7	T1 Controls n = 29	T2 Cases n = 65	T2 Controls n = 45	Total Cases n = 72	Total Controls n = 74
Gender (F/M%)	86%/14%	86%/14%	83%/17%	69%/31%	83%/17%	76%/24%
Females - Age Mean Range	57.3 41-68	63.0 38-79	51.1 19-80	59.6 33-83	51.7 19-80	61.2 33-83
Males - Age Mean Range	24.7*	71.6 64-80	60.0 38-83	61.0 36-88	57.1 25-83	63.6 36-88
Females & Males - Age Mean Range	52.6 25-68	64.3 38-80	52.6 19-83	60.2 33-88	52.6 19-83	61.8 33-88
Females - Years Education Mean Range	15.7 13-19	12.0 6-17	12.9 6-20	12.9 9-16	13.2 6-20	12.4 6-17
Males -Years Education Mean Range	12*	11.8 9-14	14.2 9-27	11.0 6-16	14.0 9-27	11.5 6-16
Females & Males Yrs Education Mean Range	15.2 12-19	11.7 6-17	13.2 6-27	12.5 6-16	13.4 6-27	12.2 6-17
Females - Years RA Mean Range	13.0 2-22	15.0 2-36	8.9 0.7-38	8.3 0.6-23	9.3 0.7-38	11.4 0.6-36
Males - Years RA Mean Range	0.5*	19.3 2-57	7.4 1-17	7.6 1-17	6.8 0.5-17	10.2 1-57
Females & Males Years RA Mean Range	11.2 5-22	15.8 2-57	8.7 0.7-38	8.1 0.6-23	8.9 0.5-38	11.1 0.6-57

* Only one male in this group of n = 7 patients

In the sample, over three-quarters of the patients with RA were women (79.4%) providing a 3.8:1 female to male ratio. Although this statistic appears high, it reflects the overall prevalence rate of RA in the general population. The gender differences between cases and controls at both time periods were not statistically significant (T1, p = 0.68; T2, p = 0.08).

As may be seen from Table 4.2 the cases at both time periods were, on average, about 8 to10 years younger than the respective control groups.

The differences in age between cases and controls at both time periods were tested using a one way analysis of variance and contrasts to compare the cases and controls at each time period. The differences in age were found to be statistically significant (T1, p = 0.04; T2, p = 0.005). The statistically significant differences in age persisted at T1 and T2 after controlling for gender (T1, F 1, 33 = 4.48, p = 0.04; T2, F 1, 107 = 6.48, p = 0.01). There was no statistically significant difference in age between males and females in the T1 and T2 control groups or in the T2 cases (p = 0.21, p = 0.67 and p = 0.06 respectively). There was a difference in age between males and females in the case group at T1 (p = 0.04), however caution should be exercised in interpretation of this result as there were n = 7 patients in this group and only one was a male.

The cases, on average, had more years of education than the controls. The largest difference (3.5 years) was between the cases and controls at T1, this difference was statistically significant (p = 0.004). The difference at T2 was not statistically significant (p = 0.21). After controlling for age and gender it was found that the statistically significant differences between cases and controls at T1 persisted (F 1, 32 = 4.49, p = 0.04). At T2, after controlling for age and gender, the differences were still not statistically significant (F 1, 106 = 0.89, p = 0.72). There were no statistically significant differences in number of years of education between males and females within any of the four groups (T1 cases, p = 0.22; T1 controls, p = 0.95; T2 cases, p = 0.23; and T2 controls, p = 0.10).

The controls at T1 had more years with RA than the cases. At T2 the length of time with RA was almost the same for both cases and controls. None of the differences in number of years with RA at T1 or T2 reached statistical significance (p = 0.28 and 0.66 respectively). After controlling for age and gender the differences were still not statistically significant (T1: F 1, 32 = 10.1, p = 0.78; T2: F 1, 106 = 0.52, p = 0.41).

In addition, there were no statistically significant differences in number of years with RA between males and females in any of the four groups (T1 cases, p = 0.23; T1 controls, p = 0.55; T2 cases, p = 0.54; and T2 controls, p = 0.66). It is emphasized that it is difficult to make meaningful interpretation of the comparisons made for the T1 cases given the small sample size (n = 7) and the fact there was only one male in the group.

Marital status, occupational status, ethnic origin and annual income for cases and controls are illustrated on bar charts 4.1, 4.2, 4.3, 4.4 and 4.5 respectively. There was no statistically significant difference between cases or controls at T1 (p = 0.13) or T2 (p = 0.07) with respect to marital status. There was a statistically significant difference on the combined data for cases and controls in that significantly more controls were married (p = 0.02) and more cases were divorced (p = 0.03).

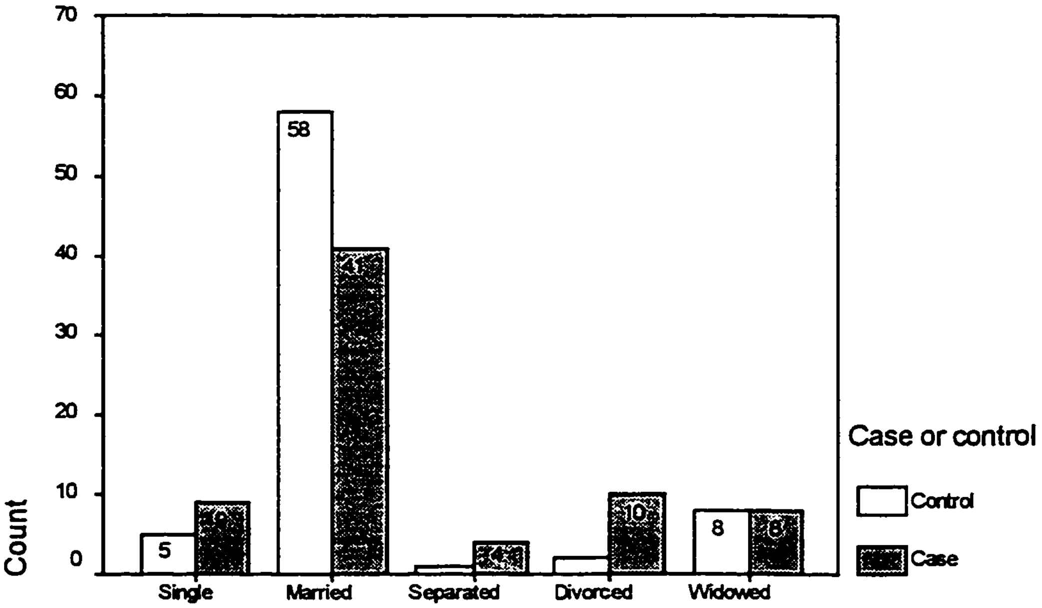


Figure 4.1 Marital status of Cases and Controls n = 146

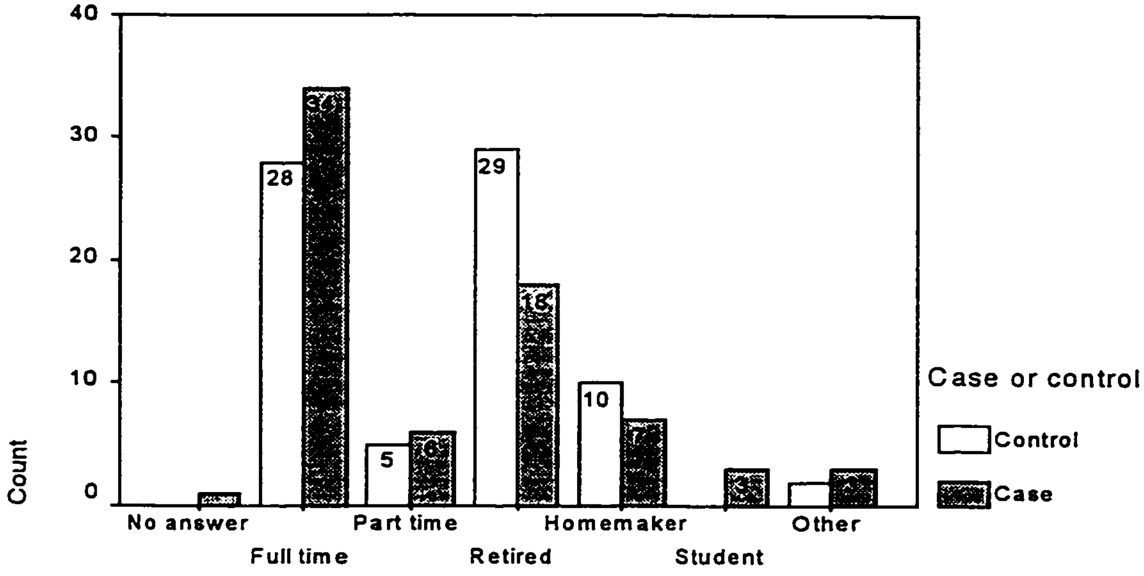


Figure 4.2 Occupational status - Cases and Controls n = 146

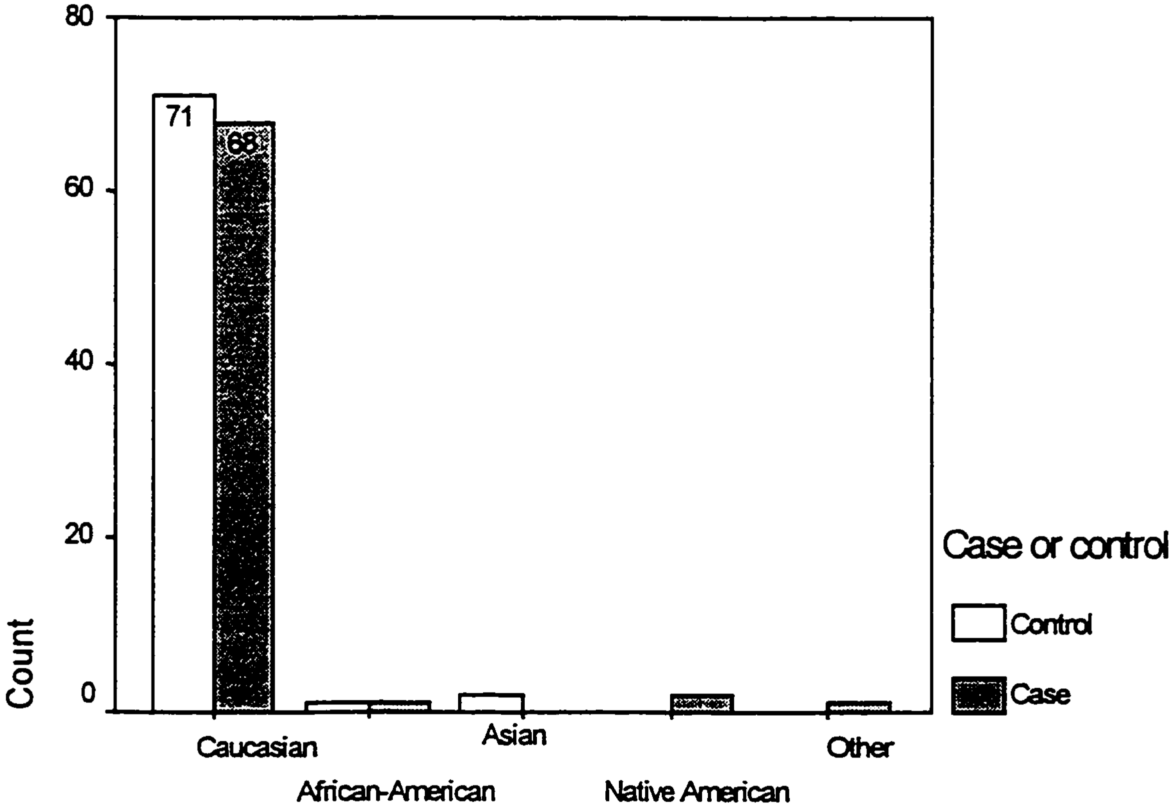


Figure 4.3 Ethnic origin - Cases and Controls n = 146

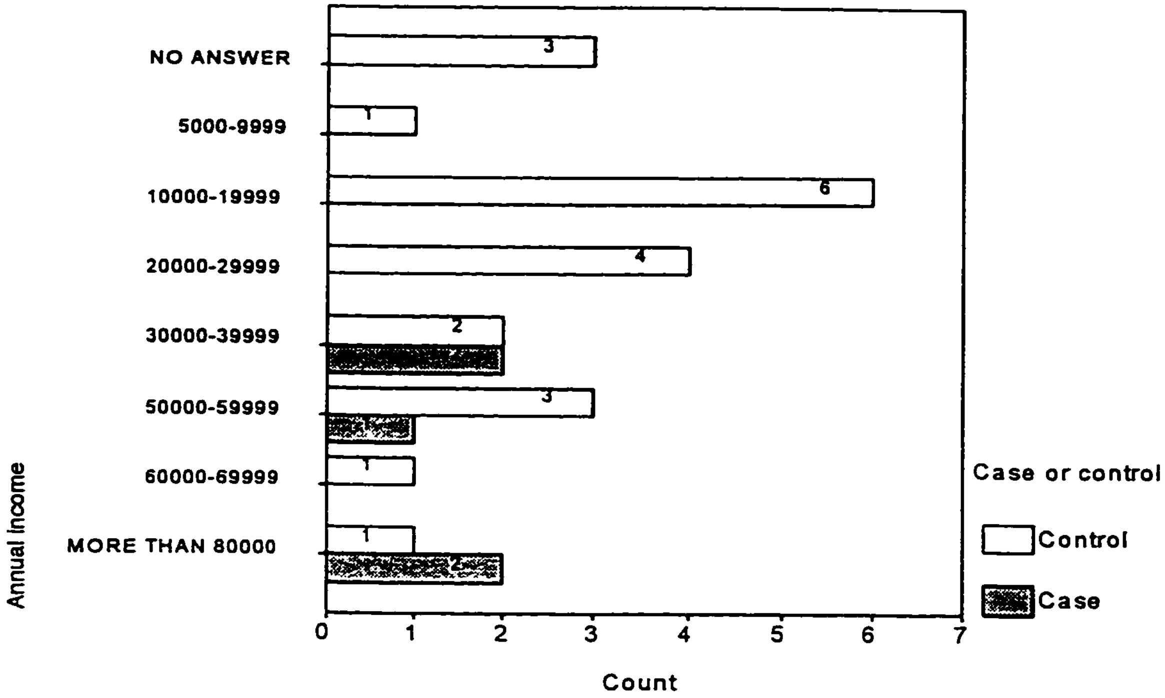


Figure 4.4 Annual income cases and controls at T1

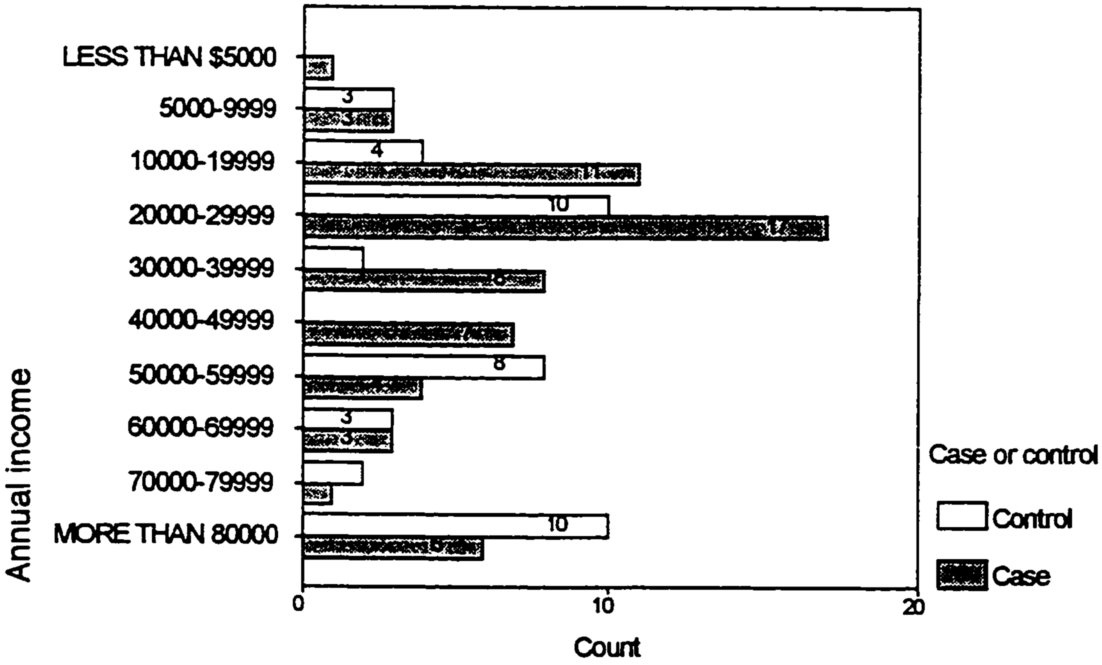


Figure 4.5 Annual income cases and controls T2

As may be seen from the bar charts (Figures 4.1 and 4.3), the majority of the patients in the sample were married and Caucasian in origin. There were two native-Americans, two African-Americans and two Asians in the entire sample. There was a bimodal distribution with respect to occupational status (Figure 4.2); more of the cases worked full-time and more of the controls were retired. The data on the numbers of patients who were retired is a reflection of the average age of the controls (61.8 years), who were over nine years older than the cases (52.6 years). There were no statistically significant differences between cases and controls at T1 (p = 0.16), T2 (p = 0.22) or in the combined data (p = 0.24) with respect to occupational status.

Of the total sample 88% (n = 129) responded to the question on annual income. Most of the controls at T1 had an annual income between $10,000 and $60,000. The cases at T1 reported annual incomes of between $30,000 and more than $80,000. At T2 the majority of the cases and controls reported an annual income between $10,000 and $60,000. More controls than cases had incomes over $80,000 at T2. There were no statistically significant differences with respect to income at T1 (p = 0.17), T2 (p = 0.06) or in the combined data (p = 0.07). Although, as may be seen, the p value approached statistical significance at T2 and in the combined data.

1.2 Arthritis Morbidity

Arthritis morbidity was assessed by obtaining data on the number of GP and specialist visits, morning stiffness, swelling and pain in the joints, self-reports of any extra-articular disease, surgical interventions and current medications.

Not all of the controls at T1 provided information about visits to their GPs and specialists hence the numbers for each group are reported separately. The average number of visits to the rheumatologist in the previous 12 months ranged from, 1.9 in the cases at T1 to, 3.1 in both the cases and controls at T2 (Table

4.3). As expected, the average number of visits to the GP was higher than visits to the specialist in all groups. There was no statistically significant difference between cases and controls at T1 and T2 with respect to visiting their GP (T1, p = 0.80; T2, p = 0.36) or rheumatologist (T1, p = 0.54; T2, p = 0.94).

Overall the patients were faithful to their rheumatologist with the average number of rhuematologists ever seen ranging from 1.4 in the controls at T2 to 2.0 in the cases at T1. There was no statistically significant difference between the cases and controls at both time periods with respect to the number of rheumatologists ever seen (T1, p = 0.21; T2, p = 0.24). As a crude indicator of arthritis morbidity, the results from Table 4.3 would suggest that the cases and controls were similar in their visitation practices to both their specialists and GPs.

Table 4.3 Average number of visits to GP and Rheumatologist in past 12 months

Variable	T1 Cases	T1 Controls	T2 Cases	T2 Controls	Total Cases	Total Controls
Visits Rheum past 12 months						
n	7	28	65	45	72	73
Mean	1.9	2.3	3.1	3.1	3	2.8
Range	1-4	0-10	0-8	0-8	0-8	0-10
Visits GP past 12 months						
n	7	28	65	45	72	73
Mean	7.4	8.5	6	5.1	6.2	6.4
Range	1-30	0-52	0-26	1-24	0-30	0-52
Number of Rheum ever seen						
n	7	27	65	45	72	72
Mean	2	1.5	1.6	1.4	1.6	1.4
Range	1-3	0-7	1-5	1-3	1-5	0-7

Table 4.4 Arthritis morbidity – Duration of morning joint stiffness, joint pain and swelling, frequency of rheumatoid nodules and RA factor

Variable	T1 Cases	T1 Controls	T2 Cases	T2 Controls	Total Cases	Total Controls
Years with RA						
n	7	29	65	45	72	74
Mean	11.2	15.8	8.7	8.1	8.9	11.1
(sd)	(9.0)	(12.0)	(7.7)	(6.0)	(7.8)	(9.6)
Duration of joint stiffness in am (min)						
n	7	28	65	45	72	73
Mean	26.6	51.8	62.7	81.6	59.2	70.4
(sd)	(25.2)	(47.6)	(60.6)	(81.6)	(59.0)	(72)
Pain Score*						
n	7	26	65	45	72	71
Mean	9.6	14.5	8.6	7.4	8.7	10.0
(sd)	(12.7)	(12.4)	(8.7)	(7.6)	(9.10)	(10.1)
Swelling Score*						
n	7	26	65	45	72	71
Mean	11.0	14.0	9.0	9.5	11.0	11.1
(sd)	(11.5)	(13.8)	(9.5)	(10.4)	(11.4)	(12.0)
Rheumatoid nodules						
n	7	25	64	45	71	70
% Yes	57.1	72.0	23.4	20.0	26.7	38.5
% No	42.9	28.0	76.6	80.0	73.2	61.4
RA Factor (self-report)						
n	7	23	64	45	71	68
% Yes	57.1	26.1	29.7	22.2	32.4	23.5
% No	14.3	4.3	0	2.2	1.4	2.9
% Don't Know	28.6	69.6	70.3	75.6	66.2	73.5

*The scores for the pain and swelling indices ranged from 0 to 84. The higher the score the greater the swelling or pain.

As may be seen from Table 4.4 the controls at T2 had the fewest number of years with the diagnosis of RA and the controls at T1 had the longest period of time with RA. There was no difference between cases and controls in the number of years with RA at T1 or T2 (p = 0. 27, p = 0.65 respectively). Despite having RA for the shortest period of time, the control group at T2 experienced the longest duration of morning joint stiffness. The differences in joint stiffness between cases and controls were not statistically significant (T1, p = 0.35; T2, p = 0.13).

The pain and swelling indices were highest with the controls at T1 (14.5 and 14.0 respectively). The lowest pain index was with controls at T2 (7.4) and the lowest swelling index was with the cases at T2 (9.0). Neither the pain nor swelling indices were statistically significant between the cases and controls at T1 (pain index, p = 0.38; swelling index, p = 0.52) or T2 (pain index, p = 0.45; swelling index, p = 0.81). After controlling for age and gender the differences between cases and controls on all three variables at T1 were still not significant (stiffness, p = 0.32; pain, p = 0.50; swelling, p = 0.21). At T2 stiffness (p = 0.32) and pain (p = 0.11) were not statistically significant. However, the swelling index was statistically significant (p = 0.014).

The cases and controls at T1 had rheumatoid nodule rates of 57.1% and 72.0% respectively. The rates for the cases and controls at T2 were similar to each other (23.4% and 20%) but less than the groups at T1. The differences in rates of rheumatoid nodules between the cases and controls at both time periods were not statistically significant (T1, p = 0.65; T2, p = 0.82). At both time periods the differences were not significant when gender was controlled (T1, males and females, p = 0. 34 and p = 0.64 respectively; T2, males and females, p = 0.73 and 0.72 respectively).

Fifty-seven per cent of the cases at T1 stated they were RA factor positive whereas 69.6% and 75.6% of the controls groups at T1 and T2 respectively did not know their RA factor status. The differences between the groups were not statistically significant (p = 0.14 and 0.35 respectively). None of the comparisons were statistically significant when gender was controlled (T1, males and females, p = 0. 20 and p = 0.38 respectively; T2, males and females, p = 0.56 and 0.41

respectively). These results should be interpreted with caution as they indicate self-reported RA factor status.

The patients were also asked if they had any co-morbid conditions which sometimes accompany RA. In addition, they were asked if they had undergone orthopaedic or any other type of surgery. The results are presented on Tables 4.5 and 4.6.

Overall there was a distinct lack of self-reported co-morbidity. The rates of co-morbid conditions reported were very similar for both groups. As may be seen from Table 4.5, the frequencies of co-morbid conditions were almost identical between cases and controls at T2. The rates of co-morbid conditions between cases and controls at T1 for Raynaud's disease, Felty's syndrome, pericarditis and vasculitis were either identical or very similar. The percentage of occurrence of Sjogren's syndrome and episcleritis between case and controls at T1 makes it appear as though the rates are quite different. However it is emphasized that a 14.3% rate of episcleritis in the cases (n = 7) represents only one patient with the condition. Similarly, rates of 42.9% and 25% of Sjogren's syndrome represent three and seven patients with the condition in the cases and controls respectively.

There was no statistically significant difference between the cases and controls at either time period for any of the comorbid conditions or surgeries (see Tables 4.5 and 4.6 for Chi square p values). After gender was controlled the statistically insignificant results persisted for the comorbid conditions and surgeries at T1 and T2, or the statistic could not be computed due to empty cells.

Table 4.5 Arthritis morbidity - frequency of certain co-morbid conditions

Co-morbid condition***	T1 Cases n = 7	T1 Controls n = 28*	T2 Cases n = 65	T2 Controls n = 45	Total Cases n = 72	Total Controls n = 73	Chi square p values: Cases vs Controls T1	Chi square p values: Cases vs Controls T2
Raynaud's								
N %	71.4	71.4	93.8	97.8	90.3	87.8	1.0	0.65
Y%	28.6	28.6	6.2	2.2	9.7	12.2		
Sjogren's								
N %	57.1	75.0	93.8	95.6	90.3	87.8	0.38	1.0
Y%	42.9	25.0	6.2	4.4	9.7	12.2		
Felty's								
N %	100	96.4	98.5	100	98.6	98.6	1.0	1.0
Y%	0	3.6	1.5	0	1.4	1.4		
Pericarditis								
N %	100	96.4	98.5	97.8	98.6	97.3	0.61	0.79
Y%	0	3.6	1.5	2.2	1.4	2.7		
Vasculitis								
N %	100	96.4	100	100	100	98.6	0.61	**
Y %	0	3.6	0	0	0	1.4		
Episcleritis								
N %	85.7	100	100	97.8	98.6	98.6	0.20	0.41
Y%	14.3	0	0	2.2	1.4	1.4		

*One patient chose not to answer to the questions on co-morbidity. ** Percentages in each cell were exactly 100%.
***For definition of co-morbid conditions see Appendix O.

Table 4.6 Arthritis morbidity - frequencies of surgical interventions

Surgery	T1 Cases n = 7	T1 Controls n = 28*	T2 Cases n = 64*	T2 Controls n = 44*	Total Cases n = 71*	Total Contr'ls n = 73*	Chi square p values: Cases vs Controls T1	Chi square p values: Cases vs Controls T2
Orthopaedic Surgery								
No (%)	28.6	50.0	68.7	53.3	64.8	52.1	0.30	0.10
Yes (%)	71.4	50.0	31.3	46.7	35.2	47.9		
Other surgery								
No (%)	0	3.6	26.6	25.0	23.9	16.9	0.60	0.85
Yes (%)	100	96.4	73.4	75.0	76.1	83.1		

*Missing data from one patient.

As may be seen from Table 4.8 the differences in rates of orthopaedic and other surgery were not statistically significant between the cases and controls at both time periods.

The patients were asked about their use of Disease Modifying Antirheumatic Drugs (DMARDs) which they were *currently* taking. Overall the rate of use of Prednisone, Plaquenil, Methotrexate and other DMARDs was similar in both the case and control groups (Table 4.7).

The cases at T1 were more frequent users of Prednisone compared with the other groups. Apart from the cases at T1, Methotrexate was the most commonly used DMARD among the groups. With the exception of the "other" DMARD category at T2, none of the differences in DMARD use reached statistical significance between the cases and controls at either time period. The data were stratified on gender and it was found that none of the comparisons (i.e. male cases versus controls at T1 and T2, and female cases versus controls at T1 and T2) reached statistical significance.

Table 4.7 Arthritis morbidity - Frequency of use of Disease Modifying Antirheumatic Drugs (DMARDs)*

DMARDs	T1 Cases n = 7	T1 Controls n = 29	T2 Cases n = 65	T2 Controls n = 45	Total Cases n = 72	Total Controls n = 74	Chi square p values: Cases vs Controls T1	Chi Square p values: Cases vs Controls T2
Prednisone								
Yes %	57.1	39.3	23.1	33.3	26.4	35.6	0.39	0.36
No %	42.9	60.7	76.9	66.7	73.6	64.4		
Plaquenil								
Yes %	14.3	6.9	26.2	33.3	25.0	22.9	0.48	0.52
No %	85.7	93.1	73.8	66.7	75.0	77.1		
Methotrexate								
Yes %	14.3	37.9	41.5	44.4	38.9	41.9	0.40	0.76
No %	85.7	62.1	58.5	55.6	61.1	58.1		
Other**								
Yes %	14.3	6.9	27.7	4.4	26.4	5.4	0.81	0.09
No %	85.7	93.1	72.3	95.6	73.6	94.6		

*None of the patients were taking Aralen, Cytoxan or Imuran

** Some of the other DMARDs included Oral Gold, I.M. Gold and Penicillamine

Data were also collected on the use of non-steroidal anti-inflammatory drugs (NSAIDs) by the patients (Appendix N). The patients were asked about their use of 14 NSAIDs which included: Ansaid, Aspirin, Clinoril, Disalcid, Feldene, Indocid, Meclomen, Ibuprofen, Nalfon, Naprosyn, Tolectin, Trilisate, Orudis, Voltaren and "other NSAIDs". None of the patients were taking Ansaid, Meclomen or Trilisate. Of those patients who were taking NSAIDs there were some patients in every group who were taking Voltaren and an "other" NSAID. At least some patients in three out of the fours groups were taking Aspirin, Indocid, Ibuprofen, Naprosyn and Orudis.

Table 4.8 Arthritis morbidity - Percentage use of certain Non-Steroidal Anti-inflammatory Drugs (NSAIDs)

NSAID	T1 Cases n = 7	T1 Controls n = 29	T2 Cases n = 65	T2 Controls n = 45	Total Cases n = 72	Total Controls n = 74	Chi Sqr p values Cases vs Cont'ls T1	Chi Sqr p values Cases vs Cont'ls T2
Aspirin Y N	0 100	13.8 86.2	7.7 92.3	13.3 86.7	6.9 93.1	14.8 85.1	0.29	0.29
Indocid Y N	0 100	3.4 96.6	13.8 86.2	2.3 97.7	8.3 91.6	5.4 94.5	0.61	0.86
Naprosyn Y N	0 100	13.8 86.2	9.3 90.7	6.7 93.3	6.9 93.1	9.4 90.5	0.29	0.83
Voltaren Y N	14.3 85.7	6.9 93.1	7.7 92.3	13.3 86.7	8.3 91.7	10.8 89.1	0.52	0.33

The use of NSAIDs was similar between both the cases and the controls with the exception of "other" NSAIDs. The cases used an "other" NSAID more frequently (26.4%) than the controls (5.4%). The most common NSAIDs used by the cases were, Voltaren and Indocid (both at 8.3%) and Naprosyn and Aspirin (both at 6.9%). Among the control group the most common NSAIDs used were Aspirin (14.8%), Voltaren (10.8%) and Naprosyn (9.4%). There were no statistically significant differences between the cases and controls at either time period with respect to the common NSAIDs used (Table 4.8 for Chi square values). In addition, the data were stratified on gender and it was found that none of the comparisons (i.e. male cases versus controls at T1 and T2, and female cases versus controls at T1 and T2) for NSAID use reached statistical significance.

1.3 Social Network

The patients' social network was determined by asking them how many close family and friends they had. They then rated the contribution of these individuals with respect to emotional and instrumental support. The results pertaining to the patients' social network are presented on Table 4.9.

Table 4.9 Social network

Persons in social network	T1 Cases n = 7	T1 Controls n = 29	T2 Cases n = 65	T2 Controls n = 45	Total Cases n = 72	Total Controls n = 74
Mean	5	4	6	6	6	6
Range	1 - 8	0 - 10	1 - 12	2 - 12	1 - 12	0 -12

As may be seen from Table 4.9 the average number of people in the social networks of the cases and controls was very similar at both time periods (T1, p = 0.79; T2, p = 0.92). The quality of instrumental and emotional support was also assessed and these results are on Table 4.10.

Both the instrumental and emotional social support scores are similar for the combined cases and controls. The cases consistently had higher levels of emotional and instrumental support over the controls for each time period.

The cases at T1 in particular had higher levels of both instrumental and emotional support compared with the other groups. However, as may be seen from the ANOVA p values on Table 4.10 the differences between the cases and controls at both time periods were not statistically significant.

Table 4.10 Instrumental and emotional support

Type of Social Support*	T1 Cases n = 7	T1 Controls n = 29	T2 Cases n = 65	T2 Controls n = 45	Total Cases n = 72	Total Controls n = 74	ANOVA p values: Cases vs Control T1 T2
Instrumental							
Mean	27.3	18.0	14.5	12.9	15.7	14.8	0.30
s.d.	21.3	11.8	7.7	9.8	10.2	10.8	0.35
Emotional							
Mean	31.2	21.1	20.7	19.6	21.8	20.2	0.29
s.d.	22.7	11.2	10.3	11.8	12.2	11.5	0.61

*The range of scores for both instrumental and social support is 0 to 60, the higher the score the greater the level of support.

1.4 Arthritis and Health

The patients were asked to provide information about their smoking, drinking and exercise habits both before and after the diagnosis of rheumatoid arthritis. In addition they were asked to provide an overall "global" rating of their health before and after the diagnosis. The results are presented on Tables 4.11 to 4.15.

Table 4.11 Global rating of general health before and after the diagnosis of rheumatoid arthritis

Global rating	T1 Cases n = 7	T1 Controls n = 29	T2 Cases n = 65	T2 Controls n = 45	Total Cases n = 72	Total Controls n = 74	ANOVA p values. Cases vs Controls: T1 T2
Before diagnosis with RA							
Mean	11.4	20.0	18.0	16.0	17.3	17.6	0.31
(s.d.)	(18.7)	(21.3)	(13.0)	(12.0)	(13.6)	(16.3)	0.42
After diagnosis with RA							
Mean	31.6	44.3	45.2	45.3	43.9	45.0	0.33
(s.d.)	(31.2)	(21.1)	(15.9)	(19.0)	(18.0)	(19.8)	0.97
Mean difference	20.2	24.3	27.2	29.3	26.6	27.4	--

Note: A low score (0 - 10) = "very well", a high score (90 - 100) = "very poor".
Scores of 10 – 30 = "very well to well" and 30 – 50 = "well to fair".

As expected, the global ratings of health (Table 4.11) consistently increased (i.e. the perception of health was worse) for each group after the diagnosis of RA. The cases at T1 had the lowest ratings of all groups both before and after the diagnosis of RA. The mean differences in ratings ranged from 20.2 in the cases at T1 to 29.3 in the controls at T2. As may be seen from Table 4.11 the differences in global ratings between the cases and controls for both time periods were not statistically significant. After controlling for age and gender the differences in global rating of health before and after the diagnosis at T1 were not statistically significant (before diagnosis, p = 0.80; after diagnosis, p

= 0.07). At T2 the comparisons also were not statistically significant (before diagnosis, p = 0.85; after diagnosis, p = 0.63).

Table 4.12 Smoking status before and after diagnosis of rheumatoid arthritis

Smoking status	T1 Cases n = 7	T1 Controls n = 29	T2 Cases n = 65	T2 Controls n = 45	Total Cases n = 72	Total Controls n = 74
Before dx (%) smoking	42.9	34.5	35.4	53.3	36.1	45.9
Before dx average # cig/day	6.0	5.0	4.0	3.0	4.0	3.0
After dx (%) started to smoke	0.0	3.4	0.0	0.0	0.0	1.4
Before & After dx (%) smoking	42.9	27.6	24.6	20.0	26.4	23.0
% Stopped smoking after dx	0.0	6.9	10.7	33.3	9.7	23.0
After dx avg # cig/day	12.0	8.0	10.0	15.0	11.0	12.0
(%) Never smoked	14.3	34.5	40.0	26.7	37.5	29.7

With the exception of cases at T1, the number of smokers in each group decreased after the diagnosis of RA. The average number of cigarettes smoked per day after diagnosis with RA increased in each group. The difference in the number of cigarettes smoked between the cases and controls at T2 after the diagnosis of RA was statistically significant (p = 0.012).

Table 4.13 Alcohol consumption before and after diagnosis of rheumatoid arthritis

Alcohol consumption	T1 Cases n = 7	T1 Controls n = 27**	T2 Cases n = 63**	T2 Controls n = 44 *	Total Cases n = 70**	Total Controls n = 71***
Before diagnosis with RA						
Yes %	85.7	79.3	80.0	82.2	81.7	81.1
No %	14.3	20.7	20.0	17.8	18.3	18.9
After diagnosis with RA						
Yes %	100	48.2	55.6	56.8	60.0	53.6
No %	0.0	51.8	44.4	43.2	40.0	46.4

* One patient did not respond **Two patients did not respond. *** Three patients did not respond.

With the exception of cases at T1, the number of individuals consuming alcohol decreased in each of the groups after the diagnosis of RA. Before the diagnosis of RA there was no statistically significant difference between the cases and controls at T1 ($p = 0.70$) or T2 ($p = 0.69$) with respect to consumption of alcohol. After the diagnosis of RA there was a statistically significant difference ($p = 0.031$) between cases and controls at T1 with respect to alcohol consumption. This was not the case for the comparison at T2 ($p = 0.96$).

Table 4.14 Exercise before diagnosis of rheumatoid arthritis

Exercise	T1 Cases n = 7	T1 Controls n = 29	T2 Cases n = 65	T2 Controls n = 45	Total Cases n = 72	Total Controls n = 74
Before dx % exercise						
Y	85.7	60.7	70.8	71.1	72.2	67.1
N	14.3	39.3*	29.2	28.9	27.7	32.8
Before dx frequency exercise/wk (s.d.)	3.7 (2.8)	2.9** (3.1)	2.3 (2.0)	2.6 (2.1)	2.5 (2.1)	2.7** (2.5)
Before dx duration of exercise (min) (s.d.)	105.0 (166.8)	44.7# (66.4)	45.1 (45.9)	59.9 (69.0)	51.0 (67.6)	54.6^ (68.1)

* One patient did not respond. ** Two patients did not respond.
^Three patients did not respond. #Five patients did not respond.

The numbers of those exercising increased in the cases and controls at T1 after the diagnosis of RA. Whereas there was a decrease in the numbers of individuals exercising in the cases and controls at T2 after the diagnosis of RA. There were no statistically significant differences between cases and controls at T1 or T2 with respect to number of individuals exercising before or after the diagnosis of RA (T1 before RA, $p = 0.40$; after RA, $p = 0.96$; T2 before RA, $p = 0.11$; after RA, $p = 0.38$).

Table 4.15 Exercise after diagnosis of rheumatoid arthritis

Exercise	T1 Cases n = 7	T1 Controls n = 29	T2 Cases n = 65	T2 Controls n = 45	Total Cases n = 72	Total Controls n = 74
After dx % exercise						
Y	100	72.4	65.6	55.8	69.0	62.5
N	0.0	27.6	34.4*	44.2**	31.0*	37.5**
After dx frequency exercise/wk (s.d.)	5.5* (1.6)	4.3 (4.4)	2.7* (3.3)	2.8* (4.0)	2.9** (3.2)	3.4* (4.2)
After dx duration of exercise (min) (s.d.)	50.0* (15.5)	21.6^ (20.9)	29.5# (30.7)	29.9** (45.9)	31.2** (30.2)	26.8# (38.6)

*One patient did not respond. **Two patients did not respond. ^Four patients did not respond. #Six patients did not respond.

After the diagnosis of RA the frequency of exercise per week increased in all groups. However, the duration of exercise consistently decreased in all groups after diagnosis (Tables 4.14 and 4.15). The frequency and duration of exercise before the diagnosis of RA was not statistically significant between cases and controls at T1 (p = 0.49 for frequency, and p = 0.38 for duration). Similarly, there was no statistically significant difference between the groups at T2 after the diagnosis of RA for frequency and duration of exercise (p = 0.85 and p = 0.95 respectively).

1.5 The Arthritis Society and ASMP

Patients were asked whether they had any previous knowledge of the Arthritis Society and whether they were members. The results appear on Table 4.16.

Table 4.16 Membership of the Arthritis Society

Arthritis Society	T1 Cases n = 7	T1 Controls n = 29	T2 Cases n = 65	T2 Controls n = 45	Total Cases n = 72	Total Controls n = 74
Heard of the Arthritis Society?						
Y %	100	93.1	93.8	95.6	94.5	94.6
N %	0.0	6.9	6.2	4.4	5.5	5.4
Member of the Arthritis Society?						
Y %	0.0	14.8	13.8	4.4	12.5	8.4
N %	100	85.2**	86.2	95.6	87.5	91.6

**Two patients did not respond

In each case and control group over 93% of patients had heard of the Arthritis Society. However, in total only 12.5% of cases were members of the Society and even fewer of the controls (8.3%) were members. Statistically, there was no significant difference between the cases and controls at T1 (p = 0.47) or T2 (p = 0.69) with respect to the question of having heard of the Arthritis Society. There was also no statistically significant difference between the groups at T1 and T2 with respect to being members of the Arthritis Society (T1, p = 0.27; T2 p = 0.10).

Patients were also asked about their awareness of the Arthritis Self-Management Program, the results are on Table 4.17.

Table 4.17 Awareness of the Arthritis Self-Management Program (ASMP), previous arthritis education and coping with RA

Variable	T1 Cases n = 7	T1 Controls n = 29	T2 Cases n = 65	T2 Controls n = 45	Total Cases n = 72	Total Controls n = 74
Ever heard of ASMP?						
Y %	100	60.7	52.3	60.0	56.9	60.3
N %	0.0	39.3*	47.7	40.0	43.1	39.7
Taken an arthritis education program?						
Y %	42.9	55.2	46.9	36.3	46.5	43.8
N %	57.1	44.8	53.1*	63.7*	53.5*	56.2*
Does arthritis education help you cope with RA?						
Y %	100	78.5	95.3	88.9	95.7	84.9
N %	0.0	21.5*	4.7**	11.1	4.3*	15.1*

* One patient did not respond. **Two patients did not respond

Chi square tests revealed that there was no statistically significant difference between cases and controls at either time period with respect to awareness of ASMP, (T1, p = 0.11; T2 0.42) previous experience with arthritis education (T1, p = 0.55; T2, p = 0.39) or belief about arthritis education helping patients to cope with their condition (T1, p = 0.35; T2, p = 0.22).

1.6 Arthritis education and program delivery

The patients were asked to give their opinion on certain aspects of ASMP program delivery. The patients were invited to offer their opinion on

when they would like to take an arthritis education program. In this instance the results were combined for the cases and the controls over both time periods. As may be seen from Figure 4.6 the cases favoured the springtime for the program whereas the control groups were reasonably well distributed over the four seasons.

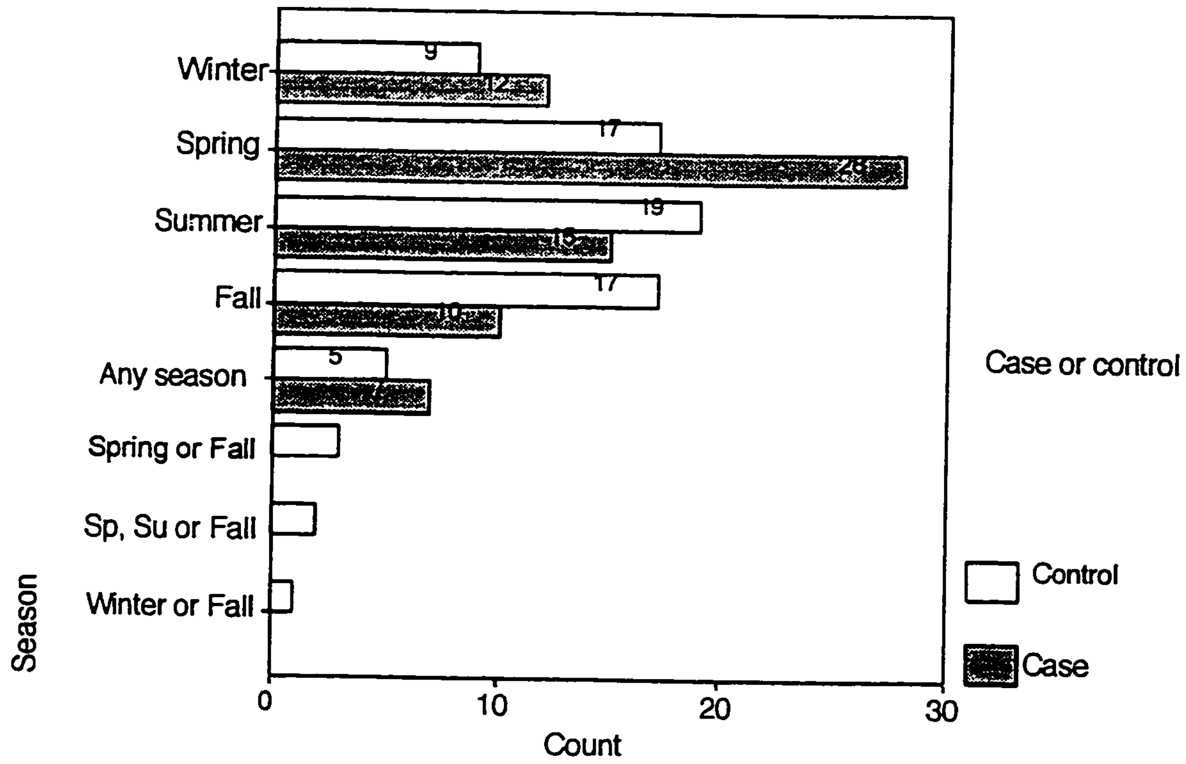


Figure 4.6 Season of the year for arthritis education?
Cases and Controls combined n = 146

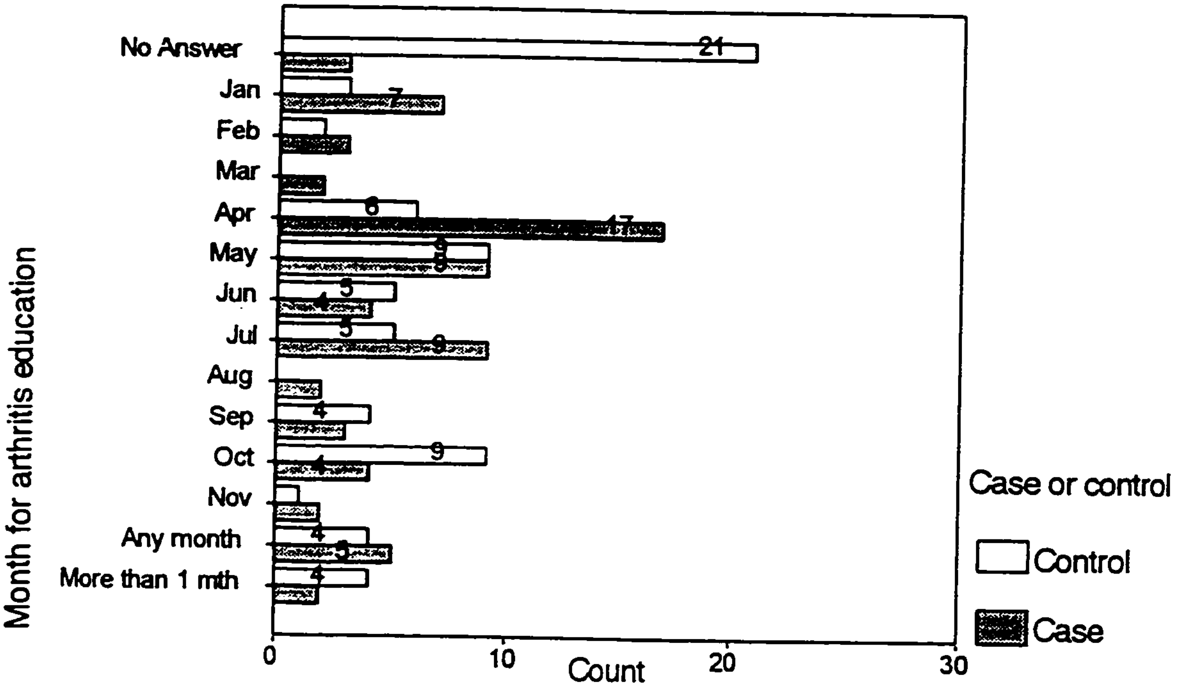


Figure 4.7 Month of the year for arthritis education?
Cases and Controls combined n = 146

The majority of the cases preferred April, May and July for taking an arthritis education program (Figure 4.7). Twenty-one of the controls chose not to respond. Of the controls who expressed a preference May and October were chosen most frequently with an even distribution over the other months of the year.

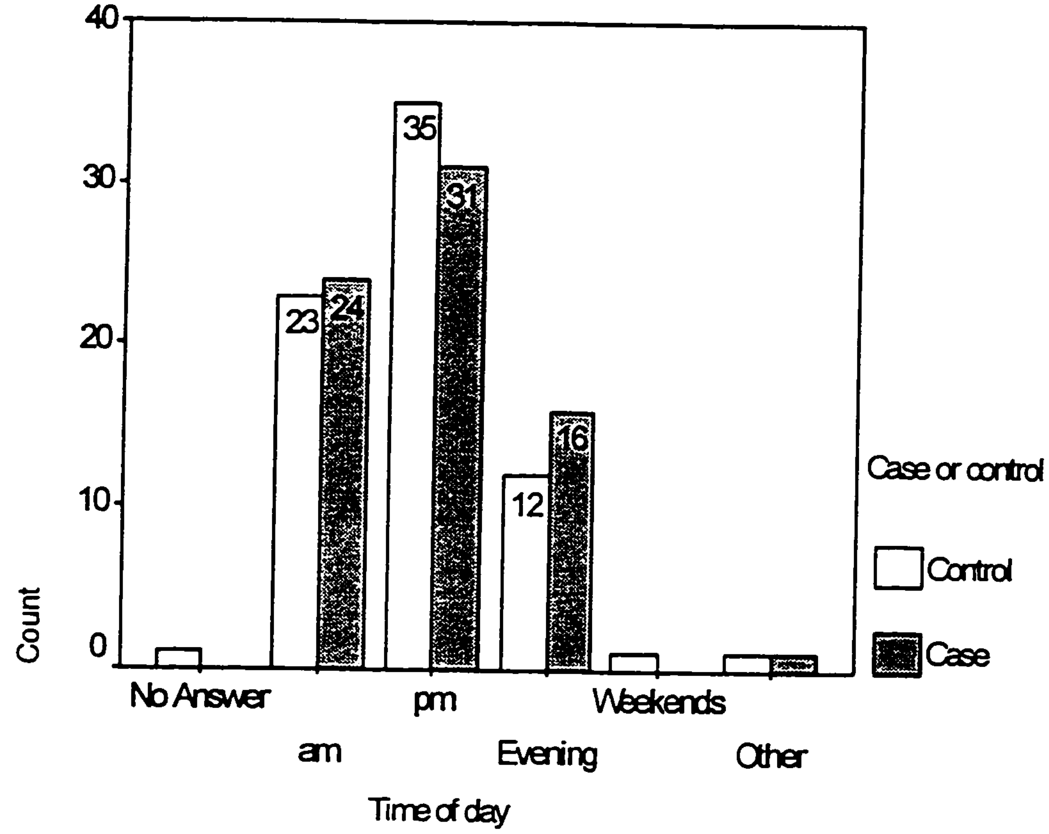


Figure 4.8 Time of day for arthritis education?
Cases and Controls combined n = 146

As may be seen from Figure 4.8, of those expressing a preference 21.2% of the cases and 23.9% of the controls preferred the afternoon time of the day to participate in arthritis education; 16.4% of the cases and 15.7% of the controls preferred the morning. The week-ends were the least preferred option.

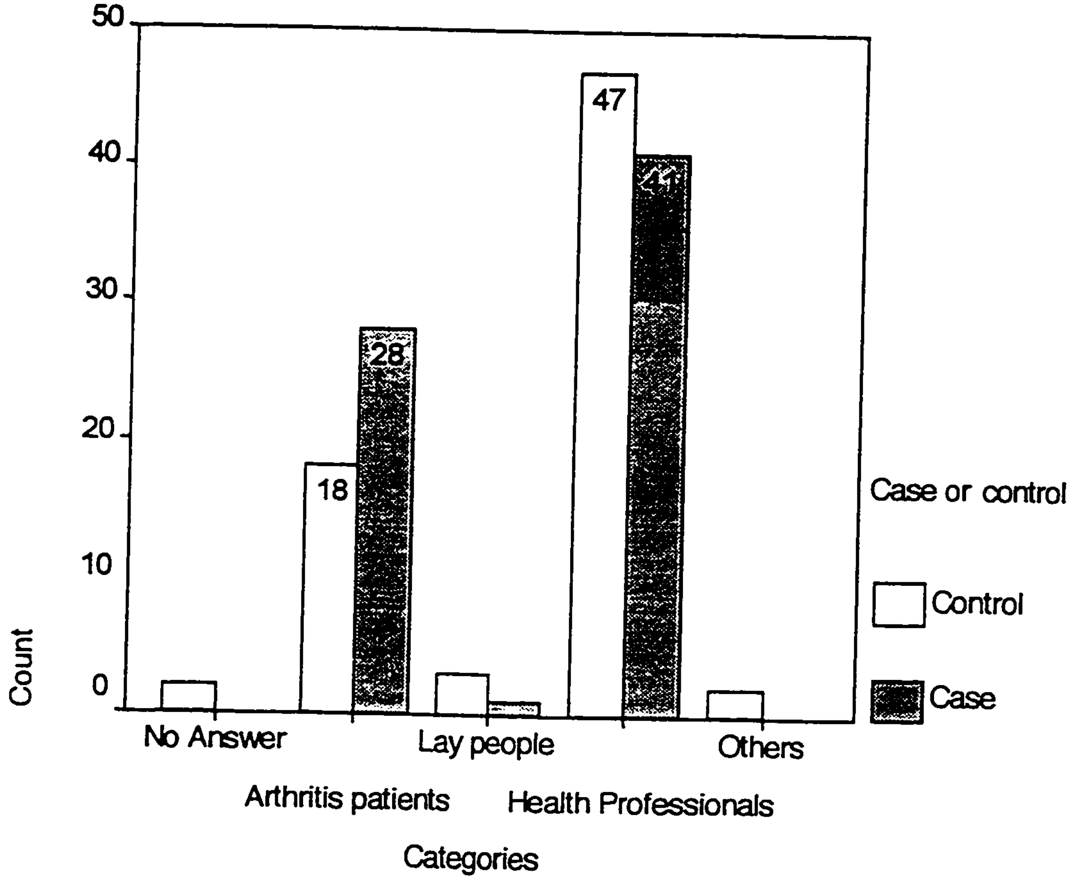


Figure 4.9 Who should teach arthritis education?
Cases and controls combined n = 146

The RA patients in this study expressed a preference to be taught by health professionals (Figure 4.9). Thirty-two per cent of the controls and 28.1% of the cases chose health professionals to teach the program. The professionals who were cited included, family physicians, rheumatologists, physiotherapists and nurses. People with arthritis were also cited as a group who could teach in an education program (19.2% and 12.3% of the cases and controls respectively).

Sixteen per cent of the cases expressed a preference for a total of six classes in an arthritis education program, with 14.4% of the controls opting for the same number of classes (Figure 4.10). The majority of both cases and controls chose between four to ten for the optimum number of classes in a program.

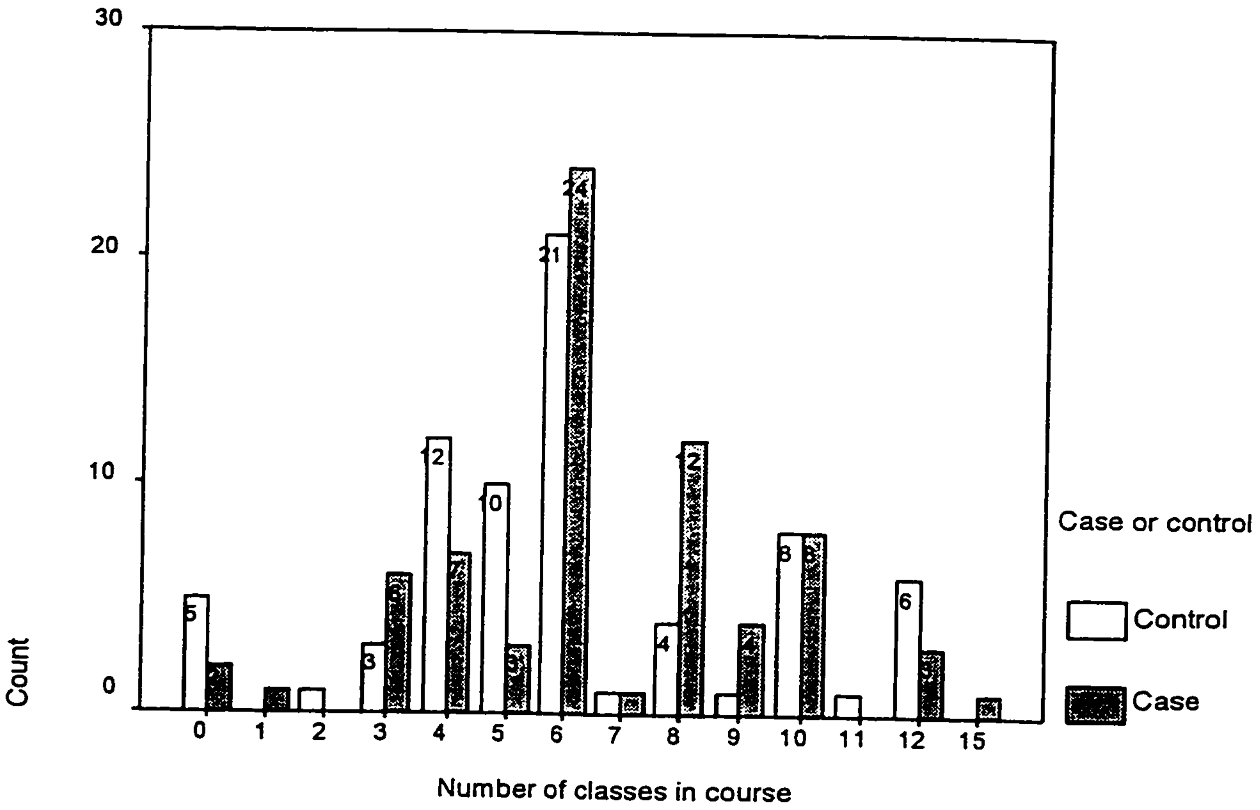


Figure 4.10 Optimum number of classes for arthritis education?
Cases and Controls combined n = 146

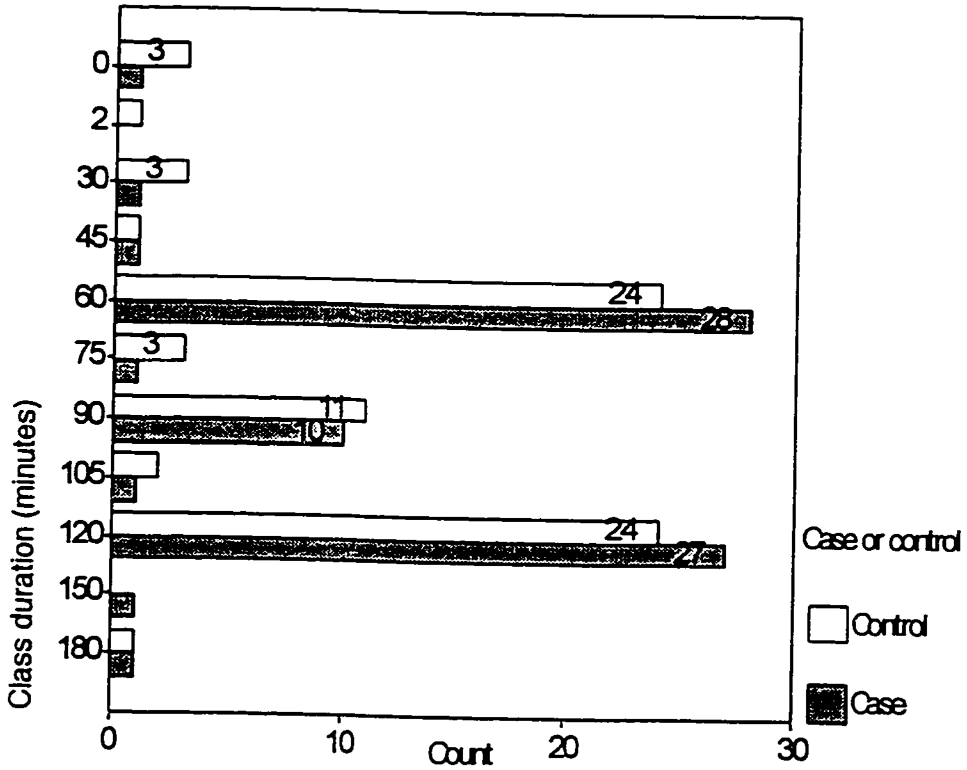


Figure 4.11 How long should each class last?
Cases and Controls combined n=146

There was a bimodal distribution with respect to how long each class should last (Figure 4.11). Nineteen per cent of the cases expressed a preference for 60 minute classes and 18.5% for 90 minute classes. Twenty-four (16.4%) of the controls decided on 60 classes and the same number (16.4%) opted for 90 minute classes.

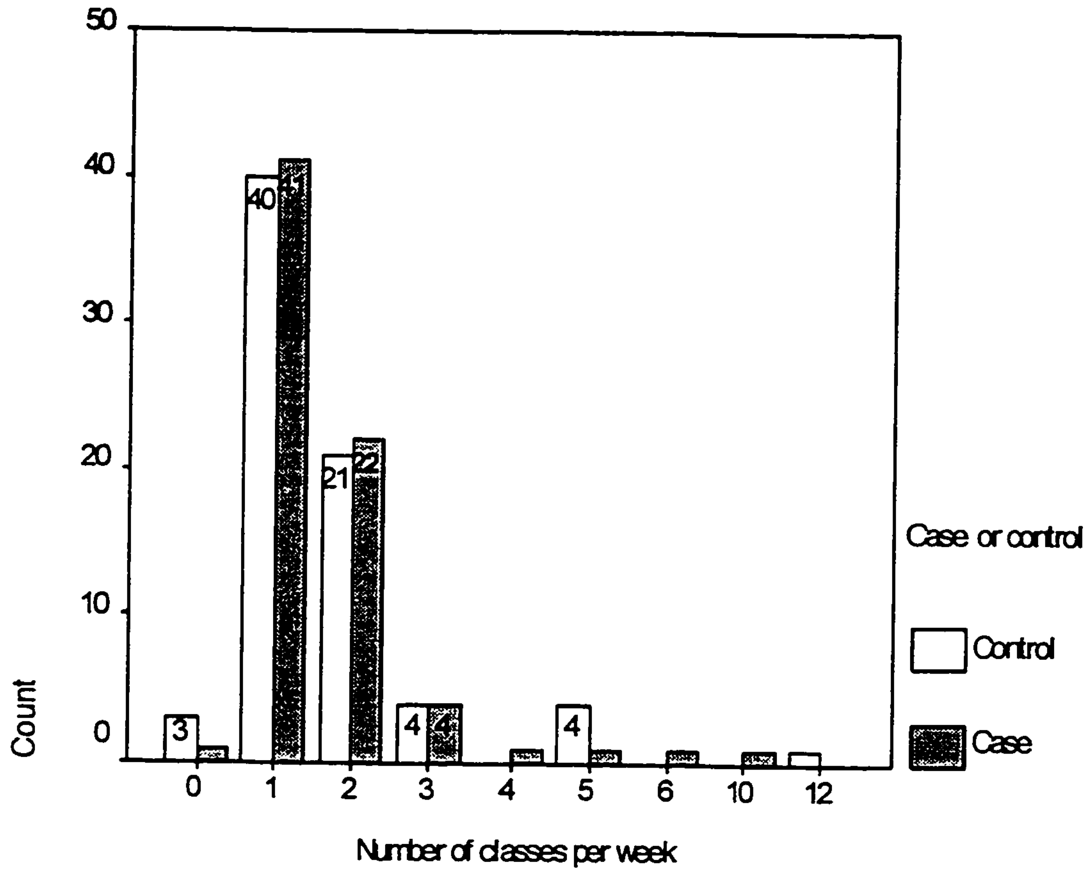


Figure 4.12 How many classes per week?
Cases and Controls combined n = 146

As may be seen from Figure 4.12 the majority (84.9%) of both cases and controls would prefer to have one to two classes per week in an arthritis education program. Most of the cases and controls would prefer to have a program that lasts from three to six weeks (Figure 4.13).

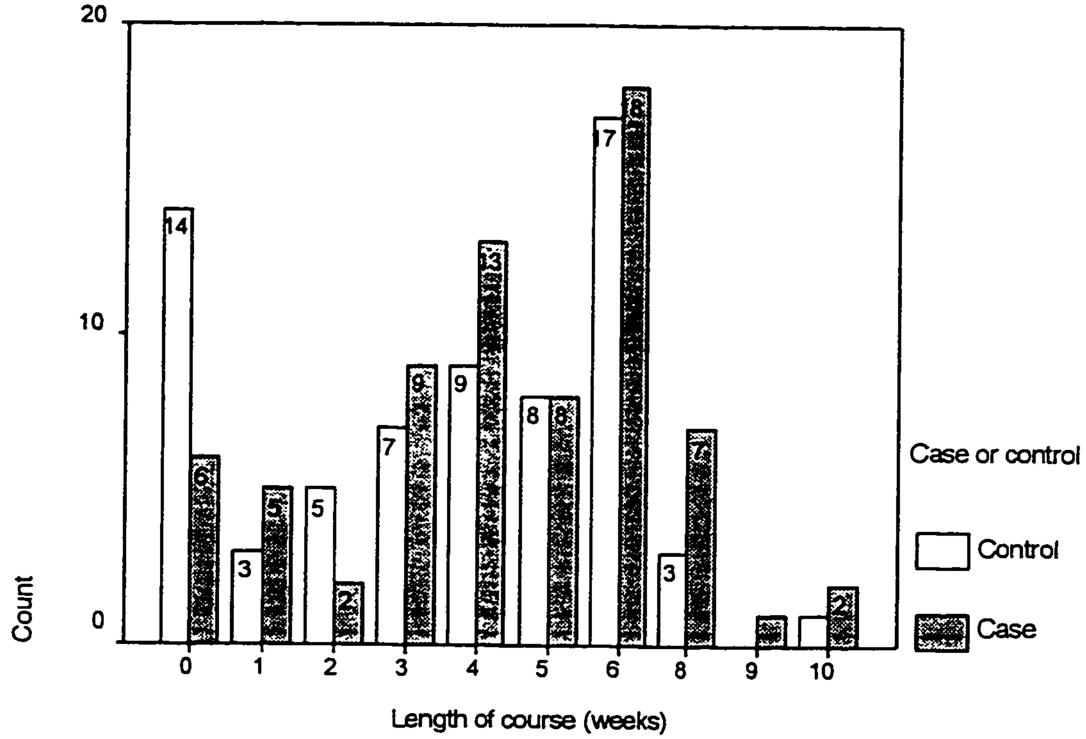


Figure 4.13 Optimum length of course?

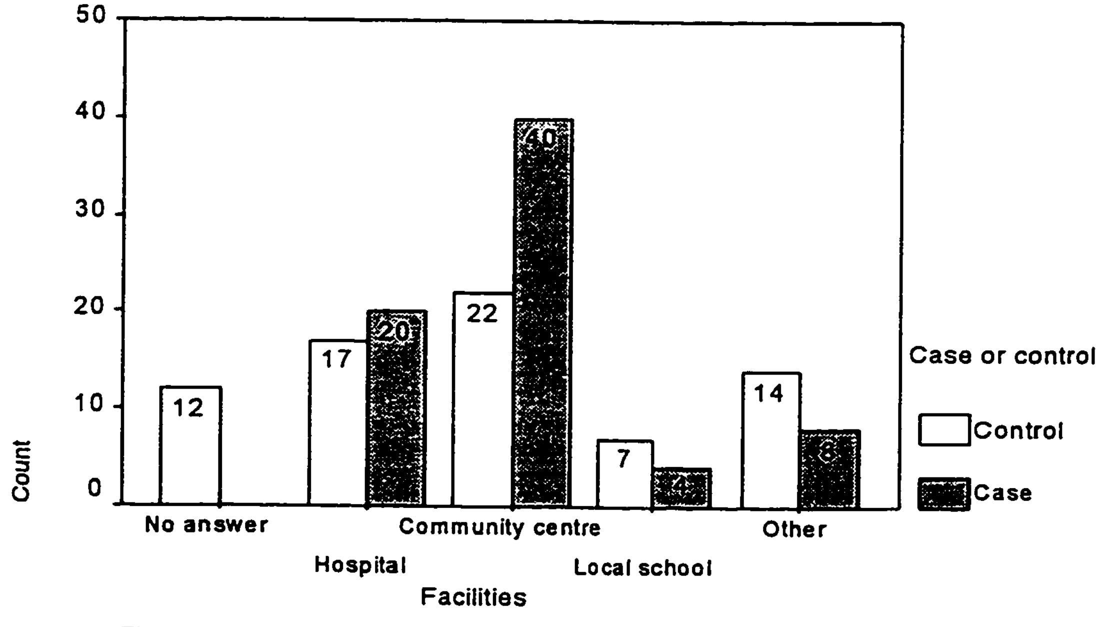
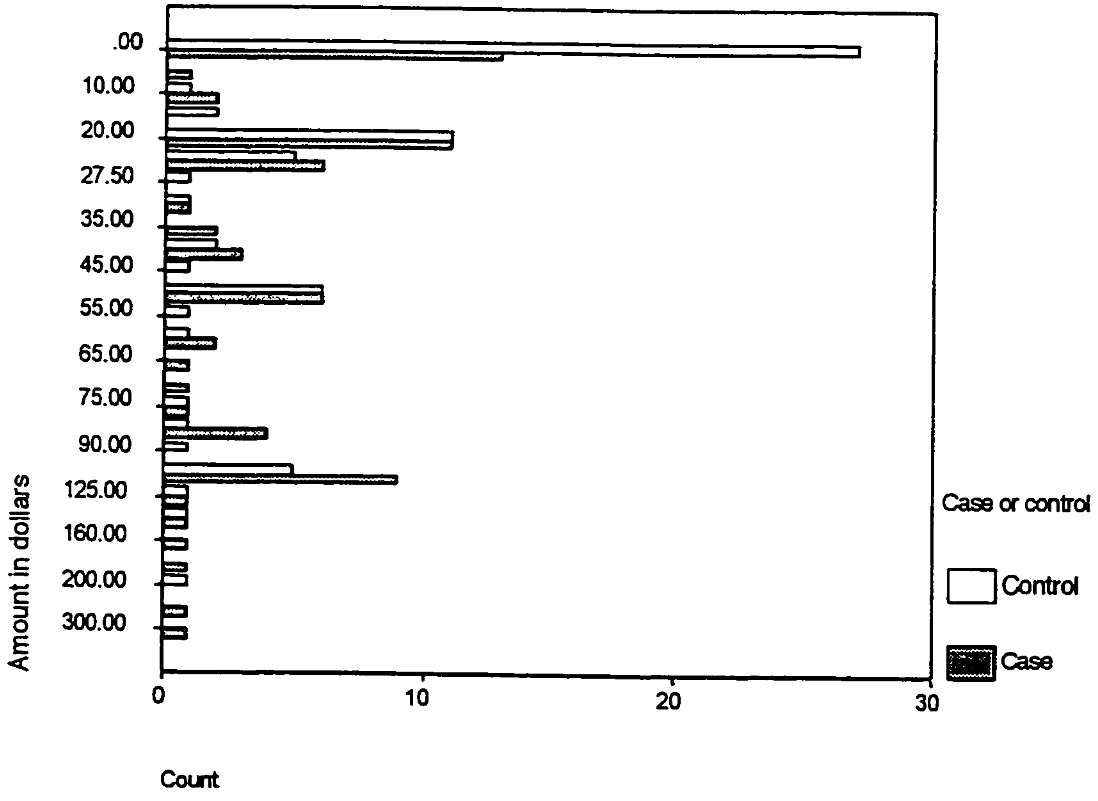


Figure 4.14 Where should the program be held?
Cases and Controls combined n = 144

The majority of cases and controls (69.5%) preferred to have the education program held locally either at a community centre (27.7% and 15.2% respectively) or a hospital (13.8% and 11.8% respectively, Figure 4.14). The patients were asked how much they would be prepared to pay for an arthritis education program (Figure 4.15). Eighteen per cent of the controls (n = 27) and 8.9% (n = 13) of the cases reported that the program should be offered free of charge. Many of these patients stated that Alberta Health should pay for the program. Twenty-eight controls (19.2%) and 27 cases (18.4%) stated that they would be prepared to pay between $10 to $35 for the program. The overall amount that patients were prepared to pay for an arthritis education program ranged from $0 to $300.

Figure 4.15 How much would you pay for arthritis education?

Cases and Controls combined n = 146



2. Phase II - Psychometric Data

The second phase of data collection involved the completion of a package of eight self-administered instruments (Self-efficacy Scale, Knowledge Test, Miller Behavioral Style Scale, Quality of Social Support Scale, Arthritis Impact Measurement Scale version 2, Illness Intrusiveness Ratings Scale, Centre for Epidemiological Studies' Depression Scale and the Marlowe-Crowne Social Desirability Scale).

Initially the intention was to combine the data from the cases at T1 with the data from the cases at T2, treat the data for the controls in the same way and make comparisons between the combined case and control groups. However, given the time periods between data collection points, a secular trend may have occurred and influenced the primary variable of self-efficacy. It was decided to analyze the data for SE separately in order to identify any obvious trend over time.

The data for SE were described over each time period, boxplots were generated and a two-way analysis of variance was done to test for interaction with time (T1 or T2) by grouping (case or control). If no interaction was present the plan was to combine the data over both time periods. However strong indicators of interaction were present, consequently the data were not combined over the two time periods for the formal analysis and the results are reported separately. The data were combined for an exploratory analysis of covariance. The internal consistency of the items on all of the instruments was assessed by computing Cronbach's α (Cronbach, 1951).

2.1 Self-Efficacy – Hypothesis 1

Those patients wishing to participate in the ASMP (i.e. the cases) will have higher self-efficacy scores than those not wishing to participate (i.e. the controls).

As may be seen from Table 4.18 the preliminary findings indicate that the overall SE scores and the SE subscale scores in the cases were higher than the controls at T1 and T2.

Table 4.18 Overall Self-Efficacy scores and SE subscale scores

Self-efficacy scores	T1 Cases n = 7	T1 Controls n = 29	T2 Cases n = 65	T2 Controls n = 45
Overall SE Mean (s.d.)	78.1 (21.2)	56.3 (25.0)	62.2 (22.4)	60.1 (25.3)
SE Pain subscale Mean (s.d.)	69.5 (26.1)	49.2 (27.5)	55.1 (22.4)	54.4 (26.4)
SE Physical subscale Mean (s.d.)	80.8 (26.6)	57.0 (31.0)	65.8 (28.1)	61.6 (29.5)
SE Other subscale Mean (s.d.)	81.2 (17.8)	61.0 (22.8)	62.8 (22.5)	62.7 (25.8)

The cases at T1 had a mean difference of almost 22 points in the overall SE score over the controls at T1 (78.1 – 56.3 = 21.8; p = 0.03). The cases at T2 had a mean difference of 2.1 over the controls at T2. While the comparison of overall SE scores did not reach statistical significance at T2 (p = 0.65) the difference was in the hypothesized direction.

All of the mean SE subscale scores at T1 were statistically significant. In fact, as hypothesized all of the mean SE subscale scores were higher in the cases compared with the controls. At T2 the overall SE score and the subscale scores were marginally higher in the cases than the controls.

None of the differences between cases and controls on SE at T2 reached statistical significance. The results of the one way analysis of variance for the SE scores are on Table 4.19.

Table 4.19 SE scores – One way analysis of variance

	Contrast	s.e.	F	df	p
SE Overall	1	10.02	4.73	3, 142	0.03
	2	4.61	0.20	3, 142	0.65
SE Pain	1	10.38	3.80	3, 142	0.05
	2	4.78	0.019	3, 142	0.88
SE Physical	1	12.24	3.80	3, 142	0.05
	2	5.63	0.53	3, 142	0.46
SE Other	1	11.59	4.16	3, 142	0.04
	2	4.54	0.0001	3, 142	0.97

*Note: Contrast 1 = cases versus controls at T1
Contrast 2 = cases versus controls at T2

As may be seen from Figure 4.16 the data in the boxplots are normally distributed. The boxplot of the cases at T1 however appears different from the boxplots of the other three groups. In the cases at T1 the median is greater and the range of scores is smaller than the other groups.

There was a signal of an interaction effect over time from assessing the mean values at T1 and T2, and from the boxplots. In addition a two-way analysis of variance (Table 4.20) revealed an indication of interaction of time by grouping.

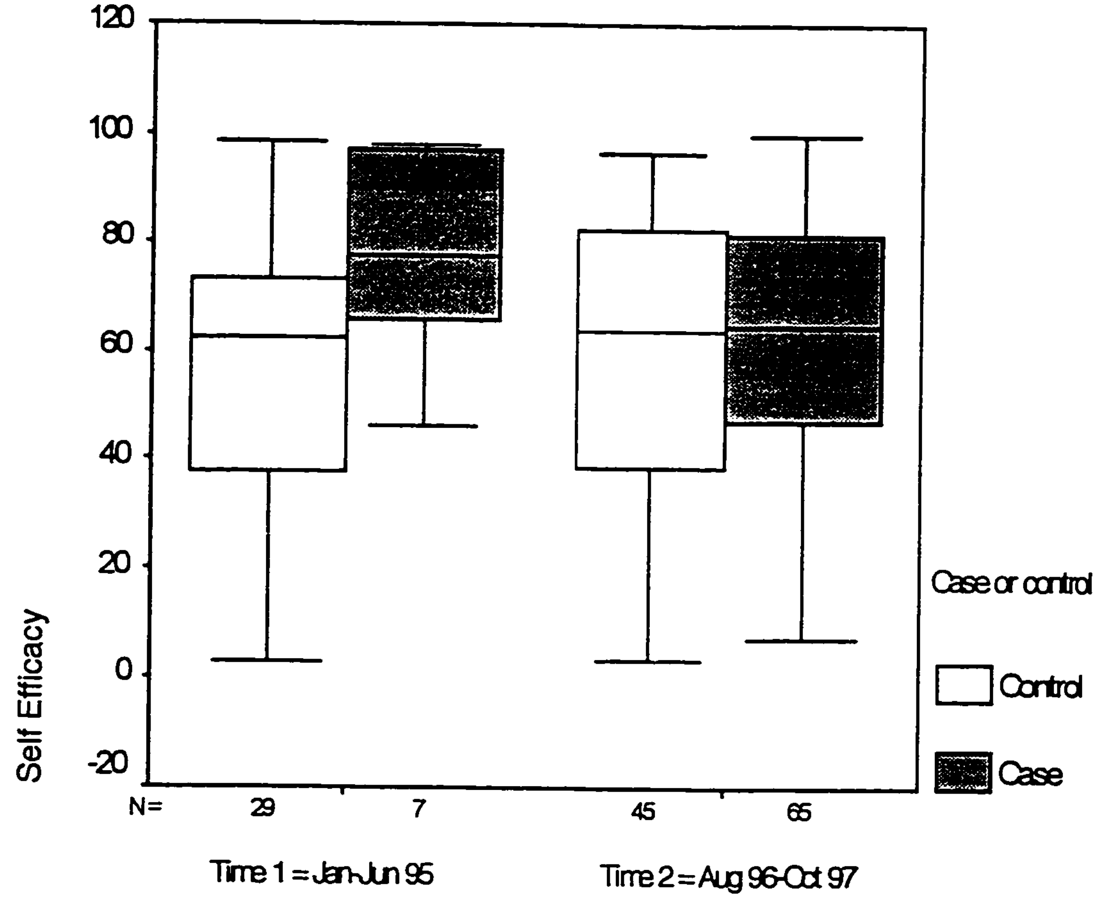


Figure 4.16 Boxplots of overall Self-Efficacy score

Based on the appearance of the boxplots, the mean SE values over time and the fact that the p value of the interaction term was approaching statistical significance (F 1, 142 = 3.21, p = 0.076), it was decided not to combine the data of the cases and controls over the two time periods for formal analysis.

Table 4.20 Two way analysis of variance of overall Self-Efficacy score

Source of Variation	SS	DF	MS	F	p values
Within cells	80437.78	142	566.46		
Time1 Time 2	684.42	1	684.42	1.21	.274
Group	2660.44	1	2660.44	4.70	.032
Time by Group (interaction term)	1815.65	1	1815.65	3.21	**.076**
(Model)	2820.40	3	940.13	1.66	.178
(Total)	83258.18	145	574.19		

The interaction terms in the pain (F 1, 142 = 2.94, p = 0.089) physical (F 1, 142 = 2.13, p = 0.145 and "other" (F 1, 142 = 3.48, p = 0.064) SE subscales did not reach statistical significance. The appearance of each of the subscale boxplots was such that there was a strong indication of interaction over time (see Figures 4.17 to 4.19).

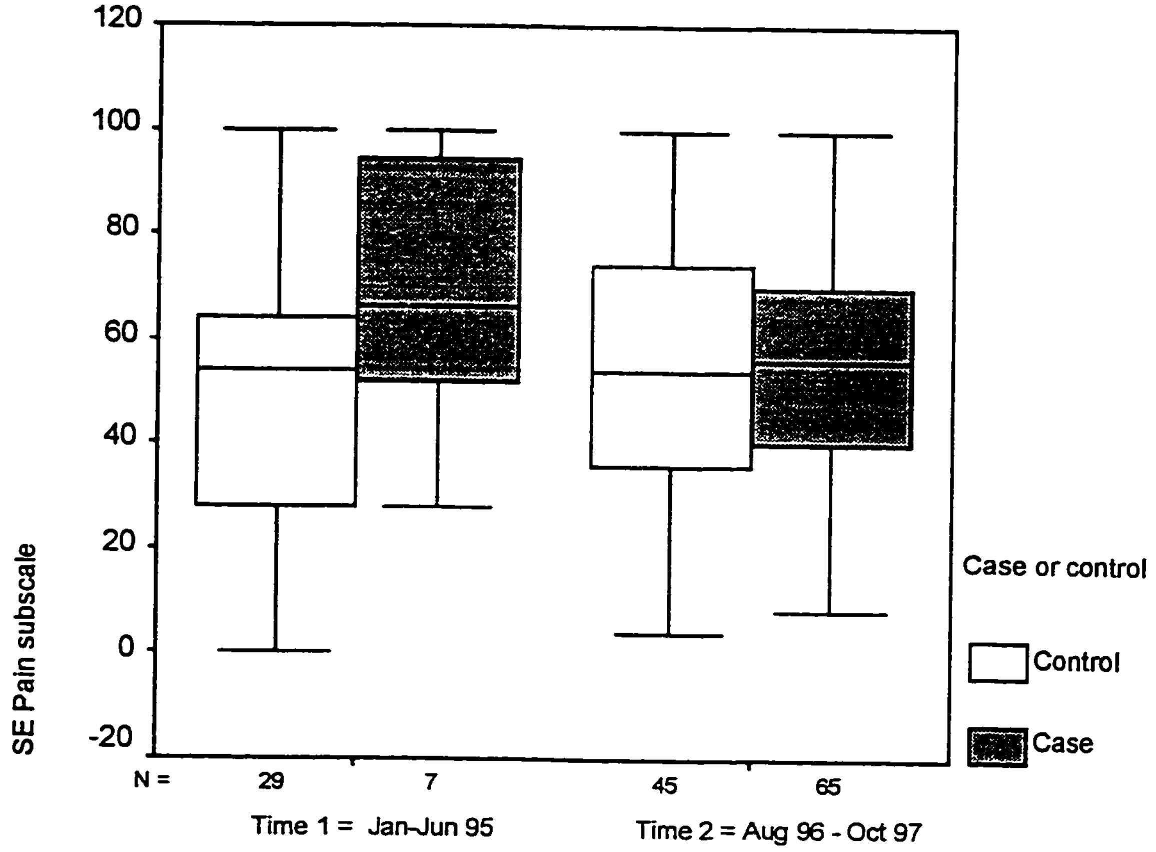


Figure 4.17 Boxplots of SE pain subscale

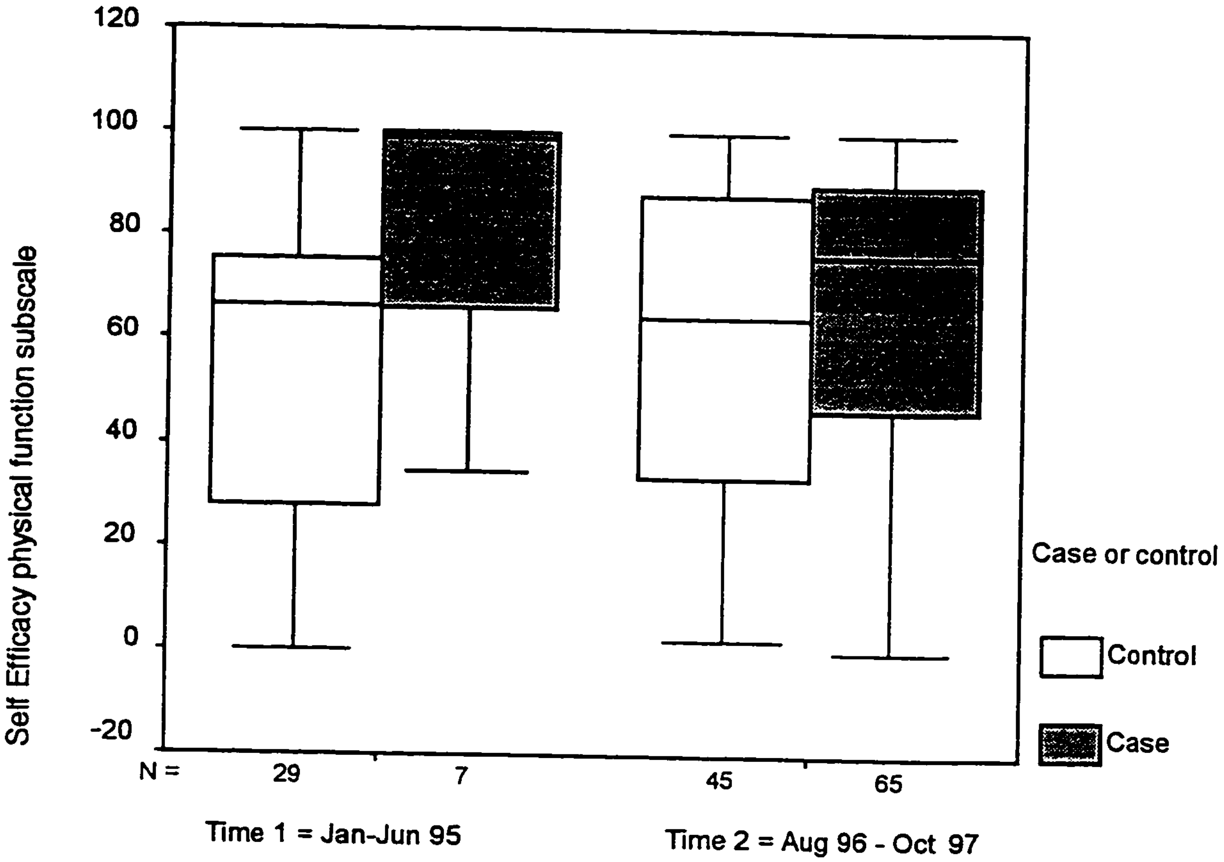


Figure 4.18 Boxplots of Self-Efficacy Physical subscale

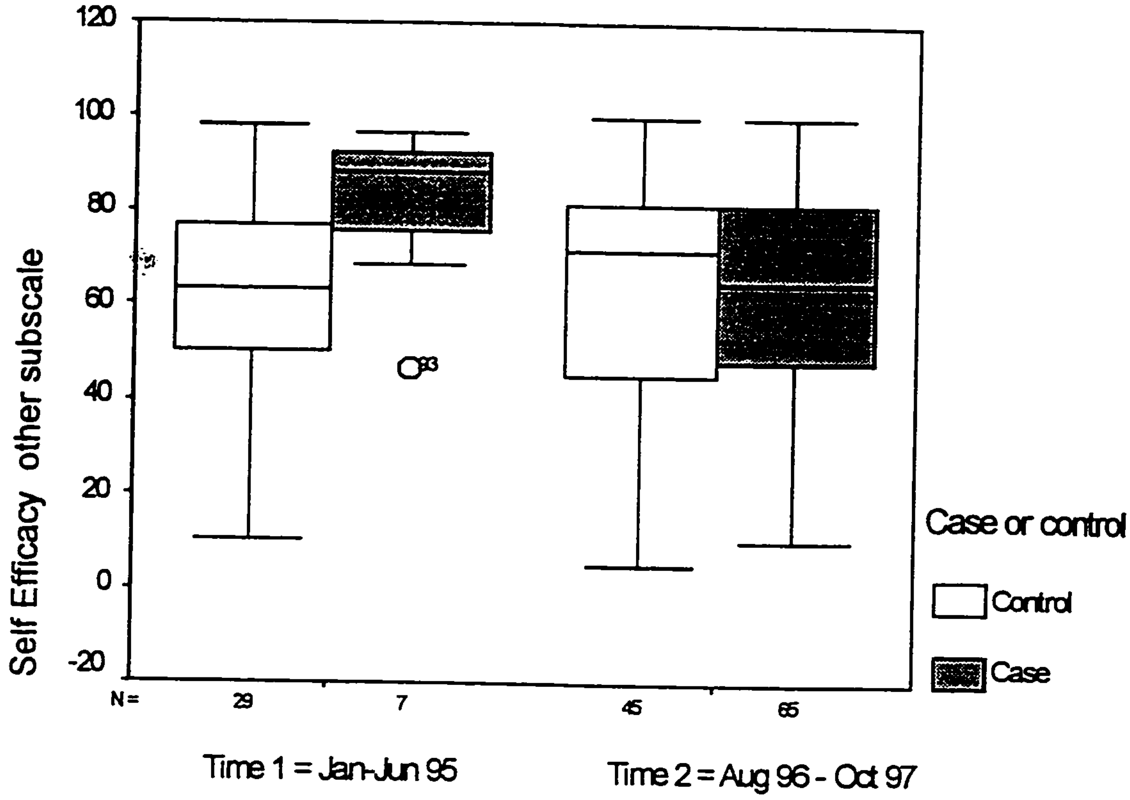


Figure 4.19 Boxplots of Other Self-Efficacy subscale

In addition, although the interaction terms for the pain, physical and other SE subscales did not reach statistical significance the p values were not too far removed from statistical significance. In particular the p values for the pain (p = 0.089) and "other" (p = 0.064) SE subscales were such that combining the data could not be justified. The outlier in the cases at T1 was checked against the raw data and the score was found to be correct. The patient 's score was in fact 46 on the SE other subscale.

The difference between the cases and controls was in the hypothesized direction, however only the SE scores between the cases and controls at T1 were statistically significant. The two-way analysis of variance revealed that the interaction term (time by group) was approaching statistical significance and therefore it was decided that it would not be meaningful to interpret the main effect of group (Table 4.20). The Cronbach's coefficient α's for the overall SE and the SE pain, physical and "other" subscales were 0.96, 0.85, 0.95 and 0.92 respectively. It was concluded that there was insufficient evidence to support the central hypothesis of the study.

2.2 Information seeking behaviour - Hypothesis 2

Those patients wishing to participate in the ASMP will demonstrate more information seeking behaviour than those not wishing to participate.

Information seeking was measured using the Miller Behavioral Style Scale. Patients who tend to seek information are categorized as "monitors" and patients who would rather not have information are categorized as "blunters". The results obtained for the cases and controls are on Table 4.21.

Table 4.21 Monitors and blunters among the cases and controls

Time 1			Control	Case	Total
Group	Monitors	Count	17	1	18
		%	58.6	14.3	50.0
	Blunters	Count	12	6	18
		%	41.4	85.7	50.0
	Total	Count	29	7	36
		%	100.0	100.0	100.0
Time 2					
Group	Monitors	Count	24	33	57
		%	53.3	50.8	51.8
	Blunters	Count	21	32	53
		%	46.7	49.2	48.2
	Total	Count	45	65	110
		%	100.0	100.0	100.0

The numbers of monitors and blunters were evenly dispersed among the cases and controls with the exception of the cases at T1. Fisher's exact tests revealed that there was no statistically significant difference between the cases and controls at T1 and T2 (p = 0.08 and 0.85 respectively).

Those patients wishing to participate in the ASMP were not more inclined to be information seekers, as measured by the Miller Behavioral Style Scale, than those not wishing to participate. The α coefficients for the monitoring and blunting scales were 0.74 and 0.64 respectively. It was concluded that there is insufficient evidence to support the second hypothesis.

2.3 Knowledge Test - Hypothesis 3

Those patients wishing to participate in the ASMP will demonstrate more knowledge about RA than those not wishing to participate.

Table 4.22 Scores on Knowledge Test

Knowledge Test	T1 Cases n = 7	T1 Controls n = 29	T2 Cases n = 65	T2 Controls n = 45	Total Cases n = 72	Total Controls n = 74
Scores out of 10 Mean (s.d.)	7.0 (1.63)	5.2 (2.35)	5.09 (2.01)	5.13 (2.37)	5.28 (2.04)	5.15 (2.34)

As may be seen from Table 4.22 the scores on the knowledge test were very similar for each of the groups. The cases at T1 scored higher than the other groups. There was a statistically significant difference between the groups at T1 but not at T2 (F 3, 142 = 3.96, p = 0.048 and F 3, 142 = 0.009, p = 0.92 respectively). Cronbach's coefficient α was 0.63. It was concluded that there is insufficient evidence to support hypothesis number three.

2.4 Quality of Social Support - Hypothesis 4

Those patients wishing to participate in the ASMP will have greater social support than those not wishing to participate.

Social support was measured by obtaining the number of people in the social networks of the cases and controls (see Table 4.9). The average number of people in the social networks was very similar at both time periods. In addition, the quality of social support was measured by the Quality of Social Support Scale. The results are on Table 4.23.

Table 4.23 Quality of Social Support

Quality of Social Support*	T1 Cases n = 7	T1 Controls n = 29	T2 Cases n = 65	T2 Controls n = 45	Total Cases n = 72	Total Controls n = 74
Mean (s.d.)	53.7 (4.4)	48.7 (6.1)	47.0 (6.2)	48.0 (6.4)	47.7 (6.4)	48.3 (6.2)

*Minimum score = 17; maximum score = 68. The higher the score the greater the degree of social support.

With the exception of the cases at T1 the Quality of Social Support scores were very similar in all groups. A one way analysis of variance revealed that there as a statistically significant difference between the cases and controls. The contrast tests showed that the statistically significant difference was with the comparison between cases and controls at T1 (F 2, 142 = 3.8, p = 0.05). The comparison at T2 was not significant (F 3, 142 = 0.76, p = 0.38). The two way analysis of variance showed that the interaction term (time by group) was significant (F 1, 141 = 4.68, p = 0.032). One would have expected the difference in social support between the cases and the controls to remain over time, however this was not the case there was a group effect within the time periods and a time effect within the groups. There is insufficient evidence to support the fourth hypothesis. The alpha coefficient for the QSSS was 0.76.

2.5 Health Status - Hypothesis 5

Those patients wishing to participate in the ASMP will perceive and report their health status to be "better" than those not wishing to participate as measured by: the Arthritis Impact Measurement Scale 2 (AIMS2), the Illness Intrusiveness Ratings Scale (IIRS) and the Centre for Epidemiological Studies' Depression Scale (CES-D).

The results obtained from the AIMS2, IIRS and CES-D instruments are on Table 4.24.

Table 4.24 Self reported health status

Health status instrument	T1 Cases n = 7	T1 Controls n = 29	T2 Cases n = 65	T2 Controls n = 45	Total Cases n = 72	Total Controls n = 74
AIMS2* Means and (s.d.)						
Physical	1.3 (1.8)	2.7 (2.3)	2.2 (1.7)	2.3 (1.9)	2.1 (1.8)	2.4 (2.1)
Affect	2.9 (1.1)	3.4 (1.5)	3.8 (1.9)	3.5 (1.5)	3.7 (1.8)	3.4 (1.5)
Pain	3.4 (2.1)	5.0 (2.4)	4.7 (2.6)	4.6 (2.7)	4.6 (2.6)	4.7 (2.5)
IIRS* Mean (s.d.)	29.0 (14.4)	38.0 (12.5)	38.4 (17.1)	34.6 (17.2)	36.0 (15.4)	37.5 (17.1)
CES-D* Mean (s.d.)	10.1 (7.8)	13.9 (9.4)	15.0 (12.3)	14.5 (8.8)	14.6 (11.9)	14.3 (8.9)

*AIMS – all scores are standardized 0 – 10, the lower the score the "healthier" the respondent.
*IIRS – scores range from 13 to 91, the higher the score the greater the illness intrusion.
*CES-D - scores range from 0 to 60, the higher the score the greater the risk for depression.

The cases at T1 consistently self-reported lower ratings on all three instruments compared with the cases at T2 and the controls at T1 and T2. The data indicate that the RA patients are equally as healthy in all groups. This is supported by the fact that none of the measures of health were statistically different in the one way ANOVA and contrast tests (Tables 4.25 and 4.26).

Table 4.25 One way analysis on measures of health

		SS	df	MS	F	p
AIMS	Between Groups	10.979	3	3.660	999	.396
Phys	Within Groups	520.452	142	3.665		
	Total	531.431	145			
AIMS	Between Groups	8.823	3	2.941	1.018	.387
Affect	Within Groups	410.087	142	2.888		
	Total	418.910	145			
AIMS	Between Groups	14.853	3	4.951	.746	.527
Pain	Within Groups	942.702	142	6.639		
	Total	957.555	145			
Illness	Between Groups	810.539	3	270.180	1.027	.383
Intrsn	Within Groups	37344.585	142	262.990		
	Total	38155.123	145			
Deprsn	Between Groups	159.358	3	53.12	.472	.702
	Within Groups	15853.635	141	112.44		
	Total	16012.993	144			

Table 4.26 Contrast tests on measures of health

	Contrast	s.e.	F	df	p
AIMS Physical	1	.806	2.66	3, 142	.105
	2	.371	0.12	3, 142	.722
AIMS Affect	1	.715	0.41	3, 142	.522
	2	.329	1.29	3, 142	.257
AIMS Pain	1	1.08	1.31	3, 142	.145
	2	.499	0.079	3, 142	.778
Illness Intrusivn	1	6.82	1.73	3, 142	.190
	2	3.14	1.29	3, 142	.256
Depresn	1	4.46	0.72	3, 141	.398
	2	2.07	0.071	3, 141	.790

*Contrast 1 = cases vs controls at T1; Contrast 2 = cases vs controls at T2

As may be seen from Table 4.26 none of the contrasts were found to be statistically significant. In addition, none of the interaction terms relating to measures of health in the two way analysis of variance were statistically significant (AIM Physical, F 1, 141 = 1.70, p = 0.19; AIM Affect, F 1, 141 = 1.0, p = 0.31; AIM Pain, F 1, 141 = 2.29, p = 0.13; Illness Intrusion, F 1, 141 = 2.85, p = 0.09; and CES-D, F 1, 141 = 0.77, p = 0.37) and neither were the main effects of group. The Cronbach's α's for the AIMS pain, affect and physical subscales were 0.87, 0.92 and 0.94 respectively. The α coefficients for the IIRS and CES-D were both 0.90.

Correlation matrices were computed for the health status instruments for the all cases and all controls (Table 4.27 and 4.28).

Table 4.27 Correlation matrix of health status instruments – All cases (n = 72)

(Pearson Correlations)	AIMS Phys	AIMS Pain	AIMS Affect	IIRS	CES-D	Global health after RA dx
AIMS Physical component	1.00	.688	.327**	.661	.290*	.488
AIMS Pain component	.688	1.00	.464	.632	.470	.423
AIMS Affect component	.327**	.464	1.00	.586	.826	.429
Illness Intrusiveness (IIRS)	.661	.632	.586	1.00	.556	.677
Depression (CES-D)	.290*	.470	.826	.556	1.00	.461
Global health after RA dx	.488	.423	.429	.677	.461	1.00

All correlation p values were <0.001, except * p = 0.014 and ** p = 0.005

Table 4.28 Correlation matrix of health status instruments – All controls (n = 74)

Pearson Correlations)	AIMS Phys	AIMS Pain	AIMS Affect	IIRS	CES-D	Global health after RA dx
AIMS Physical component	1.00	.628	.471	.700	.494	.647
AIMS Pain component	.628	1.00	.451	.633	.314*	.503
AIMS Affect component	.471	.451	1.00	.472	.581	.311
Illness Intrusiveness (IIRS)	.700	.633	.472	1.00	.420	.600**
Depression (CES-D)	.494	.314*	.581	.420	1.00	.316
Global health after RA dx	.647	.503	.311	.600**	.316	1.00

All correlation p values were <0.001, except * p = 0.007 and ** p = 0.006

As may be seen from Tables 4.27 and 4.28 all of the correlations were highly significant. The IIRS scores correlated highly with all three components of the AIMS, the highest correlation was between the physical component of the AIMS and the IIRS (cases = 0.66 and controls = 0.70). The CES-D scores correlated well with the AIMS affect component (0.82 in the cases and 0.58 in the controls). The global health rating scores correlated most strongly with the IIRS scores in the cases (r = 0.67) and most strongly with the AIMS physical component scores in the controls (r = 0.64).

2.6 Social Desirability

The Marlowe-Crowne Scale was used to obtain an estimate of the degree to which respondents may have self-reported in a socially desirable way. The results are on Table 4.29

Table 4.29 Social desirability in responding to instruments

Marlowe-Crowne Scale*	T1 Cases n = 7	T1 Controls n = 29	T2 Cases n = 65	T2 Controls n = 45	Total Cases n = 72	Total Controls n = 74
Mean (s.d.)	17.4 (3.6)	16.4 (5.1)	17.7 (4.4)	16.5 (4.6)	17.7 (4.3)	16.5 (4.7)

*M-C Scale – scores range from 0 to 33, the higher the score the greater the tendency to respond in a socially desirable way.

The results are similar (Table 4.29) for all groups of patients. The one way analysis of variance showed that there was no statistically significant difference between the cases and controls at either time period (T1, F 3, 142 = 0.29, p = 0.58 and T2, F 3, 141 = 0.06, p = 0.24). The interaction term and the main group effect in the two-way analysis were also not significant (F 1, 141 = .003, p = 0.95 and F 1, 141 = 1.10, p = 0.29 respectively). The Cronbach's α for the MC-S was 0.82.

3. Exploratory analysis – Psychometric data

The psychometric data were subjected to an exploratory analysis of covariance by combining the case and control data and controlling for potential confounders. Adjusted means were then obtained for the psychometric measures under consideration and levels of statistical significance are reported.

The demographic characteristics of the sample (see Table 4.2) revealed that the cases and controls differed from each other with respect to age and number of years of education. The one way analyses of variance on the psychometric data showed that the cases and controls differed from each other on knowledge of arthritis and quality of social support. The results from the analyses of variance for these four variables are on Table 4.30.

Table 4.30 One way ANOVA - Age, Education, Knowledge and Social Support

	Contrast	s.e.	F	df	p
Age	1	5.69	4.20	3, 142	0.041
	2	2.62	8.23	3, 142	0.005
Education	1	1.19	8.58	3, 142	0.004
	2	0.55	1.56	3, 142	0.21
Knowledge	1	0.92	3.96	3, 142	0.048
	2	0.42	0.009	3, 142	0.92
Social Support	1	2.59	3.80	3, 142	0.05
	2	1.19	0.75	3, 142	0.38

As may be seen, age is statistically significant for both contrast 1 (i.e. cases versus controls at T1, p = 0.041) and contrast 2 (cases versus controls at T2, p = 0.005). Knowledge, education and social support are all statistically significant for contrast 1 only (p values = 0.048, 0.004 and 0.053 respectively).

In a two way analysis of variance education and social support each had significant interaction terms for group by time (F 1, 141 = 4.59, p = 0.034 and F 1, 141 = 4.68, p = 0.032 respectively). The interaction term for knowledge approached statistical significance (F 1, 141 = 3.58, p = 0.060) but not for age (F 1, 141 = 0.45, p = 0.50).

The statistical results were *not* the criterion used on which to determine potential confounders (Hennekens & Buring, 1986). Rather, it was thought that any one of these four variables were plausible potential confounders.

Each one could have an effect on the decision to participate in the ASMP and, independent of this association, be associated with the SE scores. The SE scores of the cases and controls were analyzed by an analysis of covariance with age, number of years of education, knowledge of RA and quality of social support as the covariates. The adjusted means for each of the SE scores are presented on Table 4.31

Table 4.31 Adjusted means of Self-Efficacy scores

Self-Efficacy scales	Cases Mean (s.e.)	Controls Mean (s.e.)	95% CIs Cases	95% CIs Controls	p
Pain subscale	56.2 (2.99)	52.6 (2.95)	50.4-62.1	46.8-58.4	0.41 n.s.
Physical subscale	63.9 (3.22)	62.9 (3.18)	57.6-70.2	56.7-69.1	0.83 n.s.
Other subscale	64.7 (2.75)	61.9 (2.71)	59.3-70.1	56.6-67.2	0.48 n.s.
Overall SE	63.7 (2.75)	58.6 (2.71)	58.3-69.1	53.3-63.9	0.59 n.s.

Following adjustment for the potential confounders there was little difference between the cases and controls on the SE subscale or overall SE mean scores. The other psychometric measures were treated in the same way and the adjusted means are listed on Table 4.32

Table 4.32 Group and adjusted means – measures of health

Scale	Grp Mean Cases	Grp Mean Controls	Adj Mean Cases	Adj Mean Controls	95% CIs Cases	95% CIs Controls	p
IIRS	37.47	36.05	37.50	36.10	33.7-41.3	32.4-39.8	0.61
AimPhy	2.09	2.44	2.25	2.28	1.82-2.68	1.87-2.70	0.92
AimAff	3.74	3.42	3.56	3.60	3.21-3.96	3.25-3.95	0.88
AimPain	4.58	4.74	4.58	4.74	3.98-5.18	4.15-5.33	0.73
CES-D	14.55	14.26	14.04	14.76	11.79-16.29	12.53-16.99	0.66
M-CS	17.65	16.54	18.23	15.97	17.21-19.25	14.97-16.97	0.003

* IIRS = Illness Intrusiveness Ratings Scale. AimPhy = AIMS Physical subscale. AIMAff = AIMS Affect subscale. AIMPain = AIMS Pain subscale. CES-D = Centre for Epidemiological Studies' Depression Scale. M-CS = Marlowe-Crowne Scale.

After controlling for the covariates of age, education, knowledge and social support none of the measures of health were statistically different between the cases and controls. The Marlowe-Crowne Social Desirability Scale was statistically significant (p = 0.003)

4. Secular trend

Given the discrete time periods between data collection (T1, January 1995 to June 1995; T2 August 1996 to October 1996) it is possible that a secular trend may have occurred and influenced the results on the primary variable of Self-efficacy. Secular trends in chronic disease conditions tend to take place over several years to decades (Hennekens & Buring, 1987). Factors which influence secular trends include:

- Enhanced diagnostic techniques – resulting in an increased reporting of disease rates.
- Changes in age distribution of the population – this alters crude rates but age specific rates remain unchanged.
- Improved therapies and treating earlier – increases survival rates.
- Actual changes to the incidence of disease in the population – e.g. lifestyle and environmental factors.
- Changes in methods used to enumerate the population at risk – this changes incidence rates but is not a reflection of a "true" change in the frequency of the disease.

None of the factors above would appear to be pertinent to the patients in the present study. The cases at T1 are different from the other groups in the study most markedly on their Self-efficacy scores which are 46, 54.5, 77, 77.5, 95.8, 98 and 98, with an unadjusted mean of 78.1 on the overall SE. The unadjusted means for the other groups are 56.3 (controls at T1), 60.1 (controls at T2) and 62.2 (cases at T1).

From assessing the observed means, boxplots and the interaction term of the two-way ANOVA there was a clear indication of interaction. Qualitatively results were obtained in relation to what was happening during these time periods which may have influenced the results. The following factors were considered:

- Data collection procedure on cases at T1 – the investigator and a research assistant collected the data on the seven individuals in the group. The procedure was not different from the collection procedure in the other groups.
- The Self-efficacy instrument is self-administered i.e. neither the investigator nor the research assistant was present during the completion of the instruments by the patients.
- Four different rheumatologists were involved with the care of the seven cases at T1. Three different rheumatologists were seeing the cases with the four highest SE scores at T1 i.e. it was not one rheumatologist who was, in some way, influencing the SE scores.
- The activities of the Arthritis Society (TAS) were assessed during the time periods of data collection and the following was identified:
    - 1990 – The first year that the ASMP was offered in the urban centre. The ASMP is offered three times a year, in the winter spring and fall.
    - April 1996 – TAS hires a Communications Manager. The manager's responsibilities include increasing public and arthritis patient awareness of the Society.
    - September 1996 – General improvement in media communications regarding TAS and the fund raising campaign is revamped.
    - August 1996 – October 1997 – TAS is very active in raising public awareness of the Society.
    - March 1997 – An acquisition mailing is sent out to 100,000 members of the public in the province (40% to 50%) of the mailouts went to residents of the urban centre. The mailout was for the purpose of fund raising and increasing awareness of TAS.
    - September 1997 – A second acquisition mailing is repeated.

- September 1997 – TAS publicizes that September is "Arthritis Month".
- November 1997 – A sponsored run (the "Jingle Bell Run") is held to raise funds for TAS. The run is widely publicized in local media.

(personal communication, T. Cathy Miller, Executive Director of TAS, April 28, 1998).

From the foregoing data it would appear that the major activities and events of TAS took place at T2, i.e. after the data were collected on the cases and controls at T1.

Summary

In summary, the data were statistically described separately i.e. cases and controls at T1 and cases and controls at T2. With very few exceptions (e.g. alcohol consumption and smoking) the cases and controls were very similar in comparison to each other.

The one way ANOVAs revealed that there were statistically significant differences between cases and controls on the following variables: age (T1 and T2, $p = 0.041$ and 0.005 respectively; education (T1, $p = 0.004$); social support (T1, $p = 0.053$); knowledge (T1, $p = 0.048$); overall SE (T1, $p = 0.031$); SE pain (T1, $p = 0.053$); SE physical (T1, $p = 0.053$) and SE other (T1 $p = 0.043$). With the exception of age, none of the other variables were statistically significant at the T2 comparison.

Two-way analyses of variance showed that the interaction terms (time by group) for social support and education were statistically significant ($p = 0.032$ and $p = 0.034$ respectively). The interaction term for knowledge approached statistical significance ($p = 0.06$). The interaction term for overall SE did not reach statistical significance ($p = 0.076$) but it was considered to be in a "grey area" that it was decided not to interpret the main effects.

The cases and controls from T1 and T2 were combined and an analysis of covariance was performed using age, education, knowledge and social support as the covariates. The results showed that, with the exception of social desirability, none of the psychometric measures (including all of the SE scores) were statistically significant.

The cases at T1 were assessed in detail and consideration was given to TAS activities at the time of data collection. There were no clearly identifiable factors which may have caused a secular trend.

CHAPTER 5
DISCUSSION

The chapter begins with a discussion of the findings in relation to the psychometric data and hypotheses. The demographic and morbidity data will then be discussed. The possibility of a secular trend is discussed from both qualitative and quantitative aspects. Broader conceptual and theoretical issues are then considered. The chapter concludes with strengths and limitations of the study and recommendations for further research.

The original plan was to collect sufficient data at one time period in order to compare cases with controls. Unfortunately this did not occur. The data for the cases and controls were initially described separately for the two time periods. The data were then combined for the two-way analyses of variance to test for interaction and also for the analyses of covariance.

5.1 Phase II - Psychometric Data

The psychometric data were obtained from phase II of the study in which the patients completed the self-report instrument package. There was a very good return and completion rate (85.9%) of the instrument package from the entire sample of RA patients who originally agreed to participate in the study.

5.1.1 Hypothesis 1 – Self-efficacy

According to SE theory (Bandura, 1986), one might expect that those individuals wishing to participate in an ASMP would have higher SE than those who do not. It is therefore helpful to examine the findings from other studies of SE. However, one must be cautious in comparing SE scores across studies because of methodological and other issues of measurement.

For example, Lorig & Holman (1993) have reported baseline SE measures of 54 and 53 for controls and experimental groups respectively. Four months after the ASMP intervention they reported an SE of 60.1 for the experimental group. In the present study those patients who were *not* interested in taking the ASMP had a similar SE score (adjusted mean for controls = 59.8) to Lorig & Holman's (1993) ASMP participants. The SE scores in Lorig & Holman's study initially appeared rather low. However, only 15% of the participants had RA, 75% had osteoarthritis and 10% had other types of musculoskeletal conditions.

Taal and his colleagues (1993) have reported high baseline SE scores in a small group (n = 27) of Dutch RA patients. For example, the control group at baseline had SE pain and SE other scores equivalent to 73.6 and 79.0 on a zero to100 scale respectively. These scores are closer to the unadjusted means obtained in the present study by the cases at T1 (i.e. SE pain = 69.5 and SE other = 81.2 respectively). However, Taal et al (1993a) had changed some of the items on the SE instrument and reported values on a 1 to 5 scale. In addition, although every patient had RA, all had the condition for less than eight years.

Two Canadian studies have recently reported varied SE scores. Davis and his colleagues (Davis, Busch, Lowe, Taniguchi & Djkowich, 1994) using a one-group repeated measures design reported low baseline SE scores. For example, SE pain and SE physical were reported to be 23.7 and 58.6 respectively *after* an educational intervention. The standard SE scale was used as designed by Lorig and her colleagues (1989).

. Davis et al (1994) stated that the program participants mainly included newly diagnosed RA patients.

It is speculated by this investigator that the low SE scores are perhaps a reflection of the SE of newly diagnosed patients with RA. These patients may feel less efficacious in their abilities to cope with pain and physical symptoms of RA. Investigation of the SE of newly diagnosed RA patients may prove fruitful in determining whether there is a gradation of SE with the progression of the disease over time.

Bell et al (1998), in a community base randomized controlled trial, reported overall SE scores of 58.4 (n = 58) and 63.9 (n = 69) in the control and experimental groups respectively *after* the intervention. In the present study the adjusted mean for SE physical was 63.2 in the group who had no interest in taking the ASMP

It was thought that a gradient might have been observed in the present study to the extent that the controls would have the lowest SE scores, the cases would have the higher scores and patients completing the ASMP would have the highest scores. Such a gradient of SE scores did not emerge from the data.

It was originally hypothesized that patients who wished to participate in the ASMP would have higher SE scores than those who did not wish to participate. The hypothesis was upheld to the extent that all the mean SE scores in the cases were higher than the respective mean SE scores in the control groups at both time periods. At T1 all of the mean SE scores in the cases were higher and statistically significant than the controls.

However, when the data were combined it was noted that the interaction term in the two-way analysis of variance for overall SE score was close to statistical significance (0.076). It was decided not to make any meaningful interpretation of the main effect of group. An analysis of covariance with age, education, knowledge, and social support as covariates provided adjusted means for each of the SE scales. All of the mean scores were in the hypothesized direction but none of them reached statistical significance.

In the present study, had the findings for the cases at T1 been apparent in the cases at T2 there would have been substantial evidence to support the central hypothesis. The cases at T1 were somewhat of an anomaly. It is difficult to explain why their SE scores were so different from the other groups when they do not substantially differ from the other groups on most other measures. For example, there are not proportionately more men in the cases at T1, they are not younger than the cases at T2, they have not had RA for the longest nor the least amount of time, they do not have fewer co-morbid conditions and they are not significantly more healthy than the other groups based on the AIMS, IIRS and CES-D measures.

The cases at T1 did have higher scores on emotional and instrumental support but they did not reach statistical significance. However their knowledge of RA and quality of social support was higher and statistically significant. It would be important to measure these two variables in future studies of RA patients and ASMPs because knowledge and social support may be influencing SE.

In summary, other researchers have cited varied levels of SE at baseline and after intervention. None has attempted to measure SE in "true" non-participants. Caution should be exercised when comparing SE scores across studies as it is important to know such factors as, the method of SE measurement, the demographics of the subjects, whether they have RA or not and the length of time with RA, in order to make meaningful comparisons.

In the present study, it was concluded there was insufficient evidence to support the hypothesis that SE would be significantly higher in those interested in taking ASMP compared with those who are not. From the observations made in this study it may be seen that patients who do not wish to participate in an ASMP can have SE scores which are better or about the same as those who do and in those who have completed arthritis education courses.

5.1.2 Hypothesis 2 – Information Seeking Behavior

The monitoring/blunting framework has been conceptualized as a coping style. Typically when individuals are faced with a threat they tend to deal with it by seeking more information (monitors) or distract themselves from it (blunters) (Miller, 1981). Sources of threats may arise from uncertainty about the disease or from "physical" aspects of the disease such as pain. In essence anything that challenges the individual to cope with a source of stress may be perceived as a health threat (Miller, 1992).

Previous work has focussed on more immediate threats to health such as patients undergoing a gynaecological diagnostic procedure (Miller & Mangan, 1983) or cytological cervical screening (Lerman, Miller, Scarborough, Hanjani, Nolte & Smith, 1991). Within more chronic disease conditions it has been found that individuals must perceive certain situations as threatening before monitoring or blunting coping mechanisms occur (Miller, 1992). For example, in groups of cancer patients undergoing chemotherapy, it was found that monitors experienced nausea significantly more than blunters (Gard, Edwards, Harris & McCormack, 1988).

More recently, Bar-Tal (1994) has found, in a group of patients with RA, that high monitoring was more strongly associated with psychological distress when inadequate information was given to them about their condition. It is speculated that, in the present study, the decision whether to take an ASMP is probably perceived by RA patients as a situation which does not pose a threat to their immediate health. The number of monitors and blunters was fairly evenly distributed particularly among the cases and controls at T2.The majority of patients completed the MBSS in the comfort of their own homes and not in a potentially threatening environment.

There may also have been bias introduced in the data obtained as some patients neglected to follow the instructions on the instrument which requested that they check *all* of the statements that apply to them. Some patients only checked off one statement in each of the four case scenarios that were presented. It was concluded that there was insufficient evidence to support hypothesis 2.

5.1.3 Hypothesis 3 - Knowledge Test

The cases at T1 had the highest scores on the knowledge test (70%) than the other three groups. The cases at T2 and the controls at T1 and T2 had almost identical scores of 51%, 52% and 51% respectively. The former set of scores are similar to the pre-test scores reported by Davis et al (1994) and Bell et al (1998). The score obtained by the cases at T1 is higher than the score achieved (60%) by Bell et al's (1998) experimental group *after* the intervention. It is almost the same as the post-test score obtained by Davis et al's (1994) group after the educational intervention. This suggests that the cases at T1 are quite different from the other the groups.

Moore (1991) has coined the term "early adopters" within the context of marketing theory for those individuals who "buy into" new concepts very early in their development. According to Moore (1991) early adopters tend to rely on their own intuition and understanding of the product rather than relying on well-established references. It is speculated that within the context of arthritis education the individuals in the case group at T1 may have been early adopters to the extent that they were keen on trying the "product" and were highly motivated to do so. However, there is insufficient evidence to support hypothesis 3.

5.1.4 Hypothesis 4 – Quality of Social Support

There were six people, on average, in the patients' immediate social network in each group. The absolute number of people in one's social network is not necessarily a clear indicator of the *quality of* social support (Sarason, Shearin, Pierce & Sarason, 1987).

The QSSS was used to measure the quality of the social support obtained by the RA patients. The same pattern emerged with respect to the differences among groups at the two time periods as has been seen for the other measures, in that the cases at T1 had the highest score (53.7) on the QSSS. The scores of the other three groups were very similar (controls T1 = 48.7; cases T2 = 47.0 and controls T2 = 48.0). All of the scores indicate a fairly high degree of quality of social support.

The average scores obtained by the RA patients in the present study compare favourably with the only other comparative QSSS score to be reported in the literature of 54.3 (Goodenow, Reisine & Grady, 1990). The sample Goodenow et al used comprised exclusively of women (n = 194) with RA.

The score of 54.3 most closely approximates the one obtained from the cases at T1. Interestingly, the cases at T1 have the highest percentage of women (85.7%) of all four groups. It might be expected that the group with the most men (controls T2) would have the lowest score among the groups, this was not the case (48.0).

The contrast comparison between the cases and controls at T1 was statistically significant (0.05). This provides further support to the notion that the cases at T1 are uniquely different on some variable or variables from the rest of the sample.

5.1.5 Hypothesis 5 – Health Status, AIMS2, IIRS and CES-D

The overall health status of the patients was assessed using three instruments: the three component form of the Arthritis Impact Measurement Scale version 2 (AIMS2) (Meenan personal communication, 1994), the Illness Intrusiveness Ratings Scale (IIRS) (Devins, Binik, Hutchinson, Hollomby, Barre & Guttmann, 1983) and the Centre for Epidemiological Studies' Depression Scale (CES-D) (Radloff, 1977). The cases at T1 consistently scored lower (i.e. lower = healthier) on all scales but statistically there was no difference between the cases and controls at T1 or T2. After adjusting for the potential confounders of age, education, knowledge and social support the adjusted means were almost identical and there was no statistically significant differences between the combined cases and controls.

AIMS

The AIMS was specifically developed (Meenan et al, 1980) to assess well being in individuals with RA. In an earlier study of 726 patients (60% of whom had RA) Kazis, Meenan & Anderson (1983) reported pain and physical subscale values of 5.8 and 2.8 respectively. These results compare favourably with the present study in which the adjusted means for the physical subscale for cases and controls was 2.27. The pain subscale scores in the present study were slightly lower at 4.59 and 4.73 respectively for cases and controls.

Spiegel et al (1988) have reported scores of 2.4 (physical) and 4.9 (pain) from a group (n = 92) of RA patients half of whom were hospitalized and the other half were attending a rheumatology clinic. The AIMS affect scale was not used. The physical score is slightly lower than the adjusted means in the present study and the pain score is slightly higher, possibly reflecting the influence of the hospitalized patients on the overall means.

In a British study (Hill, Bird, Lawton, & Wright, 1990) with 30 RA patients (90% female, mean age = 53 years) the subscale scores were slightly higher than the present study. They obtained scores of 4.41, 3.41 and 6.22 for the physical, affect and pain subscales respectively. The differences may in part be due to the use of a modified AIMS instrument adapted for British patients. However it is more likely that these patients had more serious disease.

In a Dutch study (Taal et al, 1993a) reported scores of 5.9 for pain and 3.4 for affect in a sample of 30 RA patients (73% female, mean age = 49, years with RA = 4.7). The physical component score (i.e. the combined score of five "physical scales") was not reported *per se* but the physical activity scale score was 6.6. Apart from the physical component score, with which it is difficult to make comparisons, the other scores were similar to the present study.

In summary, the results reported in the present study are similar to those for previous studies taking into account variation in reporting methods and patient morbidity. The indication from the AIMS2 instrument results is that the patients perceived the impact of their arthritis in about the same way and rated themselves to be reasonably healthy.

Comparisons of AIMS scores among studies are not facilitated by the fact that researchers use a variety of reporting methods. Some choose not to report mean scores at all while others report the individual scale scores and not the combined scores for each of the components of the instrument. A standardized reporting system would make for more meaningful comparisons across studies.

IIRS

Individuals with RA experience illness-induced stressors which tend to disrupt their lifestyle (Devins, Edworthy, Paul, Mandin, Seland & Klein, 1993). The IIRS developed by Devins and his colleagues (Devins, Binik, Hutchinson, Hollomby, Barre & Guttman, 1983) was designed to measure the *perceived* intrusiveness of a chronic condition on certain aspects of daily living.

In the present study IIRS scores of 29.0 (cases T1), 38.0 (controls T1), 38.4 (cases T2) and 34.6 (controls T2) were obtained. Once again the pattern of the T1 cases being different from the other groups emerged. There was no statistically significant difference between the cases and controls at either time period. The adjusted means were almost identical between the cases (37.36) and controls (36.06).

Binik & Devins (1986) have reported scores of 32.1 (n = 36), 38.1 (n = 9) and 27.1 (n = 21) in patients at various treatment stages of end-stage renal disease. Devins, Edworthy, Guthrie, & Martin (1992) have measured IIRS scores in RA patients (n = 110) who had similar demographic characteristics to the patients in the present study (age = 53 years, 86% female, education = 12.7 years and duration of RA = 10.6 years). Devins et al (1992) reported IIRS scores in three groups based on their Steinbrocker et al (1949) classification which were: Class 1, 30.3 (n = 48), Class 2, 39.9 (n = 4) and Class 3 53.6 (n = 15).

In comparison to the present study's IIRS scores, those reported by Devins et al (1992) for the class 1 patients closely resemble the scores obtained for the cases at T1 (29.0). The scores for the class 2 patients (39.9) approximate the scores of the other three groups (controls at T1 = 38.0, cases at T2 = 38.4 and controls at T2 = 34.6). Interestingly the patients in the present study are either class 1 or class 2 RA patients. The adjusted means for the IIRS scores (cases = 37.4 and controls = 36.06) closely approximate the class 2 patient score (39.9) in the Devins et al (1992) study.

From these results, the RA patients in the study perceived the intrusion of their disease on their lives to be reasonably mild.

CES-D

The CES-D scale was originally developed for use with the general population in the community to assess possible symptoms of depression (Radloff, 1977). In his original work Radloff (1977) reported mean values of 9.25 (n = 2514) and 8.17 (n = 1060) in samples obtained from surveying all white communities. He obtained a score of 24.4 (n = 70) from residents of a private psychiatric facility. The generally accepted cut points for the instrument are: 16 or > "at risk" for depression (Radloff, 1977), and 23 or > probable depression (Husaini, Neff, Harrington, Hughes & Stone, 1980).

More recently Devins, Orme, Costello et al, (1988) have reported community based scores from healthy undergraduate students (n = 175) and patients attending GP offices (n = 126) of 14.4 and 16.4 respectively. From the same study scores from patients with end-stage renal disease (n = 107) and lung cancer (120) were reported to be 17.3 and 15.6 respectively. Goeppinger and her colleagues (1989) have reported a CES-D score of 13.8 from a sample (n=374) of predominantly female (87%) Caucasian (96%) patients (16% had RA, and 77% had OA) with an average duration of disease of 12.7 years.

It has been suggested that the CES-D may invite some biased responses with the RA population as some of the items in the scale (e.g. "I felt that everything I did was an effort") may be indicative of *somatic* aspects of the disease rather than relating to *psychological* symptoms of depression (Callahan, Kaplan & Pincus, 1988; Pincus & Callahan, 1993). However, Blalock and her colleagues (1989) have suggested that while the CES-D used on RA patients may overestimate the prevalence of depressive symptoms the magnitude of the bias is modest and should not prevent researchers from using the instrument in population studies.

From the foregoing discussion of CES-D scores from other studies it would appear that the RA patients in the present study have scores that are within the normal range of scores for individuals with chronic conditions and are not indicative of "at risk" for depression.

In summary, from the results of the health status assessment the RA patients were "equally healthy" with respect to the AIMS2, IIRS and CES-D scores. There is therefore insufficient evidence to support the fifth hypothesis.

5.1.6 Social Desirability – Marlowe-Crowne Scale

The Marlowe-Crowne Scale (M-CS) (Crowne & Marlowe, 1960) was used in an attempt at estimating the degree to which patients may have answered the items on the psychometric instruments in a socially desirable way. The difference in scores between cases and controls at both time periods was found not to be statistically significant (T1, $p = 0.58$ and T2, $p = 0.24$). In the two-way analysis of variance the interaction and main effects term (group) were also not significant ($p = 0.95$ and $p = 0.29$ respectively). However, the results from the analysis of covariance (controlling for age, education, knowledge and social support) indicate that the difference between the cases (18.23) and controls (15.96) is statistically significant ($p = 0.003$).

A variety of normative scores for the M-CS have been reported. Crowne & Marlowe (1960) reported 13.72 in their original work with U.S. college students. However other authors have reported higher mean values, for example, Fisher (1967) has reported 16.1 (n= 425) and 16.4 (n = 225) in male and female Peace Corps volunteers respectively. Cosentino & Kahn (1967) have reported mean levels of 15.4 (n = 580) and 16.4 (n = 399) in male and female U.S. college students. O'Gorman (1974) has cited a mean value as high as 19.7 (n = 729) in Australian National Service army recruits. Selby (1984) reported mean M-CS values of 16.4 (n = 50) and 18.78 (n = 50) in violent and non-violent prison inmates respectively. Muhlenkamp & Joyner (1984) found a mean value of 18.2 (n = 30) in a sample of hospitalized female RA patients who had a mean age of 52.8 and 12.7 years with RA.

As may be seen there is some variation in mean values on the M-CS. The values for the cases in the present study most closely approximate the hospitalized RA patients (Muhlenkamp & Joyner, 1985) and the non-violent inmates (Selby, 1984).

The two groups of patients who wished to take part in the ASMP (the cases) had higher scores on the M-CS. During the interview process it became apparent to the investigator (despite repeated efforts stating the contrary) that *some* patients assumed that they would be taking part in the ASMP at some point in the study. It is possible, that those patients may have wanted to place themselves in a "favourable light", and consequently answered the items on the instruments in such a way which they believed would facilitate their admission into the ASMP.

Alternatively, the cases may have presented themselves in as "bad a light" as possible in the belief that they would "qualify" for the program sooner. If the cases wished to present themselves in a "good light" the implication is that their scores on the instruments would be overinflated. This could be a possible explanation for the very different scores (e.g. high SE, low scores for AIMS) observed in the cases at T1 in particular.

Conversely if the cases wished to present themselves in a "bad light" the implication is that their scores, for example on the SE scales, are underestimated and are, in reality, much higher than observed. This could be a possible explanation for the scores in the cases at T2 not being more closely aligned with the cases at T1. All of this assumes that the cases at T1 would choose to bias their responses in one direction while the cases at T2 would choose to bias their responses in the other direction.

The M-CS only detects the potential for responding in a socially desirable way it cannot quantify the magnitude of the bias. Unfortunately, there is little that can be done *post hoc* except to be extremely cautious in interpreting the results (Streiner & Norman, 1989).

5.2 Phase I – Interview Data

5.2.1 Demographics and Morbidity

The majority of the sample comprised married Caucasian women. The average age of the cases was 56.6 and the average age of the controls was 61.8. There were more full time employees among the cases and more retired people among the controls reflecting the average older age in this group. The method by which patients were recruited into the study may have impacted on their willingness to take part. Patients may have found it relatively easy to refuse participation in the study by simply checking off "No" on the patient reply form and returning it to the investigator. Whereas, if the patients had been approached "face to face" by the investigator or their rheumatologist, they would have had more opportunity to ask questions about the study and the nature and extent of their involvement in it.

The investigator anticipated that those patients who did not wish to participate in an ASMP would have greater morbidity with their arthritis. It was speculated that those with greater morbidity might be less inclined to want to take part in a self-management program.

The groups were very similar to each other with respect to crude estimates of morbidity such as specialist and GP visits. There was not any evidence of "doctor shopping" among the groups as one might expect with a chronic disease condition such as RA. The patients in the control group at T1 had the greatest range with up to seven rheumatologists ever being seen. This group also had experienced RA for the longest time (15.6 years).

The cases and controls were surprisingly homogeneous with respect to RA morbidity. Estimates of RA morbidity such as pain, swelling and joint stiffness were similar among the groups and none of these measures reached statistical significance in comparison procedures. After controlling for age and gender there was a statistically significant difference found in the swelling index between cases and controls at T2 ($p = 0.01$).

While very few of the morbidity measures reached statistical significance in comparison procedures, it was important to examine the results from the point of view of *clinical* significance between the cases and controls at both time periods. From a clinical perspective, the pain and swelling indices and the average morning joint stiffness indicated that the patients' RA was not particularly active. In a recent Canadian randomized controlled trial Bell, Lineker, Wilkins, Goldsmith & Badley (1998) reported baseline morning stiffness averages of 171 and 154 minutes in their experimental and control groups respectively.

The rates of co-morbid conditions were low and almost identical between the cases and controls at T2. No groups had a frequency of any one co-morbid condition greater than 6.2% (e.g. Sjogren's syndrome for cases at T2). At T1 the rates of co-morbid conditions between the cases and controls were similar or identical with two exceptions. The frequency of episcleritis in the cases was

14.3% and zero in the control group. While this rate may appear clinically very different, it is worth noting that the 14.3% figure represents only one patient in the cases (n = 7). A larger sample size in the cases at T1 for comparison procedures may have revealed similar rates of episcleritis as indeed was the case with the cases (0%) and controls (2.2%) at T2.

The frequency of rheumatoid nodules in the cases and controls at T2 was very similar (cases = 23.4%, n = 15; controls = 20%, n = 9) and not statistically significant even after controlling for gender. The frequency of RA nodules was much higher at T1 (cases = 57.1% and controls = 72%). This difference was not statistically significant. There were no statistically significant differences between cases and controls with respect to number of years with RA, joint pain, swelling or stiffness.

However, from a clinical perspective the controls in general had RA for a longer time. They also had more joint pain and stiffness, and marginally more swelling than the cases. It is possible that these differences in clinical profile may have impacted on whether patients decided on becoming cases or controls. For example, patients with RA nodules, increased stiffness and more pain may have considered themselves to have had more advanced disease and therefore believed that participation in an education program had little or no utility to offer them.

The frequency of orthopaedic surgery was over 10% higher in the control group compared to the cases. This is perhaps a reflection of the average older age in the controls. While this may be a crude indicator of RA morbidity it could also be an indication of other disease conditions in the older age group such as osteoarthritis. With the exception of the "other" DMARDs category, the frequency of use of both DMARDs and NSAIDs was very similar among the groups.

Notwithstanding the points mentioned above concerning rates of episcleritis and RA nodules at T1, it would appear that from the overall analysis of the morbidity data collected at interview there was no evidence which would indicate that the control group had any worse RA than the cases. The fact that the RA morbidity was not different between the cases and controls does not mean that, from a clinical perspective, the patients' perception of their disease might not be different and therefore influence their decision with respect to becoming a case or a control group member.

It is, however, interesting to note that, from the discussion of patients' perceived health ratings in section 5.1.5 above, all of the patients rated themselves to be "equally healthy" with respect to the data from the psychometric instruments used to measure health. A topic worthy of future research might be the differences in perceptions that patients have with respect to the impact their disease has on participation in education programs compared with their perceptions of their own health. It is possible that individuals might perceive themselves to be healthy and yet view the extent and severity of their disease as a barrier to participating in education programs.

5.2.2 Social Network

The patients were asked to state the number of people in their social network which included close friends and family. The groups were almost identical in the average number of people in their social networks. In addition to identifying the number of people in their network it was important to identify the *quality* of instrumental and emotional support given by the family and friends to the patients with respect to coping with their RA.

During the interviews conducted by the investigator it was noted that many of the patients had difficulty in rating the quality of the support given by their family and friends. Their unease with this aspect of the interview was detectable by the way they responded. For example, some patients would quickly brush over the question by saying "Oh, give them all a 5", others would be hesitant to answer at all.

There may well have been a response bias by the patients to present the people in their social network in a favourable light. This potential bias was validated by the two research assistants who detected the same verbal and non-verbal cues at interview as the investigator. If there were a response bias it would appear to be reasonably well distributed among the groups, as there was no statistically significant difference between the cases and controls at either time period. The results obtained from the general Quality of Social Support Scale were discussed in section 5.1.4.

5.2.3 Arthritis and Health

All of the groups rated their general health to be "well" to "very well" before their diagnosis of RA. As expected there was a consistent increase in global health rating (i.e. health was rated as "fair" to "well") after the diagnosis of RA. Interestingly one young woman at interview rated her health as having improved *after* the diagnosis of RA. The improved rating was verified with the patient by the investigator. She indicated that she did intend to rate her health as being better after the diagnosis. The patient stated that because she had a young family she wanted to "take better care" of herself and she had made some deliberate lifestyle changes to cope with RA and generally improve her health,

With the exception of the cases at T1 the groups were similar in their smoking and drinking habits. Based on the patients' recall of after their RA diagnosis their response to the standardized questions on the interview schedule concerning smoking and drinking habits revealed that the number of smokers in each group decreased as did the number of people drinking alcohol. Although there were fewer smokers overall after the diagnosis of RA the number of cigarettes smoked per day increased. The reasons for this observation would be worthy of further investigation.

The debate concerning smoking having a causative role in the onset of RA continues in the literature (Masi, Fecht, Aldag, Malamet & Hazes, 1998;

McDonough & Walker, 1997; Silman, Newman & MacGregor, 1996). However, there has been significant association found between smoking and vasculitis, and general vascular endothelial damage (McVeigh, Lemay, Morgan & Cohn, 1996).

It has been demonstrated that patients with RA who participate at the appropriate level of exercise can *lessen* their fatigue without exacerbating their condition (Neuberger, Kasal, Smith, Hassanein & DeViney, 1994; Neuberger, Press, Lindsley et al, 1997). In addition, it has been demonstrated that there is a strong association between self-efficacy for exercise and actual exercise participation in individuals with rheumatoid and osteoarthritis (Gecht, Connell, Sinacore & Prohaska, 1996).

There was a marginal decrease in the number of individuals overall who were exercising after the diagnosis of RA. The frequency of exercising per week increased in all groups, however, as expected the duration of exercise decreased. In other words, the patients exercised more often but for shorter periods of time after the diagnosis of RA. These results are encouraging as they tend to suggest that the RA patients in the present study may have an appreciation for the importance for exercise despite having a disease that affects the musculoskeletal system and which can also be extremely fatiguing.

5.2.4 The Arthritis Society and The Arthritis Self-Management Program

It was important to assess whether the patients had any knowledge of the Arthritis Society (TAS) and to establish whether they were members of the Society. As members of TAS patients would have access to literature and other learning materials which, potentially at least, could impact on their self-efficacy through vicarious experience (Bandura, 1986). While over 94% of all the patients in the study were aware of TAS, surprisingly just over 10% of the entire sample were members (nine cases and six controls).

Approximately equal numbers of cases and controls were aware of the ASMP, had taken another arthritis education course in the past and believed that arthritis education could help them cope with their condition. Almost all of the cases (95.7%) believed that arthritis education could help them cope with their RA. This figure was to be expected, as it was the patients in this group who were interested in taking part in an ASMP. One might have expected fewer patients among the controls (84.9%) to state that they believed that arthritis education could help them cope with their condition.

There was a potential for bias in the study if more patients belonging to the control group had taken a previous arthritis education course. For example, it might have been argued that the reason for patients not wishing to participate in an ASMP was because they had previously taken an education course. It could be further argued that only those patients who had not taken an arthritis education course in the past would be interested in one now. In fact there was one less patient in the control group (32 controls compared with 33 cases) who had taken a previous course.

It was important to obtain the views of all the patients regarding ASMP program delivery, including those who had stated their lack of interest in being involved in an ASMP. Those patients who were not interested in ASMP participation might have made some suggestions regarding how the program could be run differently, which may have made it more appealing to them. However there were no major differences between the cases and controls on this issue.

The cases preferred the spring as the season of the year they would most like to have the ASMP offered. The controls favoured the spring, summer or fall equally. This is perhaps a reflection of the number of retirees in the control group. November through to March were the least favoured months for both groups. Interestingly most of the cases and controls chose the morning or afternoon over the evening as their preferred time of day. Very few individuals opted for weekends to hold the course.

It has been demonstrated that there is no difference in certain outcome measures between programs taught by professionals and those taught by lay people (Cohen, van Houten, Souter, DeVellis & DeVellis, 1986; Lorig, Feigenbaum, Regan, Ung, Chastain & Holman, 1986). However, the patients in the present study expressed a preference for health professionals to teach arthritis education, followed by patients with arthritis.

The patients expressed a preference for six classes in total in a course, lasting from 60 to 120 minutes and being offered once a week. This schedule is precisely how TAS offers the ASMP. The patients expressed a preference for holding the ASMP locally in their own community, in either a community centre or a nearby hospital. Approximately 27% of the sample thought that the ASMP should be free of charge, most of the patients indicated that the program should be covered by the provincial health plan. Over 37% of the sample indicated that they would be prepared to pay between $10 to $35 for the course.

5.3 Sample Size & Power

5.3.1 Sample Size

A total sample size of 146 patients with rheumatoid arthritis was obtained from the target population of a major urban centre. Patients were recruited from the day lists of five rheumatologists in the city. There was difficulty in recruiting patients into the study resulting in data being collected over two periods of time.

The investigator did not go outside of the city limits to recruit patients. There is obviously a finite population of RA patients from which to recruit. The precise number of RA patients in the city is unknown. A crude estimate would be one per cent of the adult population of the city, of these patients approximately 50% would be seen by a rheumatologist (Edworthy, personal communication, 1998). This would provide an approximate population of 2,917 adult RA patients from which to draw based on the population of the city in 1995 (Health of Calgarians, 1995).

During the period of data collection 665 patients participated in the ASMP offered by the Arthritis Society (Miller, personal communication, 1998). This represents a significant number of patients who would have been excluded from the present study.

In addition, at the beginning of data collection for the present study another large RA study involving ASMP participation was reaching completion in the same city. The patients who participated in the ASMP study would have been ineligible to participate in the present study.

It also became evident to the investigator, as data collection proceeded, that some of the patients who were interviewed were expecting to be enrolled in an arthritis self-management program at some point in the study. This caused the investigator to re-evaluate the protocol when patients were approached for participation. The rheumatologist's letter, the patient consent form and the telephone protocol were re-evaluated. No changes were made to the documentation however every effort was made when talking with the patients to emphasize that their participation in an ASMP was *not* a requirement of participation in the study.

Despite strenuous efforts to make this point clear the investigator continued to encounter a few patients who had an expectation of ASMP participation. It is possible that other patients who were approached for participation in the study may also have held this erroneous belief and decided not to participate.

Another factor with respect to recruitment was that the investigator learned from telephone conversations with relatives of potential participants that some of the older patients in particular would go south during the winter months. The implication is that RA patients in the retirement age group can be difficult to recruit in a cold climate! Recruitment "windows" are only open at certain times of the year. Notwithstanding the fact that some of the patients stated their preference for participation in an ASMP program during June, July and August, the summer months were extremely difficult times of the year from which to recruit patients to participate in the study. The recruitment problem was further compounded by a warm and lengthy summer in 1997 which extended well into September.

5.3.2 Power

Given that data were collected at two different time periods and the number of patients in each group are different, it was decided to examine the power with respect to the sample sizes achieved at each time period (Table 5.1).

Table 5.1 Power and sample sizes

Mean difference in SE score	Effect size	n (in each group)	Comments
12	0.49	63	Original sample size calculation
14.5	0.59	45	T2 cases (n = 45) and T2 controls (n = 65) - sufficient power to compare
18	0.74	27	T1 controls n = 29 but T1 cases n only = 7
36	1.48	7	T1 cases n = 7

*The power calculations were based on: $\alpha = 0.05$, B = 0.20, Power = 0.80 and $\sigma = 24.25$.

As may be seen from Table 5.1, if the T1 cases and T1 controls are compared, there is insufficient power to detect a difference of 12 on the SE scores. There is sufficient power to detect a mean difference of 36. The actual difference observed was 21.8. There would have to be a minimum of 19 patients in each group to make meaningful comparison.

If the cases (n = 65) and controls (n =45) at T2 were compared, there is insufficient power to detect a mean difference of 12. There is sufficient power to detect a difference of 14.5. The actual difference observed was 2.1. The sample size necessary to make a meaningful comparison to detect a difference of 2.1 is extremely high (n = 2,240). Moreover a difference of 2.1 has little or no utility or clinical significance.

If the data from the cases and controls were combined (n = 72 and n = 74 respectively) there is sufficient power to detect the hypothesized difference. This in fact was done in the two-way analyses of variance, however it was decided not to interpret the main effect of group in the presence of possible interaction (p = 0.076).

5.4 Chance

The p value provides the investigator with the information to assess the role of chance in the study (Hennekens & Buring, 1986). In the present study the probability of erroneously rejecting the null hypotheses (i.e. Type I error) was set at 0.05. Notwithstanding the M-CS result, the p values comparing the cases and controls on the SE scales and health status instruments ranged from 0.41 to 1.0. These non-statistically significant results do not mean that only chance is responsible for the observed results. Rather that chance cannot be excluded as a likely explanation. The p values assess the role of chance, however it is important to assess the role that bias and confounding may have had on the results as well.

5.5 Bias

The hypotheses of the present study were not upheld. When null results are found it is important to consider other possible explanations for the findings. Sources of bias include selection bias and observation bias.

With respect to the former, the cases and controls were selected using the same criteria applied to both. It is unlikely that the groups differ from each other based on selection differences. Another source of selection bias is those who refused or did not respond may well have influenced the results differently had they participated in the study. Unfortunately it was not possible to ascertain any meaningful data on those patients who refused to participate.

Being aware of the study hypotheses may have introduced interviewer bias with respect to recording the data collected at interview. It was not possible to know the SE score of the patients *before* the interview but their preference for participating in the ASMP was known. The research assistants, to the extent possible, were blinded to the overall objectives of the study.

The investigator, of course, was aware of the study objectives and was cognizant of the potential for introducing bias. Every effort was made to remain vigilant during the interviews of this possibility and the investigator endeavoured to remain neutral when asking the questions. In addition, the questions on the interview schedule were objective and closed ended. The research assistants were trained in interviewing and the protocol for data gathering during the interview was made explicit to them.

With respect to a response bias, as previously discussed, it is possible that the patient responses in the case group were biased in favour of showing themselves in a "good" or "bad" light. Unfortunately it is not possible to quantify the magnitude of the effect of this potential bias. It is important however to be aware of it when interpreting the study findings.

5.6 Confounding

Confounding has been described as a mixing of effect of the independent variable on the dependent variable with a third factor i.e. the confounder. The confounder must be associated with the independent variable and, independent of that association, be associated with the dependent variable (Rothman, 1986). The presence of a confounder might lead to an over or underestimate of the true association between the independent and dependent variables (Hennekens & Buring, 1987).

In the present study it was thought that age, education, knowledge and social support were plausible potential confounders. An analysis of covariance with age, education, knowledge and social support as covariates revealed that the adjusted means of the SE scores did not change that much from the original group means, The comparisons between cases and controls on the SE scores were not significant. Similarly the comparisons on the health status measurements (AIMS, IIRS and CES-D) were not statistically significant.

5.7 Secular trend

Factors, which influence secular trends in chronic disease conditions, were previously described in Chapter 4. In addition, the activities of TAS were outlined during the time periods of data collection.

The intervening time period between T1 and T2 data collection was 12 months, from July 1995 to July 1996. It is possible that the 12 month time period was of sufficient length in which a secular trend may have occurred. During the time period between T1 and T2 there was much change in the regional health authority in which the patients resided.

There were hospital closures and considerable "downsizing" in existing hospitals. In addition, large numbers of registered nurses were made redundant, which produced a considerable amount of movement in the system due to "bumping" (i.e. the ability of a registered nurse who had been made redundant to displace or "bump" another registered nurse who had fewer years of seniority). In this environment there was uncertainty in the health care system which affected both health professional and patients.

The general ethos with respect to patients was that individuals were to take greater control and responsibility over their own health and not be so dependent on the system. In this climate of "self-reliance" for being healthy, it is possible that more individuals with RA decided to participate in the ASMP, who might not otherwise have done so, thereby reducing the number of potential subjects for recruitment into the present study. In addition, those who decided not to participate but still enroll in the present study may have been engaging in efficacy enhancing behaviors which resulted in the null finding between the cases and controls at T2 with respect to SE.

Major TAS activities (e.g. acquisition mailing, publicizing the "Jingle Bell Run") took place during the T2 data collection period. According to Bandura (1986), SE may be increased through successfully accomplishing personal performance behaviors, vicarious experience, verbal persuasion and physiological state. It is possible that during the TAS activities patients were exposed to vicarious experiences (e.g. observing certain events and people with RA related to the Jingle Bell Run) and verbal persuasion (e.g. family members encouraging ASMP participation). However, such activity would be more likely to increase patients' SE in those predisposed to taking the ASMP. The observations made in the present study indicate that there is in fact little or no difference between the cases and controls with respect to SE at T2.

Another possible explanation is that the controls at T2 increased their SE to "match" the SE of the cases, as the SE scores of the controls at T1 were lower than those of the controls at T2. Conversely the SE scores of the cases at T1 were very high during the period of TAS inactivity. It is possible that the group of seven individuals in the cases represent the upper end of the tail in the normal distribution of SE scores and it was the "luck of the draw" that they were recruited at that time.

5.8 Theoretical issues

According to Bandura et al (1977) SE is regarded as one of the most fundamental pre-requisites for behaviour change. Self-efficacy theory relates to the perceptions and beliefs of individuals to the extent that they will be capable of performing a particular behaviour which results in a particular outcome (Bandura 1977a; 1977b; 1986). One would expect that RA patients who are motivated to want to take an ASMP would have higher SE for particular behaviours (e.g. SE Pain) than those patients who are not interested in taking the ASMP. Moreover, one would expect that RA patients who have successfully completed the ASMP would have higher SE than those who have not.

The findings from previous studies tend to support the latter, to the extent that statistically significant differences in SE have been reported between experimental and control groups (Lorig & Holman, 1993; Taal et al, 1993a).

In the present study, notwithstanding the issue of recruitment over two time periods, the findings suggest that those motivated to take the ASMP do not have higher SE than those not so inclined. One possible explanation for this null finding is that a potential response bias affected the data resulting in an underestimate of SE in the cases (particularly at T2). Alternatively the bias could have operated in the opposite direction causing an overestimate of SE in the cases at T1.

It is possible that RA patients who perceive themselves to be reasonably healthy have more than adequate SE for the behaviors that were measured. Those who did not want to participate chose not to, not because they had low SE, but in fact they had high SE and were managing quite well without the need for an ASMP.

Other studies have reported that patients in both experimental and control groups have a reasonably high SE prior to taking the course (Lorig & Holman, 1993; Taal et al, 1993). The amount of increase in SE, while statistically significant, amounts to about eight points on a 1 to 100 scale. In the present study attempts were made to measure SE in "true" non-participants. The non-participants did not want to the ASMP but were willing to take part in the study. It is likely that these were patients who coped well with RA and had high SE. It is further possible that the "real" non-participants with low SE were among those who refused to participate in the study. It would be difficult to recruit real non-participants, however further investigation would be warranted in this area.

Based on the findings from previous studies, it might be assumed that there is a "dose response" in relation to ASMP and SE scores and that those patients who do not want to participate have low SE and are sicker with RA. The present study findings indicate that there is a group of RA patients who do not wish to participate in the ASMP and yet have high SE for certain behaviours. The reasons why these patients did not want to participate were not, theoretically at least, because of low SE.

Another possible explanation for the control groups not wishing to participate is derived from a general transitions framework (Robertson, 1992). According to the model adults experiencing chronic disease may go through a series of stages ranging from psychological disequilibrium at the time of diagnosis to "normal" adaptation of the disease into their lifestyle. The adjustment process that adults go through varies from individual to individual. People may remain at a stage, regress or skip a stage. Not all patients reach the point of reintegration and adaptation of their lifestyle to cope with the condition (Schlossberg, 1984).

It is therefore possible, that even although the patients in the case and control groups were similar to each other with respect to certain variables (e.g. number of years with RA and morbidity), they may have been at different stages in their development with respect to the transition (i.e. diagnosis with RA) that occurred in their lives. For Schlossberg (1984) it is not the transition *per se* that is important rather it is the person's *perception* of the transition. For example, those patients who did not want to participate in an ASMP may have been experiencing a degree of psychological disequilibrium which is not conducive to taking part in an arthritis education program. Conversely, those who did want to participate may have been at a different developmental stage in which participation in an ASMP was viewed as a beneficial component of their adjustment to their chronic condition.

In addition, the controls at T1 (64.3) and (T2 (60.2) were, on average, 12 and 8 years older respectively than the cases. It is possible that, given the age and life stage at which the controls were, they simply did not want to participate in an ASMP as they had other "developmental tasks" to fulfil (Bornstein, 1986; Robinson, 1986). The "true" reason for non-participation lies in further research.

From the perspective of practising rheumatologists the implications from this study would suggest that it is important to assess patients' SE *prior* to recommending participation in an arthritis education program. Participation in an education program *per se* will not necessarily increase a patient's SE level to the extent that it will have meaningful clinical significance.

From the results of the present study, it has been demonstrated that patients, who have had RA for some years and have no interest in participation in an education program, have reasonably high SE for those very behaviors which are addressed in the ASMP. In addition, patients who are interested in ASMP may also have a high SE going into the program and it is unlikely that their SE will be increased substantially. While an increase in SE may achieve statistical significance, what Is less clear is the extent of increase necessary to achieve clinical significance.

From the perspective of the Arthritis Society, the findings of the present study refute the assumption that those patients who are not interested in the ASMP are sicker, less knowledgeable and have lower SE for certain behaviors. It would be important for TAS to assess patients individually *prior* to participation in the ASMP and tailor the program to the specific needs of the patients. A systematic evaluation of the nature and extent of the contribution that the ASMP makes, with respect to SE and clinical changes in RA for these patients, would be timely given the growth in popularity of the program nationally.

In summary, although the original hypotheses were not upheld the findings challenge previous research and literature which suggests that people with RA have their SE increased by participating in ASMP. This study suggests that people come to the course with high SE and the contribution the ASMP makes in increasing that SE is negligible (i.e. practically not statistically). In addition, people with RA who do *not* wish to participate have just as high SE as those who do want to participate not lower as, theoretically, one might expect.

5.9 Strengths of the study

The study had sufficient power to detect a difference of 12 points on the SE scale using the combined data. The data that were collected on the patients accurately measures the severity of their RA, their co-morbid conditions and their overall health status. The RA patients were exceptionally good at completing the package of psychometric instruments. The difference (or lack thereof) between the cases and controls is unlikely to be due to differences in health status. In addition the social and psychological variables were measured using established psychometric instruments.

The study findings challenge currently held beliefs about ASMP and the extent to which ASMP is able to influence SE. In addition, it has been demonstrated that patients with RA who do not want participation in the ASMP have, in fact equally high levels of SE with those who do wish to participate.

5.10 Limitations

The study was limited with respect to the timing of the recruitment of patients into the investigation. It would have been preferable to have recruited the sample required in a much shorter period of time. The research was undertaken at a time when another RA study was ending and during a time when the Arthritis Society had enrolled 665 patients into the ASMP.

The implication is that sampling was restricted to a finite population of urban dwelling patients who had other study and TAS demands placed upon their time. If sufficient research funds had been available to the researcher he would have extended the recruitment outside of the city limits thereby making larger numbers of RA patients available from which to recruit.

It would also have been preferable to have had one blinded research assistant to collect all of the data. This would have decreased the amount of interviewer bias during data collection.

5.11 Conclusion

In conclusion, none of the study hypotheses were upheld. The cases did not differ from the controls in any substantive way other than social desirability of response. Unfortunately the effect of this finding is difficult to estimate with respect to the magnitude of bias which may possibly have been introduced into the psychometric data. Evidence has been provided which demonstrates that RA patients who do not wish to take part in an ASMP have as much SE for certain behaviours as those patients who do wish to participate.

The implication is that the effect of ASMP on enhancing SE may be overestimated. While the differences in SE between ASMP experimental and control groups may be statistically significant the clinical significance of the difference requires further elaboration. From the perspective of clinical rheumatology, it is not necessary for RA patients to take the ASMP if the reason for doing so is to enhance SE. It would be advisable to measure an individual patient's SE score for certain behaviors before recommending the ASMP.

5.12 Directions for further research

It would be interesting to measure SE scores on "real" non-participants, that is patients such as those who refused to take part in the present study. By definition, it would be extremely difficult to recruit such patients. However it might be possible to gain an estimate of this group's SE scores by asking that RA patients routinely complete the SE scales at office visits to their rheumatologist. Data gathered on such patients would have utility with respect to the provision of different yet more appropriate arthritis educational interventions tailored to suit the needs of these particular patients with RA.

A qualitative research design might be a fruitful approach in describing RA patients' reasons for not participating in ASMP. Such research would provide a depth of understanding which is not possible to obtain from a quantitative approach. The data obtained might then generate hypotheses for testing in a quantitative design. It would also be interesting to identify the reasons for non-participation in ASMP in those patients who had high SE. Similarly it would be important to describe why the high SE participants wished to take the course. The findings would be helpful in determining what other factors may influence a patient's decision in taking an arthritis education program.

It would be interesting to determine what levels of SE are present in RA patients at different stages in the disease trajectory. It would be useful to relate SE levels with the stage of adjustment the individual is experiencing. For example, the SE levels of newly diagnosed RA patients are not known. It is possible that SE levels are low among newly diagnosed patients. In addition, the low SE levels may be related with the developmental stage of psychological disequilibrium.

It is possible that the only meaningful changes in SE which are *clinically* significant take place following an intervention with this group of patients which facilitates their adjustment from the stage of disequilibrium to adaptation. At present it is known that SE may be changed by certain activities what is unclear is the magnitude of change necessary for meaningful clinical differences.

5.13 Summary

There is increasing popularity of community-based patient education programs such as the ASMP. It is important to encourage patients to learn more about their condition and be knowledgeable consumers of health care. However, it is also important for health care researchers to critically examine the claims and utility of such programs from both a practical and theoretical perspective. The programs have appeal and certainly patients should never be dissauded from increasing their understanding of the chronic conditions that they have to live with on a day to day basis. Investment in such programs should be based on sound research which examines the theoretical and practical contribution that the programs make to patient education.

This study highlights the importance of theoretical work as it relates to SE theory in particular and its application to patient education programs such as the ASMP.

REFERENCES

Anderson, K. O., Dowds, B. N., Pelletz, R. E., Edwards, W. T. & Peeters-Asdourian, C. (1995). Development and initial validation of a scale to measure self-efficacy beliefs in patients with chronic pain. Pain. 63(1), 77-84.

Bandura, A. (1977a). Self-efficacy: Toward a unifying theory of behavioral change. Psychological Review, 84(2), 191-215.

Bandura, A. (1977b). Social Learning Theory. Englewood Cliffs, NJ: Prentice Hall.

Bandura, A. (1978). The self system in reciprocal determinism. American Psychologist, 33(3), 344-358.

Bandura, A. (1982). Self-efficacy mechanism in human agency. American Psychologist. 37(2), 122-147.

Bandura, A. (1986). Social foundations of thought and action: A social cognitive theory. Ch. 7, pp. 283-334. Englewood Cliffs, New Jersey: Prentice Hall Inc.

Bandura, A., Adams, N. E., & Beyer, J. (1977). Cognitive processes mediating behavioral change. Journal of Personality and Social Psychology, 35(1), 125-139.

Bandura, A., Blanchard, E. & Ritter, B. (1969). Relative efficacy of desensitization and modeling approaches for inducing behavioral, affective, and attitudinal changes. Journal of Personality and Social Psychology. 13(3), 173-199.

Bandura, A., & Walters, R. H. (1963). Social learning and personality development. New York: Rinehart & Winston.

Barlow, J. H. & Barefoot, J. (1996). Group education for people with arthritis. Patient Education & Counseling. 27(3), 257-267.

Barlow, J. H., Williams, B. & Wright, C. (1996). The generalized self-efficacy scale in people with arthritis. Arthritis Care & Research. 9(3), 189-196.

Barrera, M. & Ainlay, S L. (1983). The structure of social support: A conceptual and empirical analysis. Journal of Community Psychology. 11(2) 133-143.

Bar-Tal, Y. (1994). Monitoring and blunting and the ability to achieve cognitive structure. Anxiety, Stress & Coping: an International Journal 6(4), 265-274.

Bastani, R., Maxwell, A. E., Carbonari, J., Rozelle, R., Baxter, J. & Vernon, S. (1994). Breast cancer knowledge, attitudes and behaviors: A comparison of rural health and non-health workers. Cancer Epidemiology Biomarkers Prevention. 3(1), 77-84.

Bell, M. J., Lineker, S. C., Wilkins, A. L., Godsmith, C. H. & Badley, E. M. (1998). A randomized controlled trial to evaluate the efficacy of community based physical therapy in the treatment of people with rheumatoid arthritis. Journal of Rheumatology, 25(2), 231-237.

Belcon, M. C., Haynes, R. B., & Tugwell, P. (1984). A critical review of compliance studies in rheumatoid arthritis. Arthritis and Rheumatism, 27(11), 1227-1233.

Bendix, G. & Bjelle, A. (1996). A 10 year follow up of parenteral gold therapy in patients with rheumatoid arthritis. Annals of Rheumatic Diseases, 55,(3), 169-176.

Binik, Y. M. & Devins, G. M. (1986). Transplant failure dos not compromise quality of life in end-stage renal disease.

Blalock, S. J., DeVellis, R. F., Brown, G. K. & Wallston, K. A. (1989). Validity of the Center for Epidemiological Studies Depression Scale in arthritic populations. Arthritis and Rheumatism, 32(8), 991-997.

Bornstein, R. (1986). Cognitive and psychosocial development of older adults. In: C. S. Schuster & S. S. Ashburn (Eds.), The process of human development: A holistic lifespan approach (2nd. ed.). Boston: Little Brown and Company.

Bowling, A. (1991). Measuring health: A review of quality of life measurement scales. Ch. 6 pp.120-148. Philadelphia: Open University Press.

Bradley, L. A. (1989). Adherence with treatment regimens among adult rheumatoid arthritis patients: Current status and future directions. Arthritis Care and Research, 2(3), 533-539.

Bradley, L. A., Young, L. D., Anderson, K. O., McDaniel, L. K., Turner R. A. & Agudelo, C. A. (1984). Psychological approaches to the management of arthritis pain. Social Science and Medicine. 19(12), 1353-1360.

Brant, R. (1994). Personal communication, Faculty of Medicine, University of Calgary.

Buckelew, S. P., Huyser, B., Hewett. J. E., Parker, J. C., Johnson, J. C. Conway, R. & Kay, D. R. (1996). Self-efficacy predicting outcome among fibromyalgia subjects. Arthritis Care & Research. 9(2), 97-104.

Buckelew, S. P., Parker, J. C., Keefe, F. J., Deuser, W. E., crews, T. M., Conway, R., Kay, D. R. & Hewett, J. E. (1994). Pain. 59(3), 377-384.

Burckhardt, C. S., Mannerkorpi, K., Hedenberg, L. & Bjelle, A. (1994). A randomized controlled clinical trial of education and physical training for women with fibromyalgia. Journal of Rheumatology. 21(4), 714-720.

Buescher, K. L., Johnston, J. A., Parker, J. C., Smarr, K. L., Buckelew, S. P., Anderson, S. K. & Walker, S. E. (1991). Relationship of self-efficacy to pain behavior. Journal of Rheumatology. 18(7), 968-972.

Callahan, L. F., Kaplan, M. R. & Pincus, T. (1988). Response patterns of rheumatoid arthritis patients on four widely used depression questionnaires (abstract). Arthritis and Rheumatism, 31, (suppl 4), S76.

Caplan, G. (1974). Support systems and community mental health. New York: Behavioral Publications.

Carpenter, B. N. (1992). Issues and advances in coping research. In: B. N. Carpenter (Ed.). Personal coping: Theory research and application. Westport, Connecticut: Praeger.

Cohen, J. (1988). Statistical power analysis for the behavioral sciences (2nd ed.). New Jersey: Lawrence Erlbaum Associates.

Cohen, J. L., van Houten Souter, S., DeVellis, R. F., & DeVellis, B. M. (1986). Evaluation of arthritis self-management courses led by laypersons and by professionals. Arthritis and Rheumatism, 29(3), 388-393.

Cohen, S., Mermelstein, R., Kamarck, T. & Hoberman, H. (1985). Measuring the functional components of social support. In I. Sarason & B. Sarason (Eds.). Social support: Theory research and applications. pp. 73-94. Dordrecht, Netherlands: Martinus Nijhoff.

Cohen, S. & Syme, S. L. (1985). Social Support and Health. Orlando, Florida: Academic.

Cohen, S. & Willis, T. (1985). Stress, social support, and the buffering hypothesis. Psychological Bulletin, 98(4), 310-357.

Cosentino, F. & Kahn, M. (1967). Further normative and comparative data on the repression-sensitization and social desirability scales. Psychological Reports, 20, 959-962.

Crowne, D. P., & Marlowe, D. (1960). A new scale of social desirability independent of psychopathology. Journal of Consulting Psychology, 24(4), 349-354.

Daltroy, L. H., & Liang, M. H. (1991). Advances in patient education in rheumatic disease. Annals of the Rheumatic Diseases, 415-417.

Daltroy, L. H., & Liang, M. H. (1993). Arthritis education: Opportunities and state of the art. Health Education Quarterly, 20(1), 3-16.

Davis, P., Busch, A. J., Lowe, J. C., Taniguchi, J. & Djkowich, B. (1994). Evaluation of a rheumatoid arthritis patient education program: impact on knowledge and self-efficacy. Patient Education & Counselling, 24(1), 55-61.

Decker, J. L. (1982). Summary. Journal of Rheumatology, 9 (5), 802-806.

Desmeules, M., Huang, J., & Mao, Y. (1993). Projections of deaths and hospitalizations among elderly Canadians. Chronic Diseases in Canada, 14(4), 145-150.

Devins, G. M., Binik, Y. M., Hutchinson, T. A., Hollomby, D. J., Barre, P. E. & Guttman, R.D. (1983). The emotional impact of end-stage renal disease: Importance of patients' perceptions of intrusiveness and control. International Journal of Psychiatry in Medicine, 13(4), 327-343.

Devins, G. M., Edworthy, S. M., Guthrie, N. G. & Martin, L. (1992). Illness intrusiveness in rheumatoid arthritis: Differential impact on depressive symptoms over the adult lifespan. Journal of Rheumatology, 19(5), 709-715.

Devins, G. M., Edworthy, S. M., Seland, T. P., Klein, G. M., Paul, L. C. & Mandin, H. (1993). Differences in illness intrusiveness across rheumatoid arthritis, end-stage renal disease and multiple sclerosis. Journal of Nervous and Mental Disease. 181, 377-381.

Devins, G. M., Edworthy, S. M., Paul, L. C., Mandin, H., Seland, T. P. & Klein, G. M. 1993. Illness intrusiveness and depressive symptoms over the adult years: Is there a differential impact across chronic conditions?. Canadian Journal of Behavioural Science, 25(3) 400-413.

Devins, G. M., Orme, C. M., Costello, C. G., Binik, Y., Frizzell, B., Henderikus, J. S. & Pullin, W. M. (1988). Measuring depressive symptoms in illness populations: Psychometric properties of the Center for Epidemiologic Studies Depression (CES-D) Scale. Psychology and Health, 2, 139-156.

Deyo, R. A. (1982). Compliance with therapeutic regimens in arthritis: Issues, current status, and a future agenda. Seminars in Arthritis and Rheumatism, 12(2), 233-244.

DiFranceisco, W., Kelly, J. A., Sikkema, K. J., Somlai, A. M., Murphy, D. A. & Stevenson, L. Y. (1998). Differences between completers and early dropouts from 2 HIV intervention trials: A health belief approach to understanding prevention program attrition. American Journal of Public Health. 88(7), 1068-1073.

Donovan, J. (1991). Patient education and the consultation: The importance of lay beliefs. Annals of the Rheumatic Diseases, 50(Suppl.3), 418-421.

Donovan, J. L., Blake, D. R., & Fleming, W. G. (1989). The patient is not a blank sheet: Lay beliefs and their relevance to patient education. British Journal of Rheumatology, 28(1), 58-61.

Drew, L. L., Craig, D. M., & Beynon, C. E. (1989). The Neuman systems model for community health administration and practice: Provinces of Manitoba and Ontario, Canada. In B. Neuman (Eds.), The Neuman Systems Model Norwalk: Appleton & Lange.

Drummond, J. & Rickwood, (1997). Childbirth confidence: Validating the childbirth self-efficacy inventory (CBSEI) in an Australian sample. Journal of Advanced Nursing. 26(3), 613-622.

Edworthy, S. (1993). Personal communication, Faculty of Medicine, University of Calgary.

Edworthy, S. (1994). Personal communication, Faculty of Medicine, University of Calgary.

Edworthy, S. (1998). Personal communication, Faculty of Medicine, University of Calgary.

Edworthy, S. M., Devins, G. M. & Watson, M. M. (1995). The arthritis knowledge questionnaire: A test for measuring patient knowledge of arthritis and its self-management. Arthritis & Rheumatism. 38(5), 590-600.

Efran, J. S., Chorney, R. L., Ascher, L. M., & Lukens, M. D. (1989). Coping styles, paradox, and the cold pressor task. Journal of Behavioral Medicine, 12(1), 91-103.

Feinberg, J. (1988). The effect of patient-practitioner interaction on compliance: A review of the literature and application in rheumatoid arthritis. Patient Education and Counselling, 11(3), 171-187.

Ferguson, K., & Bole, G. G. (1979). Family support, health beliefs, and therapeutic compliance in patients with rheumatoid arthritis. Patient Counselling and Health Education, 1(3), 101-105.

Fifield, J., Affleck, G., Reisine, S., Tennen, H., Goodenow, C. & Pfeiffer, C. (1988). Specifying the relationship between social support and adaptation to RA. Paper presented at the Arthritis Health Professionals Association meeting, June 1988, Houston, Texas.

Fisher, G, (1967). Normative and reliability data for the standard and cross-validated Marlowe-Crowne Social Desirability Scale. Psychological Reports, 20, 174.

Frank-Stromborg, M. (1988). Instruments for clinical nursing research. Norwalk: Appleton & Lange

Fries, J. F., Spitz, P. W., & Young, D. Y. (1982). The dimensions of health outcomes: The health assessment questionnaire, disability and pain scales. Journal of Rheumatology, 9(5), 789-793.

Froman, R. D. (1997). Response to "Bandura's theory of self-efficacy: Applications to oncology". Scholarly Inquiry for Nursing Practice. 11(1), 39-43.

Gard, D., Edwards, P. W., Harris, J. & McCormack, G. (1988).Sensitizing effects on pretreatment measures on cancer therapy nausea and vomiting. Journal of Consulting and Clinical Psychology. 56(1), 80-84.

Gecht, M. R., Connell, K. J., Sinacore, J. M. & Prohaska, T. R. (1996), A survey of exercise beliefs and exercise habits among people with arthritis. Arthritis Care and Research, 9(2), 82-88.

Gibson, D., Harvey, A. J., Everett, V. & Parmar, M. K. (1994). Is double data entry necessary? Controlled Clinical Trials 15(6), 482-488.

Gilchrist, L. D. & Schinke, S. P. (1983). Coping with contraception: Cognitive and behavioral methods with adolescents. Cognitive Therapy Research. 7(), 379-388.

Goeppinger, J., Arthur, M. W., Baglioni, A. J., Brunk, S. E., & Brunner, C. M. (1989). A reexamination of the effectiveness of self-care education for persons with arthritis. Arthritis and Rheumatism, 32(6), 706-716.

Goeppinger, J. & Lorig, K. (1997). Interventions to reduce the impact of chronic disease: Community based arthritis patient education. Annual Review of Nursing Research 15 101-122.

Goodenow, C., Reisine, S. T., & Grady, K. E. (1990). Quality of social support and associated social and psychological functioning in women with rheumatoid arthritis. Health Psychology, 9(3), 266-284.

Green, L. W., & Kreuter, M. K. (1991). Health promotion planning: An educational and environmental approach Toronto: Mayfield Publishing Company.

Haynes, R. B. (1979). Introduction. In R. B. Haynes, D. W. Taylor, & D. L. Sackett (Eds.), Compliance in health care Baltimore: Johns Hopkins University Press.

Health of Calgarians (1995). Calgary Health Services: Working together for a healthy tomorrow!. Calgary Regional Health Authority. Author.

Hennekens, C. H. & Buring, J. E. (1987). Epidemiology in medicine. Boston: Little Brown and Company.

Hickey, M. L., Owen, S. V. & Froman, R. D. (1992). Instrument development: cardiac diet and exercise self-efficacy. Nursing Research. 41(6):347-51.

Hill, J., Bird, H. A., Lawton, C. & Wright, V. (1991). The development and use of a patient knowledge questionnaire in rheumatoid arthritis. British Journal of Rheumatology. 30(1), 45-49.

Hill, J., Bird, H. A., Lawton, C. W. & Wright, V. (1990), The arthritis impact measurement scales: An Anglicized version to assess outcome of British patients with rheumatoid arthritis. British Journal of Rheumatology, 29(3), 196-196.

Hiltabiddle, S. J. (1996). Adolescent condom use, the health belief model, and the prevention of sexually transmitted disease. Journal of Obstetric, Gynecologic, & Neonatal Nursing. 25(1), 61-66.

Hochbaum, G. M., Sorenson, J. R., & Lorig, K. (1992). Theory in health education practice. Health Education Quarterly, 19(3), 295-313.

Hull, C. L. (1943). Principles of Behavior. East Norwalk: Appleton & Lange.

Husaini, B. A., Neff, J. A., Harrington, J. B., Hughes, M. D. & Stone, R. H. (1980). Depression in rural communities: Validating the CES-D scale. Journal of Community Psychology. 8(1), 20-27.

Huskisson, E. C. (1974). Measurement of pain. Lancet, 2(7889), 1127-1129.

International Association for the Study of Pain. (1979). Pain terms: A list with notes and usage. Pain 6, 249-252.

Jacobson, D. (1986). Types and timing of social support. Journal of Health and Social Behavior. 27(3), 250-264.

Janz, N. K., & Becker, M. H. (1984). The health belief model: A decade later. Health Education Quarterly, 11(1), 1-47.

Jerusalem, M. & Schwarzer, R. (1992). Self-efficacy as a resource factor in stress appraisal processes. In: R. Schwarzer (Ed.). Self-efficacy: Thought control of action. Washington D. C. : Hemisphere.

Jette, A. M. (1982). Improving patient cooperation with arthritis treatment regimens. Arthritis and Rheumatism, 25(4), 447-453.

Kaye, R. L., & Hammond, A. H. (1978). Understanding rheumatoid arthritis. Journal of the American Medical Association, 239(23), 2466-2467.

Kazis, L. E., Meenan, R. F. & Anderson, J. J. (1983). Pain in the rheumatic diseases. Investigation of a key health status component. Arthritis & Rheumatism, 26(8), 1017-22.

Keefe, F. J., Caldwell, D. S., Baucom, D., Salley, A., Robinson, E., Timmons, K., Beaupre, P., Weisberg, J & Helms, M. (1996). Spouse-assisted coping skills training in the management of osteoarthritic knee pain. Arthritis Care & Research. 9(4), 279-291.

Keefe, F. J., Kashikar-Zuck, S., Robinson, E., Salley, A., Beaupre, P., Caldwell, D., Baucom, D. & Haythornthwaite, J. (1997a).Pain coping strategies that predict patients' and spouses' ratings of patients' self-efficacy. Pain 73(2), 191-199.

Keefe, F. J., Lefebre, J. C., Maixner, W., Salley, A. N. & Caldwell, D. S. (1997b). Self-efficacy for arthritis pain: Relationship to perception of thermal laboratory pain stimuli. Arthritis Care & Research. 10(3), 177-184.

Klug Redman, B. (1993). The process of patient education (7th. ed.). St. Louis: Mosby.

Knudson, K. G., Spiegel, T. M., & Furst, D. E. (1981). Outpatient educational program for rheumatoid arthritis patients. Patient Counselling and Health Education, 3(2), 77-82.

Laborde, J. M., & Powers, M. J. (1983). Evaluation of education interventions for osteoarthritics. Multiple Linear Regression View, 12(1), 12-37.

Laraque, D., McLean, D. E., Brown-Peterside, P., Ashton, D. & Diamond B. (1997). Predictors of reported condom use in central Harlem youth as conceptualized by the health belief model. Journal of Adolescent Health. 21(5), 318-327.

Last, J. M. (Ed.). (1988). A dictionary of epidemiology. (2nd. ed.). Toronto: Oxford University Press.

Lazarus, R. S. & Folkman, S. (1984). Stress, appraisal and coping. New York: Springer Publishing Company.

LeFort, S. M., Gray-Donald, K., Rowat, K. M. & Jeans, M. E. (1998). Randomized controlled trial of a community-based psychoeducation program for the self-management of chronic pain. Pain. 74(2,3), 297-306.

Lenker, S., Lorig, K., & Gallagher, D. (1984). Reasons for the lack of association between changes in health behavior and improved health status: An exploratory study. Patient Education and Counselling, 6(2), 69-72.

Lineker, S. C., Badley, E. M., Hughes, A. & Bell, M. J. (1997). Development of an instrument to measure knowledge in individuals with rheumatoid arthritis: The ACREU rheumatoid arthritis knowledge questionnaire. Journal of Rheumatology. 24(4), 647-653.

Lerman, C., Miller, S. M., Scarborough, R., Hanjani, P., Nolte, S. & Smith, D. (1991). Adverse psychologic consequences of positive cytologic cervical screening. American Journal of Obstetrics & Gynecology, 165, 658-662.

Lev, E. L. (1992). Patients' strategies for adapting to cancer treatment. Western Journal of Nursing Research. 14(5), 596-617.

Lomi, C. (1992). Evaluation of a Swedish version of the Arthritis Self-Efficacy Scale. Scandinavian Journal of Caring Sciences. 6(3):131-138.

Lomi, C., Burckhardt, C., Nordholm, L., Bjelle, A. & Ekdahl, C. (1995). Evaluation of a Swedish version of the arthritis self-efficacy scale in people with fibromyalgia. Scandinavian Journal of Rheumatology. 24(5), 282-287.

Lomi, C. & Nordholm, L. A. (1992). Validation of a Swedish version of the Arthritis Self-efficacy Scale. Scandinavian Journal of Rheumatology. 21(5):231-237.

Lorig, K. R. (1980). Arthritis self-management: A joint venture, a multiple outcome patient education evaluation. Doctoral dissertation. University of California at Berkeley. Ann Arbor: UMI Dissertation Services.

Lorig, K., Chastain, R. L., Ung, E., Shoor, S., & Holman, H. (1989). Development and evaluation of a scale to measure perceived self-efficacy in people with arthritis. Arthritis and Rheumatism, 32(1), 37-44.

Lorig, K., Cox, T., Cuevas, Y., Kraines, R. G., & Britton, M. C. (1984). Converging and diverging beliefs about arthritis: Caucasian patients, Spanish speaking patients and physicians. Journal of Rheumatology, 11(1), 76-79.

Lorig, K., Feigenbaum, P., Regan, C., Ung, E., Chastain, RL. & Holman H. R. (1986). A comparison of lay-taught and professional-taught arthritis self-management courses. Journal of Rheumatology, 13(4), 763-767.

Lorig, K., & Fries, F. J. (1990). The arthritis helpbook: A tested self-management program for coping with your arthritis (3rd ed.). New York: Addison Wesley.

Lorig, K., & Holman, H. (1993). Arthritis self-management studies: A twelve year review. Health Education Quarterly, 20(1), 17-28.

Lorig, K., & Holman, H. R. (1989). Long-term outcomes of an arthritis self-management study: Effects of reinforcement efforts. Social Science and Medicine, 29(2), 221-224.

Lorig, K., Chastain, R. L., Ung, E., Shoor, S. & Holman, H. R. (1989). Development and evaluation of a scale to measure perceived self-efficacy in people with arthritis. Arthritis & Rheumatism. 32(1), 37-44.

Lorig, K., Konkol, L., & Gonzalez, V. (1987). Arthritis patient education: A review of the literature. Patient Education and Counseling, 10(3), 207-252.

Lorig, K., Laurin, J., & Gines, G. E. S. (1984). Arthritis self-management: A five year history of a patient education program. Nursing Clinics of North America, 19(4), 637-645.

Lorig, K. Lubeck, D. & Holman, H. R. (1982). Nonassociation of new behaviors with favorable outcome in effective arthritis health education. Abstract. Arthritis and Rheumatism 25(Suppl.) S148.

Lorig, K., Lubeck, D., Kraines, R. G., Seleznick, M., & Holman, H. R. (1985). Outcomes of self-help education for patients with arthritis. Arthritis and Rheumatism, 28(6), 680-685.

Lorig, K., Mazonson, P. D., & Holman, H. R. (1993). Evidence, suggesting that health education for self management in patients with chronic arthritis has sustained health benefits while reducing health care costs. Arthritis and Rheumatism, 36(4), 439-446.

Lorig, K., Seleznick, M., Lubeck, D., Ung, E., Chastain, R. L., & Holman, H. R. (1989). The beneficial outcomes of the arthritis self-management course are not adequately explained by behavior change. Arthritis and Rheumatism, 32(1), 91-95.

Lorig, K. R. (1980) Arthritis self-management: A joint venture, a multiple outcome patient education evaluation. University of California at Berkeley (Doctoral dissertation).

Lorish, C. D., Parker, J., & Brown, S. (1985). Effective patient education: A quasi-experiment comparing an individualized strategy with a routinized strategy. Arthritis and Rheumatism, 28(11), 1289-1297.

Lowe, N. K. (1993). Maternal confidence for labour: Development of the Childbirth Self-Efficacy Inventory. Research in Nursing & Health. 16(2), 141-149.

Maggs, F. M., Jubb, R. W., & Kemm, J. R. (1996). Single-blind randomized controlled trial of an educational booklet for patients with chronic arthritis. British Journal of Rheumatology. 35(8), 775-777.

Maiman, L. A., & Becker, M. H. (1974). The health belief model: Origins and correlates in psychological theory. Health Education Monographs, 2(4), 336-353.

Mannerkorpi, K. & Ekdahl, C. (1997). Assessment of functional limitation and disability in patients with fibromyalgia. Scandinavian Journal of Rheumatology. 26(1), 4-13.

Masi, A. T., Fecht, T., Aldag, J. C., Malamet, R. L. & Hazes, J. M. W. (1998). Smoking and rheumatoid arthritis: comment on the letter by McDonough and Walker. Arthritis and Rheumatism, 41(1), 184-185.

Mazucca, S. A. (1982). Does patient education in chronic disease have therapeutic value? Journal of Chronic Diseases, 35, 521-529.

McDonough, J. E. & Walker, D. J. (1997). Smoking and rheumatoid arthritis – observations from a multi-case family study: Comment on the article by Silman et al [letter]. Arthritis and Rheumatism. 40(4), 594.

McVeigh, G. E., Lemay, L., Morgan, D. & Cohn, J. N. (1996). Effects of long-term cigarette smoking on endothelium-dependent responses in humans. American Journal of Cardiology, 78(6), 668-72.

Meenan, R. F. (1982). The AIMS approach to health status measurement: Conceptual background and measurement properties. Journal of Rheumatology, 9(5), 785-788.

Meenan, R. F. (1994). Personal communication, School of Medicine, Boston University, Boston, Massachusetts.

Meenan, R. F., Gertman, P. M. & Mason, J. H. (1980), Measuring health status in arthritis: The arthritis impact measurement scales. Arthritis and Rheumatism, 23(2), 146-152.

Miller, S. (1981). Predictability and human stress: Towards a clarification of evidence and theory. In L. Berkowitz (Ed.). Advances in experimental social psychology pp. 203-256. New York: Academic Press.

Miller, S. M. (1987). Monitoring and blunting: Validation of a questionnaire to assess styles of information seeking under threat. Journal of Personality and Social Psychology, 52(2), 345-353.

Miller, S. M. (1992). Monitoring and blunting in the face of threat: Implications for health. In: L. Morrison, S. H. Filip & M. J. Lerner (Eds.). Life Crises and Experiences of Loss in Adulthood. Hillsdale N. J.: Erlbaum.

Miller, T. C. (1998). Personal communication. Executive Director, Arthritis Society, Calgary.

Miller, W., & Dollard, J. (1941). Social Learning and Imitation. New Haven: Yale University Press.

Miller, S. & Grant, R. P. (1979). The blunting hypothesis: A view of predictability and human stress. In P. Sjoden, S. Bates & W. Dockens (Eds.). Trends in behavior therapy. New York: Academic Press.

Miller, S. M., & Mangan, C. E. (1983). Interacting effects of information and coping style in adapting to gynecologic stress: Should the doctor tell all? Journal of Personality and Social Psychology, 45(1), 223-236.

Mischel, W. (1973). Toward a cognitive social learning reconceptualization of personality. Psychological Review, 80(2), 252-283.

Moinpour, C. M., McCorkle, R., & Saunders, J. (1988). Measuring functional status. In M. Frank-Stromborg (Eds.), Instruments for clinical nursing research Norwalk: Appleton & Lange.

Moll, J. H. M., Wright, V., Jeffrey, M. R., Goode, J. D., & Humberstone, P. M. (1977). The cartoon in doctor-patient communication. Annals of the Rheumatic Diseases, 36(3), 225-231.

Muhlenkamp, A. F. & Joyner, J. A. (1985). Arthritis patients' self-reported affective states and their caregivers' perceptions. Nursing Research. 35(1), 24-27.

Mullen, P. D., Laville, E. A., Biddle, A. K., & Lorig, K. (1987). Efficacy of psychoeducational interventions on pain, depression and disability in people with arthritis: A metaanalysis. Journal of Rheumatology. 14(Suppl.15), 33-39.

Murphy, C. A. & Kraft, L. A. (1993). Development and validation of the Perinatal Nursing Self-Efficacy Scale. Scholarly Inquiry for Nursing Practice. 7(2):95-106.

Myers, R. E., Ross, E., Jepson, C., Wolf, T., Balshem, A., Milner, L. & Leventhal, H. (1994). Modeling adherence to colorectal cancer screening. Preventive Medicine. 23(2), 142-151.

Myers, A. M., Weigel, C., & Holliday, P. J. (1989). Sex- and age-linked determinants of physical activity in adulthood. Canadian Journal of Public Health, 80(4), 256-260.

Nederhof, A. J. (1985). Methods of coping with social desirability bias: A review. European Journal of Social Psychology, 15, 263-280.

Neuberger, G. B., Kasal, S., Smith, K. V., Hassanein, R., & DeViney, S. (1994). Determinants of exercise and aerobic fitness in outpatients with arthritis. Nursing Research, 43(1), 11-17.

Neuberger, G. B., Press, A. N., Lindsley, H. B., Hinton, R., Cagle, P. E. Carlson, K., Scott, S., Dahl, J. & Kramer, B. (1997). Effects of exercise on fatigue, aerobic fitness, and disease activity measures in persons with rheumatoid arthritis. Research in Nursing & Health. 20(3),195-204.

Oermann, M. H., Doyle, T. H., Clark, L. R., Rivers, C. L., & Rose, V. Y. (1986). Effectiveness of self-instruction for arthritis patient education. Patient Education and Counseling, 8(3), 245-254.

O'Gorman, J. G. (1974). Limits to the generality of the Marlowe-Crowne measure of social desirability. Journal of Clinical Psychology, 30(1), 81.

Parker, J. C., Singsen, B. H., Hewett, J. E., Walker, S. E., Hazelwood, S. E., Hall, P. J., Holsten, D. J., & Rodon, C. M. (1984). Educating patients with rheumatoid arthritis: A prospective analysis. Archives of Physical Medicine and Rehabilitation, 65, 771-774.

Parker, J. C., Smarr, K. L., Buckelew, S. P., Stucky-Ropp, R. C., Hewitt, J. E., Johnson, J. C., Wright, G. E., Irvin, W. S. & Walker, S. E. (1995). Effects of stress management on clinical outcomes in rheumatoid arthritis. Arthritis & Rheumatism. 38(12), 1807-1818.

Pechachek, T. G. F. & Danaher, B.G. (1979). How and why people quit smoking: A cognitive behavioral analysis. In: P. C. Kendall & S. D. Hollow (Eds.). Cognitive-Behavioral interventions: Theory, research and procedures. New York: Academic Press.

Perry, C. L., Baranowski, T., & Parcel, G. S. (1990). How individuals, environments and health behavior interact: Social learning theory. In K. Glanz, F. M. Lewis, & B. K. Rimer (Eds.), Health behavior and health education San Francisco: Jossey-Bass Publishers.

Peterson, M. G. E., Horton, R., Engelhard, E., Lockshin, M. D. & Abramson, T. (1993). Effect of counselor training on skills development and psychosocial status of volunteers with systemic lupus erythematosus. Arthritis Care & Research. 6(1), 38-44.

Pincus, T. (1988). Is mortality increased in rheumatoid arthritis? The Journal of Musculoskeletal Medicine, 5(6), 27-46.

Pincus, T., & Callahan, L. F. (1993). Depression scales in rheumatoid arthritis: Criterion contamination in interpretation of patient responses. Patient Education and Counseling, 20(2/3), 133-143.

Pincus, T., Callahan, L. F., Sale, W. G., Brooks, A. L., Payne, L. E., & Vaughn, W. K. (1984). Severe functional declines, work disability, and increased mortality in seventy-five rheumatoid arthritis patients studied over nine years. Arthritis and Rheumatism, 27(8), 864-872.

Pring, J. (1993). Director of Education, Arthritis Society, Calgary, Personal communication.

Prochaska, J. O. & DiClemente, C. C. (1984). Self change processes, self-efficacy and decisional balance across five stages of smoking cessation. In: R. A. Liss (Ed.). Advances in cancer control: Epidemiology and research. New York: Alan R. Liss Inc.

Radloff, L. (1977). The CES-D scale: A self-report depression scale for research in the general population. Applied Psychological Measurement, 1, 385-401.

Rankin, J. A. (1992). An evaluability assessment of the Arthritis Self-Management Program (ASMP) Unpublished paper, MDSC 659.01 Health Program Planning & Evaluation, Department of Community Health Sciences Doctoral Program, University of Calgary, Calgary, Alberta.

Rasker, J. J. & Cosh, J. A. (1987). The natural history of rheumatoid arthritis over 20 years. Clinical symptoms, radiological signs, treatment, mortality and prognostic significance of early features. Clinical Rheumatology, 6 (Suppl. 2), 5-11.

Reynolds-Haertle, R. A. & McBride, R. (1992). Single vs double data entry in CAST. Controlled Clinical Trials, 13, 487-494.

Riemsma, R. P., Klein, G., Taal, E., Rasker, J. J., Houtman, P. M., van Passen, H. C. & Wiegman, O. (1998). The supply of and demand for informal and professional care for patients with rheumatoid arthritis. Scandinavian Journal of Rheumatology, 27(1), 7-15.

Riemsma, R. P., Taal, E., Brus, H. L. M., Rasker, J. J. & Wiegman, O. (1997). Coordinated individual education with an arthritis passport for patients with rheumatoid arthritis. Arthritis Care & Research, 10(4), 238-249.

Rimer, B. K. (1990). Perspectives on intrapersonal theories in health education and health behavior. In K. Glanz, F. M. Lewis, & B. K. Rimer (Eds.), Health behavior and health education: Theory research and practice San Francisco: Jossey-Bass Inc.

Robertson, S. E. (1992). Counselling adults with physical disabilities: A transitions perspective. In: S. E. Robertson & R. I. Brown (Eds.), Rehabilitation counselling: Approaches in the field of disability. London: Chapman & Hall.

Robinson, J. (1986). Retirement. In: C. S. Schuster & S. S. Ashburn (Eds.), The process of human development: A holistic lifespan approach (2nd. ed.). Boston: Little Brown and Company.

Rosenstock, I. M. (1974). Historical origins of the health belief model. Health Education Monographs, 2(4), 328-335.

Rosenstock, I. M. (1990). The health belief model: Explaining health behavior through expectancies. In K. Glanz, F. M. Lewis, & B. K. Rimer (Eds.), Health behavior and health education San Francisco: Jossey-Bass Publishers.

Rosenstock, I. M., Strecher, V. J., & Becker, M. H. (1988). Social learning theory and the health belief model. Health Education Quarterly, 15(2), 175-183.

Rothman, K. J. (1986). Modern Epidemiology. Boston: Little Brown and Co.

Rotter, J. B. (1966). Generalized expectancies for internal versus external control of reinforcement. Psychological Monographs. 80(1), 1-28.

Samuelsson, A., Ahlmen, M., & Sullivan, M. (1993). The rheumatic patient's early needs and expectations. Patient Education and Counseling, 20(2/3), 77-91.

Sarason, B. R., Shearin, E. N., Pierce, G. R. & Sarason, I. G. (1987). Interrelations of social support measures: Theoretical and practical implications. Journal of Personality & Social Psychology, 52(4) 813-832.

Sarason, I., Levine, H., Basham, R. & Sarason, B. (1983). Assessing social support: Theoretical and practical implications. Journal of Personality and Social Psychology, 52(6), 813-883.

Schlossberg, N. K. (1984). Counselling adults in transition: Linking practice with theory. New York: Springer Publishing Company.

Schumacher, H. R. (Ed.). (1988). Primer on the rheumatic diseases. 9th. ed. Atlanta, GA: Arthritis Foundation.

Selby, M. J. (1984). Assessment of violence potential using measures of anger, hostility, and social desirability. Journal of Personality Assessment, 48(5), 531-544.

Shearn, M. A., & Fireman, B. H. (1985). Stress management and mutual support groups in rheumatoid arthritis. American Journal of Medicine, 78(5), 771-775.

Shrout, P. E. Fleiss, J. L. (1979). Intraclass correlations: Uses in assessing rater reliability. Psychological Bulletin, 86(2), 420-428.

Silman, A. J., Newman, J. & MacGregor, A. J. (1996). Cigarette smoking increases the risk of rheumatoid arthritis. Results from a nationwide study of disease-discordant twins. Arthritis and Rheumatism, 39(5), 732-735.

Singh, G., Fries, J. F., Williams, C. A., Zatarain, E., Spitz, P., & Bloch, D. A. (1991). Toxicity profiles of disease modifying antirheumatic drugs in rheumatoid arthritis. Journal of Rheumatology, 18(2), 188-194.

Simeoni, E., Bauman, A., Stenmark, J. & O'Brien, J. (1995). Evaluation of a community arthritis program in Australia: Dissemination of a developed program. Arthritis Care & Research, 8(2), 102-107.

Skinner, B. F. (1953). Science and human behavior. New York: Macmillan.

Spiegel, T. M., Knutzen, K. L., & Spiegel, J. S. (1987). Evaluation of an in patient rheumatoid arthritis patient education program. Clinical Rheumatology, 6(3), 412-416.

Spiegel, J. L., Leake, B., Spiegel, T. M., Paulus, H. E., Kane, R. L., Ward, N. B. & Ware, J. E. (1988). What are we measuring?: An examination of self-reported functional status measures. Arthritis and Rheumatism, 31(6), 721-728.

Steinbrocker, O., Traeger, C. H., & Batterman, R. C. (1949). Therapeutic criteria in rheumatoid arthritis. Journal of the American Medical Association, 140(8), 659-662.

Stenstrom, C. H. (1994). Home exercise in rheumatoid arthritis functional class II: Goal setting versus pain attention. Journal of Rheumatology, 21(4), 627-634.

Strecher, V. J., McEvoy, B., Becker, M. H., & Rosenstock, I. M. (1986). The role of self-efficacy in achieving behavior change. Health Education Quarterly, 13(1), 73-91.

Streiner, D. L.& Norman, G. R. (1989). Health measurement scales: A practical guide to their development and use. Ch.6, pp. 54-66. Oxford: Oxford Medical Publications.

Stross, J. K., & Mikkelsen, W. M. (1977). Educating patients with osteoarthritis. Journal of Rheumatology, 4(3), 313-316.

Syrjala, K. L. & Chapko, M. E. (1995). Evidence for a biopsychosocial model of cancer treatment-related pain. Pain, 61(1), 69-79.

Taal, E., Rasker, J. J., Seydel, E. R., & Wiegman, O. (1993a). Health status, adherence with health recommendations, self-efficacy and social support in patients with rheumatoid arthritis. Patient Education and Counseling, 20(2/3), 63-75.

Taal, E., Riemsma, R. P., Brus, H. L. M., Seydel, E. R., Rasker, J. J., & Wiegman, O. (1993b). Group education for patients with rheumatoid arthritis. Patient Education and Counseling, 20(2/3), 177-187.

Taal, E., Rasker, J. J. & Wiegman, O. (1996). Patient education and self-management in the rheumatic diseases: A self-efficacy approach. Arthritis Care & Research, 9(3), 229-238.

Taylor, S. E. (1983). Adjustment to threatening events: A theory of cognitive adaptation. American Psychologist, 38(11), 1161-1173.

Valentine, L. R. (1970). Self-care through group learning. American Journal of Nursing, 70, 2140-2142.

Vignos, P. J., Parker, W. T., & Thompson, H. M. (1976). Evaluation of a clinic education program for patients with rheumatoid arthritis. Journal of Rheumatology, 3(2), 155-165.

Wetstone, S. L., Sheehan, T. J., Votaw, R. G., Peterson, M. G., & Rothfield, N. (1985). Evaluation of a computer based education lesson for patients with rheumatoid arthritis. Journal of Rheumatology, 12(5), 907-912.

Wolfe, F., Hawley, D. J., & Cathey, M. A. (1990). Termination of slow acting antirheumatic therapy in rheumatoid arthritis: A 14-year prospective evaluation of 1017 consecutive starts. Journal of Rheumatology, 17(8), 994-1002.

Wohl, R. E. & Kane, W. M. (1997). Teachers' beliefs concerning teaching about testicular cancer and testicular self-examination. Journal of School Health, 67(3), 106-111.

Zavela, K. J., Davis, L. G., Cotrell, R. R., & Smith, W. E. (1988). Do only the healthy intend to participate in worksite health promotion? Health Education Quarterly, 15(3), 259-269.

Zvaifler, N. J. (1989). Etiology and pathogenesis of rheumatoid arthritis. In: D. J. McCarty & W. J. Koopman (eds.). Arthritis and allied conditions (11th. ed.). (pp. 659-673). Philadelphia: Lea & Febiger.

Appendix A – Arthritis Self-Efficacy Scale

I.D.# ____________________ Date:____________________

We would like to know how confident you are in participating in certain aspects of your daily living.

For each of the following questions, please mark on the scale at the right to correspond with your certainty that you can **at the present time, perform tasks without assistive devices or help from another person.**

Please consider what you **routinely** can do, not what would require a single extraordinary effort.

Here is an example of the way someone might answer the question:

How certain are you that you can dial a telephone in 10 seconds:

0...10...20...30...40...50...60...70...80...90...100%

This shows uncertainty that the telephone could be dialed in 10 seconds.

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

As of NOW, how certain are you that you can:

		Very Uncertain ... Very Certain
1.	Walk 100 feet on flat ground in 20 seconds	0...10...20...30...40...50...60...70...80...90...100%
2.	Get out of an armless chair quickly	0...10...20...30...40...50...60...70...80...90...100%
3.	Do, then undo, 3 medium buttons in 12 seconds	0...10...20...30...40...50...60...70...80...90...100%
4.	Cut two bite-sized pieces of meat in 8 seconds	0...10...20...30...40...50...60...70...80...90...100%
5.	Turn an outdoor faucet fully on then fully off	0...10...20...30...40...50...60...70...80...90...100%
6.	Without an aid or other help get out of a car	0...10...20...30...40...50...60...70...80...90...100%
7.	Walk 10 steps downstairs in 7 seconds	0...10...20...30...40...50...60...70...80...90...100%
8.	Scratch your upper back with your right and left hands.	0...10...20...30...40...50...60...70...80...90...100%
9.	Put on a long sleeve front-opening shirt or blouse (without buttoning) in 8 seconds.	0...10...20...30...40...50...60...70...80...90...100%
10.	Decrease your pain quite a bit	0...10...20...30...40...50...60...70...80...90...100%

Appendix A – Arthritis Self-Efficacy Scale

I.D.#________________ Date:________________

As of NOW, how certain are you that you can:

		Very Uncertain	Very Certain
11.	Do most of your daily activities without extra effort	0...10...20...30...40...50...60...70...80...90...100%	
12.	Keep arthritis pain from interfering with your sleep	0...10...20...30...40...50...60...70...80...90...100%	
13.	Make a <u>small-to-moderate</u> reduction in your arthritis pain by using methods other than taking extra medication	0...10...20...30...40...50...60...70...80...90...100%	
14.	Make a <u>large</u> reduction in your arthritis pain by using methods other than extra medication	0...10...20...30...40...50...60...70...80...90...100%	
15.	Control your fatigue	0...10...20...30...40...50...60...70...80...90...100%	
16.	Regulate your activity so as to be active without aggravating your arthritis	0...10...20...30...40...50...60...70...80...90...100%	
17.	Help yourself if you are feeling "blue"	0...10...20...30...40...50...60...70...80...90...100%	
18.	Deal with the frustration of arthritis	0...10...20...30...40...50...60...70...80...90...100%	
19.	Manage your arthritis symptoms so that you can do things you enjoy doing	0...10...20...30...40...50...60...70...80...90...100%	
20.	As compared with other people with arthritis like yours. How certain are you that you can manage arthritis pain during your daily activities	0...10...20...30...40...50...60...70...80...90...100%	

SES

Appendix B Knowledge Test

I.D.#__________________ Date:__________________

Please read the following questions carefully.
Please circle the **ONE** response you feel is the **MOST** correct answer.
If you do not know the answer, circle number 5 (Please do **NOT** guess).

1. Rheumatoid arthritis is the result of :

   A. wear and tear on the body

   B. the aging process

   C. too much or too little of some kind of food

   D. a disorder of the immune system

   E. don't know

2. The most important goal of physicians caring for people with arthritis is:

   A. to keep or improve the present level of functioning

   B. to do everything they can to cure the person

   C. to give patients enough medications to stand pain

   D. to keep patients quiet and uncomplaining

   E. don't know

3. Anti-inflammatory drugs:

   A. reduce symptoms of arthritis

   B. slow down the progress of arthritis

   C. cure arthritis

   D. make arthritis worse

   E. don't know

4. Muscles operate by:

   A. pulling on where they attach to bones

   B. getting hard

   C. pulling on the tendons

   D. filling with blood

   E. don't know

5. The best type of heat to use for arthritic pain is:

   A. a hot bath

   B. a sauna

   C. a hot pad

   D. all types are about the same

   E. don't know

6. The most common abnormality of an articular joint is:

   A. osteoarthritis

   B. synovitis

   C. rheumatoid arthritis

   D. inflammation

   E. don't know

7. Pain is one of the biggest problems in arthritis. This can:

   A. never be completely controlled

   B. only be controlled with some type of medication

   C. be controlled by very few people using a combination of medication and other methods.

   D. be controlled by most people using a combination of medication and other methods.

   E. don't know

8. Aspirin is an:
    - A. antimalarial medication
    - B. anti-inflammatory mediation
    - C. immunosuppressant
    - D. anxiolytic medication
    - E. don't know

9. Prednisone:
    - A. can stop the progress of arthritis
    - B. is a steroid like the ones athletes use
    - C. helps reduce inflammation in arthritis
    - D. is a very safe drug with few side effects
    - E. don't know

10. The term "analgesic" refers to:
    - A. pain reducing properties
    - B. sodium retention
    - C. antacid like compounds
    - D. a surgical procedure
    - E. don't know

Appendix C Miller Behavioral Style Scale

I.D#__________________ Date:__________________

Please read each of the four scenarios and respond to each one as requested.

1. Vividly imagine that you are afraid of the dentist and have to get some dental work done. Which of the following would you do?
Check all of the statements that might apply to you.

___ I would ask the dentist exactly what he was going to do.

___ I would take a tranquilizer or have a drink before going.

___ I would try to think about pleasant memories.

___ I would want the dentist to tell me when I would feel pain.

___ I would try to sleep.

___ I would watch all the dentist's movements and listen for the sound of his drill.

___ I would watch the flow of water from my mouth to see if it contained blood.

___ I would do mental puzzles in my mind.

2. Vividly imagine that you are being held hostage by a group of armed terrorists in a public building. Which of the following would you do?
Check all the statements that might apply to you.

___ I would sit by myself and have as many daydreams and fantasies as I could.

___ I would stay alert and try to keep myself from falling asleep.

___ I would exchange life stories with the other hostages.

___ If there was a radio present, I would stay near it and listen to bulletins about what the police were doing.

___ I would watch every movement of my captors and keep an eye on their weapons.

___ I would try to sleep as much as possible.

___ I would think about how nice it's going to be when I get home.

___ I would make sure I knew where every possible exit was.

Appendix C Miller Behavioral Style Scale

3. Vividly imagine that due to a large drop in sales, it is rumored that several people in your department at work will be laid off. Your supervisor has turned in an evaluation of your work for the past year. The decision about layoffs has been made and will be announced in several days. Check all of the statements that might apply to you.

__ I would talk to my fellow workers to see if they knew anything about what the supervisor's evaluation of me said.

__ I would review the list of duties for my present job and try to figure out if I had fulfilled them all.

__ I would go the movies and take my mind off things.

__ I would try to remember any arguments or disagreements I might have had with the supervisor that would have lowered his opinion of me.

__ I would push all thoughts of being laid off out of my mind.

__ I would tall my spouse that I'd rather not discuss my changes of being laid off.

__ I would try to think which employees in my department the supervisor might have thought has done the worse job.

__ I would continue doing my work as if nothing special was happening.

4. Vividly imagine that you are on an airplane, thirty minutes from your destination, when the plane unexpectedly goes into a deep dive and then suddenly levels off. After a short time, the pilot announces that nothing is wrong, although the rest of the ride may be rough. You, however, are not convinced that all is well.
Check all the statements that might apply to you.

__ I would carefully read the information provided about safety features in the plane and make sure I knew where the emergency exits were.

__ I would make small talk with the passenger beside me.

__ I would watch the end of the movie, even if I had seen it before.

__ I would call for the stewardess and ask her exactly what the problem was.

__ I would order a drink or tranquillizer from the stewardess.

__ I would listen carefully to the engines for unusual noises and would watch the crew to see if their behavior was out of the ordinary.

__ I would talk to the passenger beside me about what might be wrong.

__ I would settle down and read a book or a magazine or write a letter.

Appendix D Quality of Social Support Scale

For each of the following statements indicate whether the statement is **never true, sometimes true, mostly or usually true, or always true.**

1. There is someone who will take over my tasks or chores when I feel sick.
never sometimes usually always
2. There are people with whom I can expect to have unpleasant disagreements, people who make me angry or upset.
never sometimes usually always
3. The important people in my life accept me as I am, including both my worst and best points.
never sometimes usually always
4. There is someone who will give me a hug or hold me in their arms when I need comforting.
never sometimes usually always
5. It's hard to find someone who can give me objective feedback on how I'm handling problems.
never sometimes usually always
6. There is someone whose advice I really trust.
never sometimes usually always
7. I can count on someone to listen to my innermost feelings, even when I'm angry at someone or depressed about something.
never sometimes usually always
8. Some of my friends or relatives are hard to get along with and seem more trouble than they're worth.
never sometimes usually always
9. The people I am closest to are willing to use their skills and abilities to help me out in my everyday life.
never sometimes usually always
10. The people I am close to treat me like a worthwhile person and make me feel I have something positive to contribute.
never sometimes usually always
11. When I need good information on how to get things done, I know I can get it.
never sometimes usually always
12. I find it hard to be the sort of person I'd like to be when I'm around relatives or friends.
never sometimes usually always
13. The people I'm close to are physically affectionate toward me.
never sometimes usually always
14. Someone would loan me money or loan me something else of value if I needed it.
never sometimes usually always
15. No one will really listen when I need to talk about personal problems.
never sometimes usually always
16. I can find someone to take me somewhere or run an errand for me if I need to.
never sometimes usually always
17. It is easy to talk to my friends and relatives about things going on in my life.
never sometimes usually always

Appendix E Arthritis Impact Measurement Scale version 2

ID # ________________   Date:________________

Arthritis Impact Measurement Scales 2
(AIMS2)

Thank you for agreeing to take part in this study, the information you provide is very important to us.

Instructions:

Please answer the questions on the next page about your health.

Most of the questions ask about your health **during the past month.**

There are no **right** or **wrong** answers to the questions.

Most of the questions can be answered with a simple check mark
(for example: X).

Please answer every question.

Appendix E Arthritis Impact Measurement Scale version 2

ID ________
Adm #________
Card #1

ARTHRITIS IMPACT MEASUREMENT SCALES 2

(AIMS2)

Instructions: Please answer the following questions about your health. Most questions ask about your health during the past month. There are no right or wrong answers to the questions and most can be answered with a simple check (X). Please answer every question.

Please begin by providing the following information about yourself.

NAME: ________________________________

ADDRESS: ________________________________
Number Street Apt#
____
City State Zip

PHONE: (______)__________
Area Code Number

TODAY'S DATE: ____________________
Month Day Year

Appendix E Arthritis Impact Measurement Scale version 2

Please check (X) the most appropriate answer for each question. AIMS

These questions refer to **MOBILITY LEVEL.**

DURING THE PAST MONTH..		**All Days** (1)	**Most Days** (2)	**Some Days** (3)	**Few Days** (4)	**No Days** (5)
1.	How often were you physically able to drive a car or use public transportation?	___	___	___	___	___
2.	How often were you out of the house for at least part of the day?	___	___	___	___	___
3.	How often were you able to do errands in the neighborhood?	___	___	___	___	___
4.	How often did someone have to assist you to get around outside your home?	___	___	___	___	___
5.	How often were you in a bed or chair for most or all of the day?	___	___	___	___	___

……

These questions refer to **WALKING AND BENDING.** AIMS

DURING THE PAST MONTH..		**All Days** (1)	**Most Days** (2)	**Some Days** (3)	**Few Days** (4)	**No Days** (5)
6.	Did you have trouble doing vigorous activities such as running, lifting heavy objects or participating in strenuous sports?	___	___	___	___	___
7.	Did you have trouble either walking several blocks or climbing a few flights of stairs?	___	___	___	___	___
8.	Did you have trouble bending, lifting or stooping?	___	___	___	___	___
9.	Did you have trouble either walking one block or climbing one flight of stairs?	___	___	___	___	___
10.	Were you unable to walk unless assisted by another person or by a cane, crutches, or walker?	___	___	___	___	___

Please check (X) the most appropriate answer for each question. AIMS

Appendix E Arthritis Impact Measurement Scale version 2

These questions refer to **HAND AND FINGER FUNCTION.**

DURING THE PAST MONTH:		**All Days (1)**	**Most Days (2)**	**Some Days (3)**	**Few Days (4)**	**No Days (5)**
11.	Could you easily write with a pen or pencil?	___	___	___	___	___
12.	Could you easily button a shirt or blouse?	___	___	___	___	___
13.	Could you easily turn a key in a lock?	___	___	___	___	___
14.	Could you easily tie a knot or a bow?	___	___	___	___	___
15.	Could you easily open a new jar of food?	___	___	___	___	___

……

These questions refer to **ARM FUNCTION**

DURING THE PAST MONTH:		**All Days (1)**	**Most Days (2)**	**Some Days (3)**	**Few Days (4)**	**No Days (5)**
16.	Could you easily wipe your mouth with a napkin?	___	___	___	___	___
17.	Could you easily put on a pullover sweater?	___	___	___	___	___
18.	Could you easily comb or brush your hair?	___	___	___	___	___
19.	Could you easily scratch your low back with your hand?	___	___	___	___	___
20.	Could you easily reach shelves that were above your head?	___	___	___	___	___

Appendix E Arthritis Impact Measurement Scale version 2

Please check (X) the most appropriate answer for each question.

AIMS

These questions refer to **SELF-CARE TASKS..**

DURING THE PAST MONTH..		**Always (1)**	**Very Often (2)**	**Sometimes (3)**	**Almost Never (4)**	**Never (5)**
21.	Did you need help to take a bath or shower?	___	___	___	___	___
22.	Did you need help to get dressed?	___	___	___	___	___
23.	Did you need help to use the toilet?	___	___	___	___	___
24.	Did you need help to get in or out of bed?	___	___	___	___	___

……

These questions refer to **HOUSEHOLD TASKS.**

AIMS

DURING THE PAST MONTH..		**Always (1)**	**Very Often (2)**	**Sometimes (3)**	**Almost Never (4)**	**Never (5)**
25.	If you had the necessary transportation, could you go shopping for groceries without help?	___	___	___	___	___
26.	If you had kitchen facilities, could prepare your own meals without help?	___	___	___	___	___
27.	If you had household tools and appliances, could you do your own housework without help?	___	___	___	___	___
28.	If you had laundry facilities, could you do your own laundry without help?	___	___	___	___	___

Appendix E Arthritis Impact Measurement Scale version 2

Please check (X) the most appropriate answer for each question. AIMS

These questions refer to **ARTHRITIS PAIN.**

DURING THE PAST MONTH...	**Severe (1)**	**Moderate (2)**	**Mild (3)**	**Very Mild (4)**	**None (5)**
38. How would you describe the arthritis pain you usually had?	___	___	___	___	___

	Always (1)	**Very Often (2)**	**Sometimes (3)**	**Almost Never (4)**	**Never (5)**
39. How often did you have severe pain from your arthritis?	___	___	___	___	___
40. How often did you have pain in two or more joints at the same time?	___	___	___	___	___
41. How often did your morning stiffness last more than one hour from the time you woke up?	___	___	___	___	___
42. How often did your pain make it difficult for you to sleep?	___	___	___	___	___

Please check (X) the most appropriate answer for each question. AIMS

These questions refer to **LEVEL OF TENSION.**

DURING THE PAST MONTH:	**Always (1)**	**Very Often (2)**	**Sometimes (3)**	**Almost Never (4)**	**Never (5)**
48. How often have you felt tense or high strung?	___	___	___	___	___
49. How often have you been bothered by nervousness or your nerves?	___	___	___	___	___
50. How often were you able to relax without difficulty?	___	___	___	___	___
51. How often have you felt relaxed and free of tension?	___	___	___	___	___
52. How often have you felt calm and peaceful?	___	___	___	___	___

Appendix E Arthritis Impact Measurement Scale version 2

Please check (X) the most appropriate answer for each question.

These questions refer to **MOOD**

DURING THE PAST MONTH...	**Always** (1)	**Very Often** (2)	**Sometimes** (3)	**Almost Never** (4)	**Never** (5)
53. How often have you enjoyed the things you do?	___	___	___	___	___
54. How often have you been in low or very low spirits?	___	___	___	___	___
55. How often did you feel that nothing turned out the way you wanted it to?	___	___	___	___	___
56. How often did you feel that others would be better off if you were dead?	___	___	___	___	___
57. How often did you feel so down in the dumps that nothing would cheer you up?	___	___	___	___	___

……

73. HOUSEHOLD INCOME

What is your best estimate of the total household income for last year before taxes and deductions? (Check one)

Less than $5,000 ____

$5,000 - $9,999 ____

$10,000 - $19,999 ____

$20,000- $29,999____

$30,000 - $39,999 ____

$40,000 - $49,999 ____

$50,000 - $59,999 ____

AIMS2

$60,000 - $69,999 ____

$70,000 - $79,999 ____

More than $80,000 ____

Appendix F Illness Intrusiveness Ratings Scale

INSTRUCTIONS: The following items ask about how much your illness and/or its treatment interfere with different aspects of your life.

PLEASE CIRCLE THE ONE NUMBER THAT BEST DESCRIBES YOUR CURRENT LIFE SITUATION.

If an item is not applicable, please circle the number one (1) to indicate that this aspect of your life is not affected very much. Please do not leave any item unanswered. Thank you.

Here is an example:

How much does your illness and/or its treatment interfere with your **TRAVEL?**

NOT VERY MUCH 1 2 3 4 5 6 7 VERY MUCH

……

Start here:

How much does your illness and/or its treatment interfere with your **HEALTH** (i.e. how well you feel physically)?

NOT VERY MUCH 1 2 3 4 5 6 7 VERY MUCH

How much does your illness and/or its treatment interfere with your **DIET** (i.e. the things you eat and drink)?

NOT VERY MUCH 1 2 3 4 5 6 7 VERY MUCH

How much does your illness and/or its treatment interfere with your **WORK?**

NOT VERY MUCH 1 2 3 4 5 6 7 VERY MUCH

How much does your illness and/or its treatment interfere with your **ACTIVE RECREATION** (e.g. sports)?

NOT VERY MUCH 1 2 3 4 5 6 7 VERY MUCH

Appendix F Illness Intrusiveness Ratings Scale

How much does your illness and/or its treatment interfere with your **PASSIVE RECREATION?**
(e.g. reading, listening to music)?

NOT VERY MUCH 1 2 3 4 5 6 7 VERY MUCH

How much does your illness and/or its treatment interfere with your **FINANCIAL SITUATION?**

NOT VERY MUCH 1 2 3 4 5 6 7 VERY MUCH

How much does your illness and/or its treatment interfere with your **SEX LIFE?**

NOT VERY MUCH 1 2 3 4 5 6 7 VERY MUCH

How much does your illness and/or its treatment interfere with your **RELATIONSHIP WITH YOUR SPOUSE** (or with your girlfriend or boyfriend, if you are not married)?

NOT VERY MUCH 1 2 3 4 5 6 7 VERY MUCH

How much does your illness and/or its treatment interfere with your **FAMILY RELATIONS?**

NOT VERY MUCH 1 2 3 4 5 6 7 VERY MUCH

How much does your illness and/or its treatment interfere with your **OTHER SOCIAL RELATIONS?**

NOT VERY MUCH 1 2 3 4 5 6 7 VERY MUCH

Appendix F Illness Intrusiveness Ratings Scale

How much does your illness and/or its treatment interfere with your **SELF-EXPRESSION/SELF-IMPROVEMENT?**

NOT VERY MUCH 1 2 3 4 5 6 7 VERY MUCH

How much does your illness and/or its treatment interfere with your **RELIGIOUS EXPRESSION?**

NOT VERY MUCH 1 2 3 4 5 6 7 VERY MUCH

How much does your illness and/or its treatment interfere with your **COMMUNITY AND CIVIC INVOLVEMENT?**

NOT VERY MUCH 1 2 3 4 5 6 7 VERY MUCH

Appendix G Center for Epidemiological Studies Depression Scale

Instructions:

Circle the number for each of the statements which best describes how often you felt or behaved this way - **DURING THE PAST WEEK.**

DURING THE PAST WEEK:	Rarely or none of the time (less than once a day)	Some or a little of the time (1- 2 days)	Occasionally or a moderate amount of time (3 - 4 days)	Most or all of the time (5 - 7 days)
1. I was bothered by things that don't usually bother me	0	1	2	3
2. I did not feel like eating my appetite was poor	0	1	2	3
3. I felt that I could not shake off the blues even with help from family or friends	0	1	2	3
4. I felt that I was just as good as other people	0	1	2	3
5. I had trouble keeping my mind on what I was doing	0	1	2	3
6. I felt depressed	0	1	2	3
7. I felt that everything I did was an effort	0	1	2	3
8. I felt hopeful about the future	0	1	2	3
9. I thought my life had been a failure	0	1	2	3
10. I felt fearful	0	1	2	3
11. My sleep was restless	0	1	2	3
12. I was happy	0	1	2	3
13. I talked less than usual	0	1	2	3
14. I felt lonely	0	1	2	3
15. People were unfriendly	0	1	2	3
16. I enjoyed life	0	1	2	3
17. I had crying spells	0	1	2	3
18. I felt sad	0	1	2	3
19. I felt that people disliked me	0	1	2	3
20. I could not get "going"	0	1	2	3

Appendix H Marlowe-Crowne Social Desirability Scale

I.D.#________________ Date:__________________

Instructions: Read each of the following statements and indicate whether they are true or false by circling the word.

1. Before voting I thoroughly investigate the qualifications of all the candidates. true false
2. I never hesitate to go out of my way to help someone in trouble. true false
3. It is sometimes hard for me to go on with my work if I am not encouraged. true false
4. I have never intensely disliked anyone. true false
5. On occasion I have had doubts about my ability to succeed in life. true false
6. I sometimes feel resentful when I don't get my way. true false
7. I am always careful about my manner of dress. true false
8. My table manners at home are as good as when I eat out in a restaurant. true false
9. If I could get into a movie without paying and be sure I was not seen I would probably do it. true false
10. On a few occasions, I have given up doing something because I thought too little of my ability. true false
11. I like to gossip at times. true false
12. There have been times when I felt like rebelling against people in authority even though I knew they were right. true false
13. No matter who I'm talking to, I'm always a good listener. true false
14. I can remember "playing sick" to get out of something. true false
15. There have been occasions when I took advantage of someone. true false
16. I'm always willing to admit it when I make a mistake. true false
17. I always try to practice what I preach. true false
18. I don't find it particularly difficult to get along with loud mouthed, obnoxious people. true false
19. I sometimes try to get even rather than forgive and forget. true false
20. When I don't know something I don't at all mind admitting it. true false

Appendix H Marlowe-Crowne Social Desirability Scale

21. I am always courteous, even to people who are disagreeable. true false

22. At time I have really insisted on having things my own way. true false

23. There have been occasions when I felt like smashing things. true false

24. I would never think of letting someone else be punished for my wrong doings. true false

25. I never resent being asked to return a favor. true false

26. I have never been irked when people have expressed ideas different from my own. true false

27. I never make a long trip without checking the safety of my car. true false

28. There have been times when I was quite jealous of the good fortune of others. true false

29. I have almost never felt the urge to tell someone off. true false

30. I am sometimes irritated by people who ask favors of me. true false

31. I have never felt that I was punished without cause. true false

32. I sometimes think when people have a misfortune, they only got what they deserved. true false

33. I have never deliberately said something that hurt someone's feelings. true false

Appendix I Interview Schedule

1. Demographics & Illness History

I.D.#__________ DOB: __________ Sex: M F

Occupation: __________ F/T P/T Ret. Homemaker __ Student __

Marital Status: nvm m sep d w

What is your racial background? (Check one) White Black Hispanic
Asian or Pacific Islander Native American
Other (Specify):

Level of education completed: Elem (grade) ____ Secondary (grade) ____

College: Some___ Completed ___ University: Some ___ Completed ___

Other (specify): Total #Years schooling ___

RA Class I II III IV

Duration of illness (# years/months diagnosed with RA): __________

Medications: Complete medication sheets on next two pages.

2. Arthritis Morbidity

2.1 # times seen by rheumatologist (in past year): ___ 2.2 #Rheumatologists seen (ever): ___

2.3 # times seen by family doctor (in past year): ___

2.4 Extra-articular disease? e.g.

Raynaud's Phenomenon (arteriolar vasospasm of fingers and toes - pale, numb & cold fingers/toes)	Y N
Sjogren's (a decrease in the production of tears and saliva)	Y N
Felty's (reduced white blood count sometimes with enlargement of the spleen)	Y N
Pericarditis (inflammation around the heart)	Y N
Vasculitis (inflammation of the blood vessels in the fingers, causing bruising, small brown spots, necrosis and sometimes leg ulcers)	Y N
Episcleritis (inflammation in the eye, sometimes leading to glaucoma)	Y N

Surgery:

2.5 Orthopaedic Surgery Y N If Y explain: 2.6 Surgery other Y N

If Yes, explain:

Articular disease:

2.7 Morning stiffness (min): ____ 2.8 Swelling in $\geq$ 3 joints Y N

2.9 Swelling PIP, MCP or wrist

2.10 Symmetrical swelling Y N 2.11 Nodules Y N 2.12 RF Pos Neg DK

Medications

	MONTHS		DOSE		STILL TAKING		TYPE
LUPOLYTICS							
PREDNISONE	PREDTIME	___	PARTPRED	___	ST_PREDN	___	PREDSCED ___
PLAQUENIL	PLAOTIME	___	PARTPLAO	___	ST_PLAOU	___	
ARALEN	ARALTIME	___	ARALDOSE	___	STARALEN	___	
CYTOXAN (If the patient recorded more than one form of Cytoxan, combine the forms)	CYTOTIME	___	PARTCYTX	___	ST_CYTOX	___	CYTOSCED ___
IMURAN	IMUTIME	___	PARTIMUR	___	ST_IMURN	___	
METHOTREXATE	MTXOTIME	___	PARTMETH	___	ST_METHO	___	METHSCED ___
(If the patient recorded more than one form of Methotrexate, combine the forms)							
OTHER IMMUNOSUP.	IMMUNTIM	___	PARTIMMU	___	STIMMUN	___	IMMUNTYP ___
NSAIDS							
ANSAID	ANSDTIME	___	ANSDDOSE	___	STANSAID	___	
ASPIRIN	ASATIME	___	PARTASA	___	ST_ASA	___	
CLINORIL	CLINTIME	___	PARTCLIN	___	ST_CLNRL	___	
DISALCID	DISATIME	___	PARTDISA	___	ST_DISAL	___	
FELDENE	FELDTIME	___	PARTFELD	___	ST_FELDN	___	
INDOCIN	INDOTIME	___	PARTINDO	___	ST_INDO	___	
MECLOMEN	MECLTIME	___	PARTMECL	___	ST_MECLO	___	
IBUPROFEN	IBUTIME	___	PARTMOTR	___	ST_MOTRN	___	
NALFON	NALTIME	___	PARTNALF	___	ST_NALFN	___	
NAPROSYN	NAPTIME	___	PARTNAPR	___	ST_NAPRO	___	
ORUDIS	KETOTIME	___	PARTKETO	___	ST_KETOF	___	
TOLECTIN	TOLTIME	___	PARTTOLN	___	ST_TOLEC	___	
TRILISATE	NASATIME	___	PARTNASA	___	ST_NASA	___	
VOLTAREN	VOLTIME	___	VOLDOSE	___	ST_VOLT	___	
OTHER ANTI-INFLAM.	NSAIDTIM	___	NSAIDDOS	___	STNSAID	___	NSAIDTYPE ___

MEDICATIONS

2.13. JOINT INDEX

	LEFT		RIGHT	
JOINT	PAIN	SWELLING	PAIN	SWELLING
Shoulder				
Elbow				
Wrist				
Knee				
MCP1				
MCP2				
MCP3				
MCP4				
MCP5				
PIP1				
PIP2				
PIP3				
PIP4				
PIP5				

PAIN: Pain on motion or tenderness 0 = none 1 = minimal (on questioning) 2 = moderate (spontaneous response) 3 = severe (withdrawal)

SWELLING: 0 = none 1 = mild (synovial thickening without loss of bone contour) 2 = moderate (loss of bone contour) 3 = severe (bulging synovial proliferation with cystic characteristics)

#Painful/Tender joints: #Swollen joints:

3. Social network & support

Social **network**. Number of people you feel at ease with (e.g. close friends/relatives), including those who are called on only when needed: List them in the table below and indicate frequency of contact beside each person
(e.g. 1. husband - daily, 2. oldest daughter - weekly).

Social network

1.	5.	9.
2.	6.	10.
3.	7.	11.
4.	8.	12.

Social support **(emotional)**.

With reference to the same people listed for social network: On a scale of 1 = very little support 5 = very much support. How much emotional *support* do you get in *coping* with your condition. If persons other than those already listed provide **emotional** support indicate who they are and their level of support.

Social support **(emotional)** Score 1 to 5 for each person

1.	5.	9.
2.	6.	10.
3.	7.	11.
4.	8.	12.

Social support (**instrumental**).

With reference to the same people listed for social network: On a scale of 1 = very little help 5 = very much help. How much practical ***help*** do you get in dealing with your condition. If persons other than those already listed provide **instrumental** support indicate who they are and their level of support

Social support (**instrumental**) Score 1 to 5 for each person

1.	5.	9.
2.	6.	10.
3.	7.	11.
4.	8.	12.

4. Arthritis & Health

BEFORE YOUR ARTHRITIS:

4.1 **Rate your health:** Considering all aspects of your health **before your arthritis**, rate how you were doing on the scale below by placing an X on the line at the place which you feel best represents your overall health at that time.

I _____I _____I _____I _____I _____I _____I _____I _____I _____I _____I

VERY WELL	WELL	FAIR	POOR	VERY POOR

4.2 Did you consume alcohol? N Y if Y:
4.3 **Before** your arthritis: Did you take any exercise? N Y
4.4 Frequency (# times/day/wk) ______ 4.5 Duration of exercise per session(mins)
___

SMOKING HISTORY

4.6. Have you ever smoked? Y N If N go to 4.20
4.7 If Y, How many cigarettes per day?
4.8 Did you smoke before you had arthritis? Y N
4.9 At the present time, do you smoke cigarettes? Y N
4.10 If Y How many per day? ___

AT THE PRESENT TIME:

4.11 **Rate your health:** Considering all aspects of your health, rate how you are doing on the scale below by placing an X on the line at the place which you feel best represents your overall health.

I _____I _____I _____I _____I _____I _____I _____I _____I _____I _____I

VERY WELL	WELL	FAIR	POOR	VERY POOR

4.12 Do you consume alcohol N Y if yes:
4.13 Do you engage in any exercise? N Y
4.14 Frequency (# times/day/wk) ______ 4.15 Duration of exercise per session (mins) ____

5. Arthritis Society & ASMP

5.1 Have you ever heard of the Arthritis Society? N Y
5.2 If Y, Are you a member? Y N
5.3 Have you ever heard of the ASMP? N Y
5.4 Have you ever taken any arthritis patient education course? Y N

(Person's own explanatory model)
5.5 Do you believe that arthritis patient education can help you cope with your arthritis? Y N
5.6 Under ideal circumstances when do you think an arthritis education course, for people like yourself, should run?
5.7 Season: W Sp Su F 5.8 Month: J F M A My Ju Jy Au S O N D
5.9 Time of day:
5.10 How many classes (sessions) should there be in the course?
5.11 Duration of each session (min) 5.12 #Sessions/week?
5.13 How long should the course last? 5.14 How often should it be offered?
5.15 Where should the courses be offered?
5.16 What would be a reasonable cost? 5.17 Who should teach it?

Thank you very much for taking part in the interview.

Appendix J Sample Letter from Rheumatologist

Dear NAME,

I am encouraging my patients to take part in an interesting study now taking place in Calgary. I would emphasize, however, that your decision to take part in the study in no way affects the medical care you receive.

The study is related to the Arthritis Self Management Program (ASMP). The ASMP is an arthritis patient education program offered by the Canadian Arthritis Society, and consists of 6 two hour sessions which introduces topics such as exercise, joint protection and pain control. It is presented by two leaders who themselves have arthritis. New sessions are beginning in the near future at a number of locations in Calgary.

The researcher, Dr. Steven Edworthy, who is a rheumatologist, is interested in learning about the reasons people have for choosing or not choosing to participate in arthritis education programs like the ASMP.

Each person is, of course, unique; therefore your reasons and opinions are extremely valuable and have the potential to affect the results of the study. The main objective of the study is to improve patient care.

If you are interested in finding out more about the study, please return the enclosed reply form in the stamped addressed envelope provided. You will be contacted by telephone by Jim Rankin, a member of the research team. He can answer your questions. If you wish to contact him directly, please call 220-6093 or 220-4642.

We see this study as an opportunity for patients with rheumatoid arthritis to help health professionals understand more about arthritis and thereby improve patient care.

Thank you for taking the time to read this letter, and for your consideration to take part in the study.

Sincerely,

Signature

Dr.'s Name

Appendix K Patient Reply Form

Reply Form

Please complete this form and return it in the enclosed stamped addressed envelope.

Yes, I would like to find out more about the arthritis patient education study,

I understand that I am guaranteed confidentiality and that my decisions to participate will in no way affect the medical care I receive.

I may be contacted at:

Home: (Tel. Number) ___________

Work: (Tel. Number) ___________

Name: ____________________________

(If you are not interested in the ASMP or the study it would help a great deal if you could give us some idea why you made this decision.)

Appendix L Normalization procedure for AIMS' Scores

AIMS2 SCORING AND NORMALIZATION

SCALE	ITEMS	RECODE	RAW SCORE	NORMALIZATION
Mobility	1,2, 3 4, 5	None *	5 – 25	(S^ - 5) x 0.5
Walking & Bending	6 to 10	*	5 – 25	(S^ - 5) x 0.5
Hand & Finger	11 to 15	None	5 – 25	(S^ - 5) x 0.5
Arm	16 to 20	None	5 – 25	(S^ - 5) x 0.5
Self Care	21 to 24	*	4 – 20	(S^ - 4) x 0.625
House Tasks	25 to 28	None	4 – 20	(S^ - 4) x 0.625
Pain	38 to 42	*	5 – 25	(S^ - 5) x 0.5
Tension	50,51 52 48, 49	None *	5 – 25	(S^ - 5) x 0.5
Mood	53 54 to 57	None *	5 – 25	(S^ - 5) x 0.5

*Recode = 1 = 5, 2 = 4, 4 = 2 and 5 = 1
^ S = Summed raw score of recoded values

Appendix M Patient Consent Form

CONSENT FORM

Research Project Title: Determinants of participation in arthritis patient education

Investigator(s): Dr. S. Edworthy & Mr. J. Rankin

Sponsor: University of Calgary (funded by AFNR)

This consent form, a copy of which has been given to you, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

At the present time the cause of rheumatoid arthritis (RA) is unknown. Part of the research at the Rheumatic Disease Unit at the University of Calgary is to find better treatments. Also some research has shown that people with RA may be helped by taking part in education classes. The purpose of this research study is:

To find out if there are any differences between people who like to take classes to learn about RA and those who do not want to take classes.

For your part in the research you will be:

- Asked some questions about your arthritis and your general health by a research assistant and
- Asked to complete a survey questionnaire on your own.

The research assistant will be there if you need to ask any questions about some of the items on the survey.

The questions on the survey will ask you about your health, how you are feeling, your day to day activities, pain with RA and your knowledge of RA. Your total time commitment will be about one and a half to two hours.

Your participation in this research is valuable to us because the knowledge that you have about coping with arthritis may be used to help people like yourself in the future. There is no direct benefit to you in taking part in the study but indirectly you will be helping others with RA.

The information collected will be coded so that your confidentiality is maintained at all times. All of the questionnaires will be stored in a locked filing cabinet to which only the investigators will have access. The questionnaires will be destroyed by shredding when they are no longer required for the study

CONTINUED ON BACK PAGE...

Appendix M Patient Consent Form

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject.

In no way does this waive your legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities.

You are free to withdraw from the study at any time without jeopardizing your health care.

Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

If you have further questions concerning matters related to this research, please contact:

Dr. S. Edworthy (MD FRCP(C) Rheumatologist) - 220-7725

or

Mr. Jim Rankin (RN MSc PhD student) - 220-6093 or 4642

If you have any questions concerning your rights as a possible participant in this research, please contact the Office of Medical Bioethics, Faculty of Medicine, University of Calgary, at 220-7990.

______________________ Participant	______________________ Date
______________________ Investigator	______________________ Date
______________________ Witness	______________________ Date

A copy of this consent form has been given to you to keep for your records and reference.

Appendix N Other NSAIDs Used by RA Patients

Percentage use of certain Non-Steroidal Anti-inflammatory Drugs (NSAIDs)

NSAIDs	T1 Cases n = 7	T1 Controls n = 29	T2 Cases n = 65	T2 Controls n = 45	Total Cases n = 72	Total Controls n = 74
Clinoril Y N	0 100	3.4 96.6	0 100	2.2 97.8	0 100	2.7 97.2
Disalcid Y N	0 100	3.4 96.6	0 100	2.2 97.8	0 100	2.7 97.2
Feldene Y N	0 100	0 100	3.1 96.9	2.2 97.8	2.7 97.2	1.3 98.6
Ibuprofen Y N	0 100	6.9 93.1	4.6 95.4	8.9 91.9	4.1 95.8	8.1 91.8
Tolectin Y N	0 100	0 100	4.6 95.3	0 100	4.1 95.8	0 100
Orudis Y N	14.3 85.7	0 100	1.5 98.5	2.3 97.8	2.7 97.2	1.3 98.6
Other Y N	14.3 85.7	6.9 93.1	27.7 72.3	4.4 95.6	26.3 73.6	5.4 94.5

Other = Other NSAIDs. "Other" NSAIDs included Etodolac and Nabumetone. None of the patients were taking Ansaid, Meclomen or Trilisate

Appendix O – Definitions of co-morbid conditions associated with RA*

Raynaud's Phenomenon –

Arteriolar vasospasm of the fingers and toes causing, pain, numbness, pallor and cold extremities.

Sjogren's Syndrome –

A chronic inflammatory autoimmune disorder characterized by decreased lacrimal and salivary gland activity.

Felty's Syndrome –

This syndrome is found in patients with very active arthritis. It is characterized by splenomagaly, lymphadenopathy, anemia, thrombocytopenia and selective leukopenia involving neutrophils.

Pericarditis –

Inflammation of the pericardium

Vasculitis –

Idiopathic inflammation of the blood vessels

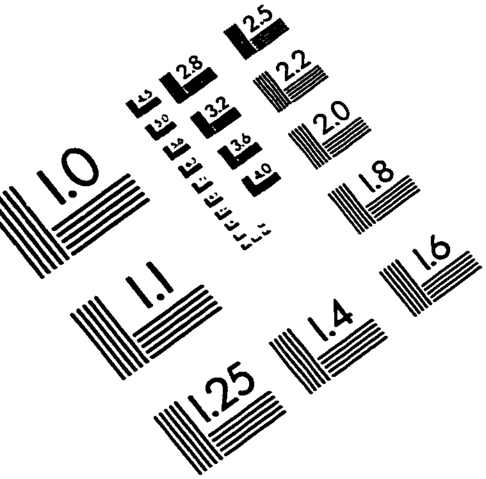
Episcleritis –

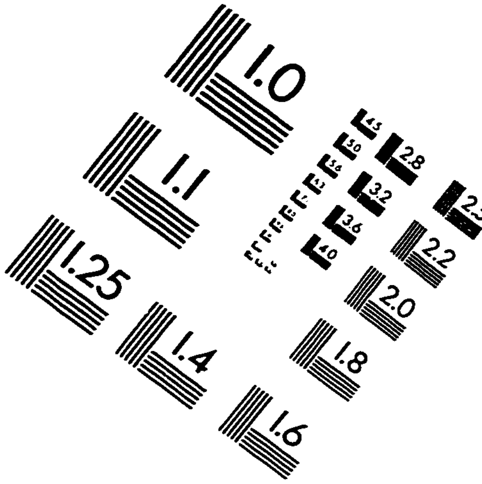
Inflammation of the sclera

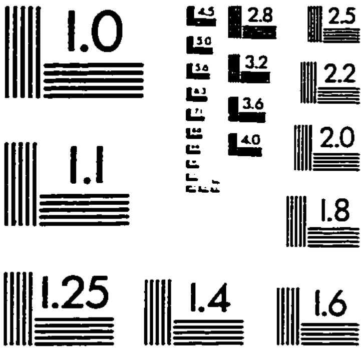
---

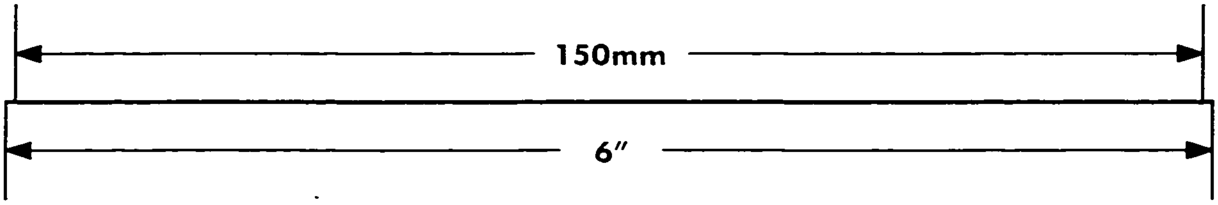
*Source: Schumacher, H. R. (Ed.). (1988). Primer on the rheumatic diseases. 9th. ed. Atlanta, GA: Arthritis Foundation.

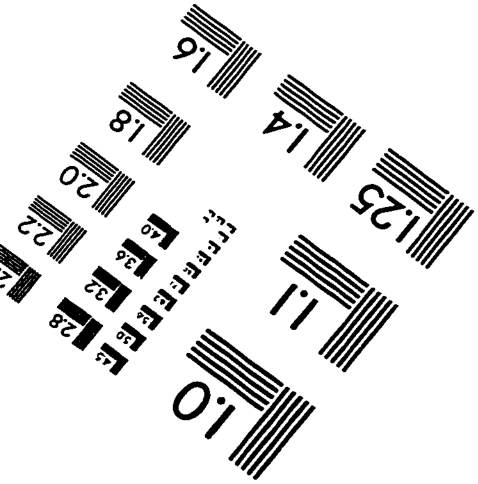
IMAGE EVALUATION
TEST TARGET (QA-3)











APPLIED IMAGE, Inc
1653 East Main Street
Rochester, NY 14609 USA
Phone: 716/482-0300
Fax: 716/288-5989