CHRONIC NONADHERENCE TO THERAPEUTIC REGIMES: AN IN-DEPTH ANALYSIS OF MALE ARTHRITIS PATIENTS

by

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ABSTRACT

Chronic nonadherence is the complete lack of adherence on the part of a patient to at least one aspect of their therapeutic regime for extended periods of time. Chronic nonadherence is similar to other forms of nonadherence in that it is a phenomena which is dangerous for patients, frustrating for practitioners, and costly to the health care system. However, unlike other forms of nonadherence, very little is known about this subject.

In order to determine factors related to chronic nonadherence to a home exercise program, 15 male arthritis patients of varying ages underwent an in-depth structured interview. Eight of these patients were identified by the Arthritis Society as being chronic, treatment nonadherents. The other seven patients were randomly chosen from among the population of male arthritis patients in order to provide a comparison to the chronic nonadherent population.

Ten variables were examined in this study in the hopes of determining factors related to chronic nonadherence. These variables were as follows: demographics, The Health Beliefs Model, patient's explanatory model, nature of the illness, satisfaction with practitioner attributes, shared responsibility, overall satisfaction, attitudes of significant others, use of unorthodox treatments, and problems with the home exercise program.
Data analysis failed to produce any statistically significant findings, however the study did point to some interesting associations. One finding from this study is that nonadherence seems to be related to patient's Health Beliefs Models. Based on this finding the study then goes on to recommend an appropriate intervention which can be used by practitioners to enhance patient adherence. A second finding from this study is that a small number of the chronic nonadherent group were actually adherent to their home exercise programs. Several explanations have been provided as to how these patients might have been falsely labelled as chronic nonadherents.
# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>ABSTRACT</td>
<td>i</td>
</tr>
<tr>
<td>LIST OF TABLES</td>
<td>vi</td>
</tr>
<tr>
<td>LIST OF FIGURES</td>
<td>ix</td>
</tr>
<tr>
<td>ACKNOWLEDGEMENTS</td>
<td>x</td>
</tr>
<tr>
<td>INTRODUCTION</td>
<td>1</td>
</tr>
<tr>
<td>ARTHRITIS AND NONADHERENCE - BACKGROUND INFORMATION</td>
<td>2</td>
</tr>
<tr>
<td>Arthritis - What Is It?</td>
<td>2</td>
</tr>
<tr>
<td>Adherence vs Compliance</td>
<td>4</td>
</tr>
<tr>
<td>The Importance of Nonadherence</td>
<td>5</td>
</tr>
<tr>
<td>Types on Nonadherence</td>
<td>6</td>
</tr>
<tr>
<td>Nonadherence - Deviance or Justified Reaction</td>
<td>8</td>
</tr>
<tr>
<td>Control - An Essential Factor</td>
<td>10</td>
</tr>
<tr>
<td>A MODEL FOR UNDERSTANDING NONADHERENCE</td>
<td>17</td>
</tr>
<tr>
<td>Pre - Interaction Phase</td>
<td>18</td>
</tr>
<tr>
<td>Interaction Phase</td>
<td>28</td>
</tr>
<tr>
<td>Post - Interaction Phase</td>
<td>37</td>
</tr>
<tr>
<td>METHODOLOGY</td>
<td>43</td>
</tr>
<tr>
<td>Subjects</td>
<td>43</td>
</tr>
</tbody>
</table>
iv

Procedures ............................................ 45
Measures ............................................... 46
  Adherence .......................................... 49
Demographics ........................................ 52
The Health Beliefs Model ......................... 52
Patient's Explanatory Model ....................... 54
Nature of the Illness ............................... 54
Satisfaction with Practitioner Attributes ....... 55
Shared Responsibility ............................... 56
Overall Satisfaction ............................... 56
Attitudes of Significant Others .................. 58
Use of Alternative Treatments ..................... 58
Problems with the Home Exercise Program ....... 59
Enhancement of Questionnaire Validity and ....... 59
  Reliability ........................................ 59
Data Analysis ....................................... 61

RESULTS .................................................. 63
  Analysis Using Self-Reported Measures of Adherence. . 64
  Demographics ....................................... 64
  The Health Beliefs Model ......................... 65
  Patient's Explanatory Model ....................... 69
  Nature of the Illness ............................... 72
  Satisfaction with Practitioner Attributes ....... 72
  Shared Responsibility ............................. 75
  Overall Satisfaction ............................... 81
vi

Patient's Explanatory Model ..................... 152
Nature of the Illness ............................. 153
Satisfaction with Practitioner Attributes .... 154
Shared Responsibility ............................ 157
Overall Satisfaction ............................. 163
Attitudes of Significant Others ................ 166
Use of Alternative Treatments .................. 167
Problems with the Home Exercise Program .... 170

Possible Explanations for the Misidentification

Phenomena ........................................ 171

Labelling Deviant Behaviour ..................... 174
LIST OF TABLES

Table 1  Health Strategic Interaction Model: Pre-Interaction Phase Variables, page 22.
Table 2  Health Strategic Interaction Model: Interaction Phase Variables, page 30.
Table 3  Health Strategic Interaction Model: Post-Interaction Phase Variables, page 40.
Table 4  Correspondence between Study Variables and Interview Schedule Questions, page 47.
Table 5  Cross-Tabulations: Patient Demographic Characteristics by Adherence, page 66.
Table 6  T-Test Analysis of the Health Beliefs Model with Adherence, page 68.
Table 7  Cross-Tabulations: The Health Beliefs Model by Adherence, page 70.
Table 8  Cross-Tabulation: Nature of the Illness by Adherence, page 73.
Table 9  Other Medical Problems Reported by Study Respondents, page 74.
Table 10 T-Test Analysis of Patient Satisfaction With Practitioner Attributes with Adherence, page 76.
Table 11 Cross-Tabulations: Patient Satisfaction with Practitioner Attributes by Adherence, page 77.
Table 12 Cross-Tabulations: Shared Responsibility Models by Adherence, page 78.
Table 13  Cross-Tabulations: Shared Responsibility Models by Adherence (Median Split), page 79.

Table 14  Median Test Analysis of Problems with the Home Exercise Program with Adherence, page 83.

Table 15  Cross-Tabulations: Patient Demographic Characteristics by Arthritis Society Categorization, page 148.

Table 16  T-Test Analysis of Health Beliefs Model by Arthritis Society Categorization, page 151.

Table 17  T-Test Analysis of Satisfaction with Practitioner Attributes by Arthritis Society Categorization, page 155.

Table 18  Cross-Tabulations: Patient Satisfaction with Practitioner Attributes by Arthritis Society Categorization, page 157.

Table 19  Cross-Tabulations: Shared Responsibility Models by Arthritis Society Categorization, page 159.

Table 20  Cross-Tabulations: Shared Responsibility Models by Arthritis Society Categorization (Median Splits), page 161.

Table 21  T-Test Analysis of Overall Satisfaction by Arthritis Society Categorization, page 164.

Table 22  Cross-Tabulation: Satisfaction with "Kind of Service Offered" by Arthritis Society Categorization, page 165.
Table 23  Cross-Tabulation: Satisfaction with "Having Needs Met" by Arthritis Society Categorization, page 167.

Table 24  Cross-Tabulation: Use of Alternative Treatments by Arthritis Society Categorization, page 168.
LIST OF FIGURES

Figure 1  A visual representation of the Health Strategic Interaction Model, page 20.

Figure 2  Classification matrix outlining the four categories of the Shared Responsibility Model, page 35.
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INTRODUCTION

Patient adherence to therapeutics is an issue which continues to be the bane of health care practitioners. No profession is free from its influence as studies have shown patients to be nonadherent to the recommendations of physicians (Nessman, Carnahan, & Nugent, 1980), physiotherapists (Carpenter, & Davis, 1976), occupational therapists (Oakes, Ward, Gray, Klauber & Moody, 1970), and psychologists (Trepka, 1986). Although no studies are available which document the degree of client adherence to social work recommendations, it is probably safe to state, on the basis of the findings of other health care practitioners, that at least a modicum of nonadherence exists. Social workers are in a position to not only influence nonadherence in their own practices, but also to assist other professionals who are part of the health care team. This applies to hospitals, psychiatric institutions, out-patient mental health centers, or any other setting which uses a team modality. Within this modality social workers have an important role, as they bring a unique psychosocial perspective to the problem. This provides a particularly apt approach for dealing with nonadherence as research shows it to be a complex issue encompassing physiological, psychological and social dimensions (Stone, 1979). This psychosocial perspective is not only useful in developing treatment interventions, but is
also invaluable in continuing research efforts to explore the many unanswered questions relating to this phenomena. The aspect of this phenomena which is being explored in this research study is that of chronic nonadherence; the complete lack of adherence to at least one aspect of treatment for extended periods of time. By looking at a number of variables normally associated with nonadherence this study is hoping to distinguish the ways in which a chronic nonadherent population is different from a random sample of male arthritis patients.

ARTHITIS AND NONADHERENCE - BACKGROUND INFORMATION

Arthritis - What Is It?

In order to understand the behaviours of arthritis patients it is necessary to know something about the disease with which they have to live. Arthritis is an umbrella term which includes more than 100 different kinds of rheumatic diseases. Some of these such as rheumatoid arthritis, osteoarthritis, and gout are well known, while other types such as ankylosing spondylitis and Reiter's Syndrome are not as prevalent. These diseases can be divided into those which affect the body's joints and those which affect joint-support structures (eg. muscles, tendons and ligaments) (Arthritis Society, 1986).

One commonality amongst all these different kinds of rheumatic diseases is that there is no known cure. This means
that once people get arthritis it will be with them for the rest of their lives. In other words, arthritis is a chronic disorder. That is not to say, however, that there are not treatments available to help keep symptoms under control. As well, the disease often fluctuates in severity on its own accord. At those periods of time when no symptoms are present, the disease is said to be in 'remission'. Periods of symptom exacerbation are known as 'flares'. The most common symptoms faced by arthritis patients are pain, stiffness, fatigue, and swelling. If these symptoms are left untreated they progressively lead to muscle weakness, decreased range of motion, and deformity (Arthritis Society, 1980).

A second commonality amongst most types of rheumatic diseases is that researchers and practitioners still do not know what causes the disease. Some factors which have been noted as being likely causal agents are heredity, congenital birth defects, trauma, and viral activity (Arthritis Society, 1986).

Thus, arthritis is a disease which still has many unanswered questions. Definite underlying causes of the disease are not known, and treatments are sometimes ineffectual. Because of the fact that traditional medicine does not have all the answers, many people turn to folk remedies or unorthodox practitioners for help. In a recent American study, Kronenfeld and Wasner (1982) determined that 94% of their sample had used at least one type of folk
treatment. In addition to the use of alternative therapies, the lack of conventional wisdom also encourages patients to have varied personal explanations as to why they have the disease.

**Adherence vs Compliance**

Current literature seems divided on whether to consider the patient's execution of a recommended therapeutic regimen as compliance or adherence. Although seemingly picayune, this distinction highlights the differing views as to where responsibility for follow-through of a prescribed behaviour should be placed. Compliance implies that control for the decision-making lies with the practitioner, and that the blame for noncompliance in some way rests with the patient. Taylor (1979) suggests that medical staff see the ideal patient role as one of passiveness and acquiescence with the expert's recommendations. When the patient does not heed this advice they are said to be noncompliant. Adherence, on the other hand, implies a working-together or cooperation between the patient and the health care practitioner (Turk, Sálovey & Litt, 1986). This point of view places the responsibility for breakdown on the interaction between the practitioner and the patient, rather than on either of the principal characters. Research is beginning to indicate that this interaction is indeed the primary cause of poor patient follow-through (Stone, 1979). For these reasons the term nonadherence is
The Importance of Nonadherence

Adherence is the degree to which a patient follows the regimen given to him or her by the health care practitioner. Failure to adhere to health advice is dangerous for patients, frustrating for practitioners, and also represents a large cost to the health care system.

Becker and Maiman (1980) describe how nonadherence can set up a causal link resulting in a number of consequences. With respect to medications, nonadherence initially can nullify the therapeutic efficacy of the treatment. This may lead the patient to seek help elsewhere resulting in a two-fold effect. Services are duplicated, and the new practitioner may prescribe treatments that are contraindicated by the first practitioner's treatments. Lack of treatment effectiveness may lead to patient dissatisfaction, which in turn may result in a higher degree of patient nonadherence.

This type of patient behaviour can be frustrating for practitioners. Considerable time may be spent in assessment and development of a therapeutic plan to then find that the patient either does not return for subsequent appointments, or does not follow the recommendations which have been given. By the time the patient returns for help it is likely that his or her condition will have worsened, such that treatment becomes
more difficult to carry out.

In an attempt to determine financial cost, Ausburn (1981) calculated the proportion of hospitalized patients whose admission to hospital was due to nonadherence. Her estimates suggest that 20% of the admissions were probably due to nonadherence to medication regimes.

Some idea of the extent of the problem surfaced when Marston (1970) reviewed 33 previously conducted nonadherence studies. Statistical analysis across these studies revealed a median of 42% nonadherence, with a range of 4 to 92%. These figures represent a large number of medication errors, missed appointments, and treatment drop-outs. Thus, not only is nonadherence widespread, but it also has important ramifications for all health care practitioners.

Types of Nonadherence

According to Haynes (1976), compliance can be defined as "the extent to which a person's behaviour coincides with medical or health advice" (p.2). This definition is good as far as it goes, but it fails to provide the nuances which are necessary in order to get a clearer picture of why nonadherence occurs. For example, the definition fails to make a distinction between involuntary and voluntary nonadherence. Involuntary nonadherence occurs when the client fails to follow advice, but is unaware of this failure, or unable to stop its occurrence. The client who does not come
to his appointment because he misunderstood the practitioner illustrates this type of nonadherence. Voluntary nonadherence occurs when the client makes a conscious decision not to follow the advice which s/he has been given. Voluntary nonadherence can be further subdivided into what Weintraub (1976) calls "intelligent noncompliance" and "capricious compliance". The difference between these is that for the former, the decision to not adhere is based on rational reasoning, while the latter lacks this rational basis.

Chronic nonadherence is similar to voluntary nonadherence in that there is a conscious decision on the part of the patient to not adhere to his or her therapeutic regime. For as Boehnert and Popkin (1986) state in describing diabetic chronic nonadherents, "these are not individuals who occasionally forget to take their insulin or who at times may stray from their diet, but rather ones who consistently and deliberately refuse to follow medical advice with respect to managing their disease" (p.11). In refusing to follow medical advice, these patients can be considered voluntarily nonadherent.

The difference between voluntary nonadherence and chronic nonadherence is that voluntary nonadherence refers to any degree of nonadherence on the part of the individual whereas chronic nonadherence only refers to extreme forms of voluntary nonadherence. For example, an individual who decides to do her exercises half as often as she was recommended to do them
would be viewed as voluntarily nonadherent. For this woman to be seen as a chronic nonadherent, she would have to completely cease exercising. From this discussion it can be seen that whereas chronic nonadherence is a form of voluntary nonadherence, the reverse is not true. Thus, the hallmark of a person who is chronically nonadherent is the complete lack of adherence to at least one aspect of his or her therapeutic regimen for extended periods of time. As little is known about this subject, the study will use variables which have been identified in previous research on nonadherence.

**Nonadherence - Deviance or Justified Reaction**

Deviance is any behaviour which differs from that which is considered to be the norm. According to Webster (1979), a norm is defined as "a standard, model, or pattern for a group" (p.1221). Thus, deviance is any behaviour which deviates from a recognized pattern.

Traditionally the practitioner-patient relationship has followed a fairly defined course. Upon experiencing certain physiological symptoms or sociopsychological problems the individual may decide to see a health care practitioner. Once in the presence of the expert, the individual takes on the role of patient or client. This role entails the patient supplying whatever information is required by the practitioner, and following whatever advice s/he has been given. This description of normative patient behaviour is
similar to the notion of "sick role" described by Parsons (1951). Parsons felt that when people became sick they were obligated to seek help from a trained practitioner, and to cooperate with any treatment recommendations prescribed by the expert. By stating this responsibility, Parsons enshrined adherence as a normative behaviour expected of anyone who is sick.

The notion of social deviation is discussed by Johnson (1960). He suggests that behaviour is only deviant when an individual is conscious that certain norms are in fact being violated. With regard to adherence, this would mean that only voluntary nonadherence would be considered as deviant behaviour. Involuntary nonadherence would not be seen as deviant behaviour because it lacks a wilful attempt to engage in non-normative conduct. A second point proposed by Johnson is that deviant behaviour is often dysfunctional. In order for any type of cooperative interaction to progress smoothly, each actor must act in a predictable fashion according to his or her allotted role. In the patient-practitioner interaction one of the reasons why it is important for the patient to follow medical advice is due to the fact that subsequent therapeutic recommendations will be based on the perceived outcome of the earlier advice. If previous advice has not been followed and the physician is not aware of this fact, there exists the possibility of harm befalling the patient.
In this situation the dysfunctional relationship between the patient and the practitioner could be attributed to the patient's deviant nonadherent behaviour. In a traditional sense, the patient would have been at fault for not following normative sick role behaviour. That is, for not cooperating fully with the ministrations of the physician. Today there is some question as to the validity of this interpretation. Part of the reason for this uncertainty comes from the fact that for a norm to be considered as such, it must enjoy a widespread consensus. However, what studies are indicating is that what is widespread is the nonadherent behaviour itself. Thus, by its increasing prevalence, nonadherence may be indicating the fact that there is something wrong with the traditional patient-physician relationship. One possible explanation proposed by Brody (1980) is that people are not satisfied with the imbalance of power inherent in this traditional relationship. Thus, although potentially dysfunctional, the attempt to wrest power away from practitioners could be considered as a healthy reaction to a perceived loss of control on the part of the patient.

Control - An Essential Factor

The point which underlies much of the current discussion is that in the traditional medical system the patient has very little control. Parsons (1951) noted this in his discussion of the institutionalized expectations of the sick role when he
stated, "the sick person cannot be expected by 'pulling himself together' to get well by an act of decision or will. In this sense also he is exempted from responsibility - he is in a condition that must be taken care of" (p.437). As mentioned previously, Parsons also felt that the only obligation which the patient had was to cooperate with recommendations made by the practitioner. In this relationship the practitioner holds a lot of power, not only because s/he provides a diagnosis and a treatment, but also because s/he legitimizes the sickness. As a gatekeeper the physician acts by deciding who is ill and who is malingering. As a point in fact, many hospital emergency departments still have printed 'Dear Employer' forms which employees can use to validate their illness.

Brody (1980) suggests that this power differential occurs because of an information and social gap which exists between the two sides. Practitioners have many years of education and clinical training, and may feel that this knowledge is too complex to be understood by patients. Other reasons suggested by Brody as to why this information gap may be difficult to close is that practitioners may regard the task of patient education as being too time-consuming, assume that it will only make patients anxious, and that patients have psychological barriers to receiving this type of information.

The existence of a social gap has been raised by Brody (1980) from evidence that shows that physicians provide more
information to patients who are of a higher social class. This may be due to the idea that physicians feel that patients of a higher social class also tend to be more educated. Having more education they are probably more capable of understanding the complexities of medicine. A second point raised by Brody is that lower class patients also tend to ask fewer questions of physicians and to generally be less assertive. This in turn may also account for the fact that lower class patients receive less information.

In contrast to the model of sick role behaviour outlined by Parsons, a typology of physician-patient relationship was developed by Szasz and Hollender (1956) based on the degree of control held by each participant. Their typology includes: activity-passivity, guidance-cooperation, and mutual participation. The first of these refers to situations when the physician has to act out of a position of authority because of the nature of the disease or injury. Trauma patients in need of immediate attention would fall into this category. Guidance-cooperation describes situations that are still acute, but in which the patient is at least able to cooperate. Brody (1980) states that a patient who is infectious would come under this category. The last type of relationship refers to a partnership which the physician and patient hold together. In this partnership the physician empowers the patient to take control of the management of his or her own illness. This is most feasible with diseases
which are of a chronic nature (e.g. arthritis, hypertension, diabetes). The benefit of this framework is that it sees the relationship as a flexible arrangement to be modified according to the severity of the illness. When patients are capable of taking more control, the practitioner yields part of his or her power in order to bring about a more equitable, satisfying interaction. In comparison, the physician-patient relationship described by Parsons is much more rigid in that it takes control away from the patient, and limits the actions which can be taken by either actor.

Fiske and Taylor (1984) indicate that individuals may react to loss of control in a variety of ways. Common responses include information seeking, increased reactions to stress, reactance and helplessness.

Information seeking is a prevalent reaction of individuals who experience loss of control as a result of a medical illness. Faced with inexplicable symptoms, the patient is dependent on the practitioner for guidance. Not only does the patient need to know what to do to deal with the illness, but information is also necessary to assist them in making sense of the events they are going through. Information is important as it has a coping function and a predictive function. Coping is improved because the patient is able to recognize what various symptoms mean, and therefore what actions to take in response to them. Prediction is beneficial because it allows the patient to plan ahead for the
future. When information is not forthcoming from the practitioner, patients will attempt to get this need met elsewhere (Fiske & Taylor, 1984). Books, popular magazines, television, friends, relatives, and others with the same disease all become potential sources of information. The danger inherent in this activity is that the patient probably does not have enough knowledge to accurately judge the validity of this advice. As a result, decisions may be made by the patient on the basis of faulty information.

A second response to loss of control is an increased reaction to stress. These reactions include physiological effects (e.g., increased adrenalin activity), reduction in the ability to concentrate, and increased self-reports of pain or discomfort (Fiske & Taylor, 1984). These reactions occur when individuals face events over which they have no control. The difficulty with this factor is that most evidence supporting its existence comes from laboratory studies which submit participants to varying levels of controllable and uncontrollable noise, or shock. Thus, it would seem difficult to generalize these findings to everyday life situations. On the other hand, it seems logical to expect people who are not in control of a part of their life to be more anxious and impatient.

The third response indicated by Fiske & Taylor (1984) is that of reactance. Of the forms of reactance mentioned, the two which are most relevant to this situation are anger and/or
aggression, and exhibition of behaviours to regain control.

Taylor (1979) describes the "bad patient" as the one who demands information, is suspicious of treatment, and who reacts angrily to the calming efforts of staff members. Although labelled by hospital staff as disruptive troublemakers, the fact of the matter is that these patients are only reacting to an environment which is devoid of any opportunity for self-control. Taylor (1979) suggests that the degree to which patients respond to the hospital environment with reactance is dependent on the amount of control which these same people normally have in their everyday environments.

An example of patients exhibiting behaviours designed to reassert control is provided by Hayes-Bautista (1976). He found that patients attempt two types of strategies when they are dissatisfied with care. They may attempt "convincing strategies" to persuade the practitioner that treatment is inadequate, and that changes are necessary. Or patients may attempt "countering strategies", such that changes are made to the regimen as the patient sees fit. The latter strategy is most often resorted to when the former strategy has failed.

The last response to loss of control is helplessness. Helplessness can be recognized by an inactivity or a lack of effort to change one's situation. Taylor (1979) suggests that hospital patients who are compliant and passive are, in effect, in a state of helplessness. At first this state is
marked by anxiety as the patient feels caught between wanting more information, yet being afraid to ask for it. In a study by Tagliacozzo and Mauksch (1972) it was shown that two-thirds of the patients had needs and criticisms of the hospital which they felt unable to vocalize. Over time continued helplessness may lead to depression.
A MODEL FOR UNDERSTANDING NONADHERENCE

Several models have been proposed in an effort to gain an understanding of why nonadherence occurs. These range from models which list variables associated with nonadherence (Green, 1980; McGuire, 1980) to more complex models which also attempt to include behavioral, cognitive, and affective dimensions (Cox, 1982; Dracup & Meleis, 1982; Kersell & Milsum, 1985). The problem which complicates development of a model is that there are over 200 variables which have been associated with nonadherence (Stone, 1979). Thus, models must walk a line between being detailed enough to provide a broad overview of the subject, yet not so intricate that one becomes lost in the details.

The model described in this paper has been developed by this author and is based on the Health Transactions Model (Kasl & Cobb, 1966; Stone, 1979). Called the Health Interaction Strategy Model, it follows the premise put forward by Stone (1979) that nonadherence arises from the interaction of the patient and the practitioner. Neither party is fully responsible for adherence as a cooperative effort is required from both.

Stone (1979) comments on the notion that adherence behaviour is the end result of a multi-stage process. In the beginning stage the patient detects some sort of symptom development or realizes that there is a problem in his or her
life for which they are needing help. Once recognition has taken place, a decision may be made to visit a health care practitioner. The middle stage of the model focuses on the interaction or series of interactions which occur between the health professional and the patient. The last stage of the model takes place once the patient has returned home, and either exhibits adherence or nonadherence to the recommended therapeutic regime. This outcome can be the result of one, or a multitude of factors which have occurred at any stage of the process. In keeping with this idea, the Health Interaction Strategy Model is divided into three stages: pre-interaction, interaction, and post-interaction (see Figure 1)

Insert Figure 1 about here

Pre - Interaction Phase

Stone (1979) stresses the importance of realizing what each person brings to this encounter. As the expert, the health care practitioner is responsible for being aware of not only his or her own beliefs and expectations, but also the stated and unstated beliefs and expectations of the patient. As he states, "in a sense, everything that has ever occurred in the lives of the expert and client is relevant to their interaction" (p.45).

Four of the study variables are predominant in this phase
of the model. As can be seen in Table 1 these variables are demographics, The Health Beliefs Model, the patient's explanatory model, and the nature of the illness.

Insert Table 1 about here

Numerous studies have been carried out to determine the relationship between demographics and adherence. On the whole, however, factors such as age, sex, education, race, socioeconomic status, and income have not been found to correlate with adherence (Zisook & Gammon, 1981). The only factor which might be considered is that patients who are elderly may be more forgetful (Ley, 1982), and thus prone to involuntary nonadherence.

The Health Beliefs Model and the patient's explanatory model are similar in that both are concerned with the effects associated with an individual's beliefs about his or her illness. The difference between the two models is that each highlights the importance of different aspects of the individual's belief structure.

The Health Beliefs Model (Becker, 1976; Hochbaum, 1958; Maiman & Becker, 1974) was originally developed to predict the acceptance of preventive health behaviours, and was adapted by Becker to predict adherence behaviours. This model works on the basis of value-expectancy theory (Kersell & Milsum, 1985).
Figure 1. A visual representation of the Health Strategic Interaction Model
Patient's Demographics

Pre-Interaction Variables
Patient's Nature
Health of
Beliefs of the
Model of
Illness of

Patient's Explanatory Model

Patient's Satisfaction With Practitioner Attributes

Interaction Variables
Overall Shared
Patient Respon-
Satisfactionability

Attitudes of Significant Others

Post-Interaction Variables
Patient's Use of Unorthodox Treatments with the Home
Patient's Problems of Exercise Program
Table 1

Health Strategic Interaction Model: Pre-Interaction Phase

<table>
<thead>
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*(table continues)*
Patient's Explanatory Model

Nature of the Illness

Severity
Impact
Duration
This means that the patient's adherence behaviour is predicted according to the value of the outcome to the individual, and the expectation the individual has as to whether the behaviour will produce the desired outcome. The Health Beliefs Model suggests that adherence to a medical regimen depends on four factors: perceived susceptibility, perceived severity, evaluation of the advocated health behaviour, and a cue to motivation (Becker, 1976).

Perceived susceptibility is concerned with the individual's belief in the accuracy of the diagnosis, or with his or her beliefs about resusceptibility (i.e. with a disease such as cancer or arthritis which at present is in remission, but which may reoccur in the future). Perceived severity is the individual's subjective perceptions of the future seriousness of his or her disease. Evaluation of the advocated health behaviour encompasses both the individual's perceptions of costs and benefits accruing from follow-through of a recommended health behaviour. Some perceived barriers to treatment, which studies have linked to nonadherence, include fear of pain or discomfort, extent to which new patterns of behaviour must be adopted, complexity of treatment, duration of treatment, and side-effects associated with treatment (Becker, 1976). Perceived benefits, also linked to adherence, include client's belief in the capability of the physician and/or the efficacy of treatment (Becker, 1976). The last element, cues to motivation, refers to the idea that some type
of a stimulus or trigger is necessary in order to catalyze appropriate health behaviour. This trigger acts by making the individual conscious of the health threat which they are facing (Davidhizar, 1983). For example, Davidhizar suggests that awareness of one's susceptibility to a severe disease is a sufficient motivational cue. This is corroborated by Rosenstock (1966) who points out that visible symptomatology is a common stimulus of health behaviours. Rosenstock (1974) further clarifies this point when he states, "the combined levels of susceptibility and severity provided the energy or force to act and the perception of benefits (less barriers) provided a preferred path of action" (p. 332). Thus, motivation cues are not a separate element, but rather point to the idea that some combination of perceived susceptibility and severity are necessary in order to catalyze health behaviour. One of the benefits of this model is that it highlights the powerful effect which beliefs have on adherence behaviour.

The importance of beliefs is also evident in any discussion of the explanatory model. Explanatory model is a term developed by Kleinman (1980) to describe the set of beliefs which individuals hold about their illness. These beliefs or personal explanations develop as a result of interpersonal, familial and cultural experiences. It is probably fair to say that the health beliefs of a young, Caucasian, male executive in Vancouver would differ
significantly from the beliefs of an elderly, recently immigrated, Jamaican woman living in the same city.

Kleinman (1980) contends that it is necessary to differentiate between disease and illness. He defines disease as an abnormality in one's physiological and/or psychological processes. This is contrasted with illness which is the individual's psychosocial experience of disease, and the meanings which are used to explain the disease (Kleinman, 1980). These meanings are collectively called the patient's explanatory model. In addition to providing a framework for understanding disease, cultural beliefs also to some degree dictate coping responses to disease. How we understand and cope with disease, in turn influences the meaning we give to our symptoms, who we go to for help, and the expectations we have of what that help should look like (Kleinman, Eisenberg, & Byron, 1978). In the same way that patients have explanatory models, practitioners also have cognitive frameworks which are based on theoretical training and clinical experience. These frameworks or explanatory models aid the practitioner in the diagnosis and treatment of disease.

Kleinman (1980) suggests that adherence is related to the degree to which patient and practitioner explanatory models converge. The closer the convergence, the greater the likelihood of the patient exhibiting adherent behaviour.

With respect to both the Health Beliefs Model and the
patient's explanatory model, any nonadherence which may occur as a result of these factors can be considered as voluntary nonadherence. With health beliefs nonadherence may result from either a lack of motivation (i.e. low susceptibility and/or low severity), or from a lack of direction (i.e. few perceived benefits and/or many barriers). With the patient's explanatory model, nonadherence results from a lack of agreement between the patient and the practitioner along key factors related to disease diagnosis and treatment.

The last variable to be discussed from the pre-interaction phase is the nature of the illness. In general, it has been found that adherence is higher when the illness is perceived to be severe and acute, than when it is chronic (Sackett & Haynes, 1976; Zisook & Gammon, 1981). Studies actually show that with a given population, as the duration of treatment increases the degree of adherence decreases (Bloom, Cerkoney & Hart, 1980). Trepka (1986) studied 118 outpatients at a psychology clinic. She found that over time appointment-keeping decreased quite dramatically. Her figures show that 11% of the patients did not attend the initial assessment, and by the time treatment had been completed, 40.7% of the initial population had dropped out.

The combined effect of these variables; that is, demographics, the Health Beliefs Model, the patient's explanatory model, and the nature of the illness; is the production in the client of a set of affective, behavioral,
cognitive and motivational manifestations. These are constantly interacting with each other, and in combination with ongoing inputs (eg. the interaction with the practitioner) form the basis for the client's subsequent adherent behaviour.

To illustrate this interaction consider the example of Mr. A. who is a middle-aged professional. He is not entirely sure, but believes that his arthritis may have been cause by the combination of a congenital deformity, and the strain which was put on his joints as the result of his active participation in sports as a young man (cognitive appraisal). Although he is upset (affective response) by his debilitation at an early age, he believes that the Arthritis Society will be able to control his symptoms (cognitive appraisal). This makes him somewhat happier (affective response) because he can see himself being able to lead a relatively normal life in the future. At the present he is in a lot of pain, and thus is anxious to receive help in dealing with his illness (motivation). In this scenario the practitioner is going to be dealing with a gentleman who is likely to be highly motivated to follow whatever suggestions are made to him.

Interaction Phase

The pre-interaction phase looks at the characteristics which the patient brings to the interview. Now that this is understood, it is important to understand the dynamics of the
interaction which occurs when the patient and the practitioner meet. This is aptly called the interaction phase. During this phase three elements have been considered necessary for facilitating patient adherence. These are satisfaction with practitioner attributes, shared responsibility, and overall satisfaction (see Table 2).

Insert Table 2 about here

Satisfaction with practitioner attributes refers to three elements of the patient-practitioner relationship which are felt to be related to adherence. These attributes are communication, affective care, and technical competence (Stone, 1979).

Ley (1982) who conducted extensive research on the relationship between communication and adherence indicates three factors which are critical to effective communication: transmission of information from doctor to patient, patient recall, and the transmission of information from patient to doctor.

Commonsense dictates that if a patient is not clear about all aspects of the therapeutic regime, errors will be inevitable. As well, errors will also occur if the client knows what to do, but then forgets those instructions. Both of these factors have been identified by Svarstad (1976).
Table 2

Interaction Phase Variables

<table>
<thead>
<tr>
<th>Satisfaction with Practitioner Attributes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication</td>
</tr>
<tr>
<td>Affective Care</td>
</tr>
<tr>
<td>Technical Competence</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Shared Responsibility</th>
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</thead>
<tbody>
<tr>
<td>Moral Model</td>
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<tr>
<td>Medical Model</td>
</tr>
<tr>
<td>Compensatory Model</td>
</tr>
<tr>
<td>Enlightenment Model</td>
</tr>
</tbody>
</table>

| Overall Satisfaction                    |
She found that one week following a visit to the doctor, 52% of the patients made at least one error in describing their doctor's recommendations for treatment. Lastly, errors will also occur if the patient does not communicate full information to the practitioner. In one study it was found that patients did not mention 65% of their expectations, and failed to indicate 76% of their main worries (Korsch, Gozzi & Francis, 1968). When the practitioner makes a diagnosis and prescribes a treatment without taking the undisclosed information into consideration, the patient may feel that the treatment could not be correct because the withheld problem remains unexplained (Becker & Maiman, 1980).

In the first two instances described in the previous paragraph nonadherence is involuntary because cause can be attributed to lack of knowledge in the first case, and forgetfulness in the second. In the last case nonadherence is a voluntary decision on the part of the patient due to his or her dissatisfaction with the adequacy of the diagnosis and treatment regimen. As mentioned earlier, current thinking places responsibility for adherence on both the patient and practitioner. The patient is responsible for asking for clarification when unsure of what has been stated by the practitioner. The practitioner is responsible for eliciting information from, and in providing clear, concise information back to the patient.

The second practitioner attribute which has been linked
to adherence is the client's perception of the practitioner's level of affective care. Affective care has been defined by researchers according to two main parameters. The first of these relates to the type of atmosphere which the practitioner creates. Is the tone formal or informal? Is the practitioner open or closed to discussion? Does the practitioner evince patience or impatience? Does the practitioner give off an air of warmth and friendliness, or is s/he cold and brusque? Garrity (1981) states the importance of the practitioner offering emotional support which entails sympathy, understanding, and encouragement. He also mentions the work Svarstad (1974) has done on approachability, which is "an amalgamation of signs of friendliness, interest, and respect for the patient" (p.220). The second feature of affective care is the ability of the practitioner to reduce the negative affective arousal which the patient may be experiencing. Cox (1982) states that reduction of arousal can be carried out through a combination of reassurance and other anxiety-reducing interventions.

The last element of the interaction phase is the client's perception of the practitioner's competence. DiMatteo and Hays (1980) studied overall patient satisfaction with respect to a number of practitioner characteristics, one of which was technical competence. Their findings suggest that client's perception of practitioner competence is important, but difficult to separate from the patient's perception of
The second element of the interaction phase is shared responsibility. Basically shared responsibility refers to attempts made by the practitioner to include patients in the decision-making process or to share control.

Including patients in the decision-making process is a form of sharing control. As defined by Schorr and Rodin (1982), control is "the ability to have an impact on an outcome" (p.160). Perceived control has been shown to be beneficial in a number of ways: it increases patient satisfaction (Liem, 1975), it reduces the stress associated with an aversive event (Thompson, 1981), and it also increases adherence to medical regimes (Eisenthal, Emery, Lazare & Udin, 1979). Although control is usually advantageous, some studies indicate that rather than mitigating stress, control actually promotes it (Thompson, 1981). She suggests that an important factor to be taken into consideration is the meaning which control has for the individual. In some situations an individual may believe that others are better able to look after his/her problems, and thus less personal control will be desired.

One theory which elaborates on this explanation was developed by Brickman, Rabinowitz, Karuza, Coates, Cohn & Kidder (1982). Known as the models of helping and coping, it is used to explain the behaviours of both helpers and recipients of aid. Brickman et al. felt that individuals could
be classified according to the degree of responsibility they take for their problem. The concept of responsibility is then sub-divided into the extent of self-blame for the origin of the problem, and the extent of control taken for finding a solution to the problem. As an example, consider a middle-aged woman who has just become sick with a cold. She may feel that she has brought the cold upon herself from having stood in the rain on the previous day (High Self-Blame), or she might think that she is not to blame as everyone at the office had a cold this week, and so she must have caught it from one of them (Low Self-Blame). In the same way, she may believe that she can make it go away by taking Vitamin C (High Control), or she could feel that she has no control as it will go away once it has run its course (Low Control). From these distinctions a four cell matrix can be developed (see Figure 2). At any point in time an individual can be categorized according to one of these four models.

Insert Figure 2 about here

Similarly, helpers can also be classified according to where they place responsibility for problem blame and solution. By using the term 'helpers', reference is being made not only to individual practitioners, but also programs (e.g. A.A, weightwatchers), and systems (i.e hospitals, social
Figure 2. Classification matrix outlining the four categories of the Shared Responsibility Model.
## Degree of self-responsibility for solution

<table>
<thead>
<tr>
<th></th>
<th>High</th>
<th>Low</th>
</tr>
</thead>
<tbody>
<tr>
<td>High</td>
<td>Moral Model</td>
<td>Enlightenment Model</td>
</tr>
<tr>
<td>Low</td>
<td>Compensatory Model</td>
<td>Medical Model</td>
</tr>
</tbody>
</table>

Degree of self-blame for problem
agencies, government ministries). The theory suggests that the degree of concurrence between the individual's and the practitioner's adopted model can be used to help predict the outcome of the helping relationship. Karuza, Zevon, Rabinowitz & Brickman (1982) suggest that problems are solved most quickly, and effectively when there is a match or compatibility between the adopted models of both the recipient and helper. It has been further suggested that when recipient/helper models are incompatible, the client may react by seeking help elsewhere (Cohn, 1983). A less severe reaction to model incompatibility might be some degree of nonadherence on the part of the patient.

The last element of the interaction phase is overall satisfaction. According to Linder-Pelz and Streuning (1985), satisfaction is an attitude which combines both a thought process and affective evaluation. Thus, satisfaction is not only based on how the patient feels about the practitioner, but what they think about the interaction which has just occurred. Overall satisfaction has been shown in previous studies to be related to client adherence behaviours (Haynes, Taylor & Sackett, 1979; Ley, 1982).

Post - Interaction Phase

In this phase two basic processes are occurring. First of all, the client is leaving the practitioner with a certain level of motivation to adhere to the practitioner's
recommendations. Cox (1982) argues that motivation must also be considered in relation to the client's cognitive appraisal and affective response to the situation due to the interrelatedness of each of these factors.

Cox suggests that the patients make a cognitive appraisal of the following three elements; their current health status, the treatments which are available to deal with their health state, and the nature of their relationship with the health care practitioner. She goes on to state that each of these cognitions may have an attendant affective response, and these in combination are related to motivation. For example, a physiotherapist may recommend a certain type of exercise to a male patient. The patient knows someone who has tried this exercise in the past, but who found it to be painful. Therefore, when the practitioner recommends this treatment the patient may be afraid of trying this exercise himself (affective response) as he thinks of how much pain the exercise has caused his friend in the past. As a result he will not be very motivated to try this exercise himself.

The second process occurring in the post-interaction phase is a further set of variables influencing the client's motivation to exhibit adherent behaviour. These variables include problems with the home exercise program, attitudes of significant others, and use of unorthodox treatments (see Table 3).
With regards to problems with the home exercise program, Schultz (1980) outlines a number of factors regarding the treatment regimen which various researchers have related to nonadherence. She states that as the degree of behaviour change required of the patient increases, adherence decreases. Similarly, as complexity and duration of the treatment regimen increases, adherence decreases. Lastly, severe side-effects associated with the treatment will also cause a decrease in adherence behaviour.

Social support has been proposed by many researchers to be an integral part of adherence behaviour (Blackwell, 1979; Haynes, Taylor & Sackett, 1979; Levy, 1983). Becker and Green (1975) suggest that friends and family provide support on two major levels: dependency and formation of norms. Many individuals are dependent on their social network to provide direct assistance in facilitating adherence behaviour. Rides to appointments and the lending of money to pay for prescriptions would both be considered types of direct assistance. Formation of norms refers to the attitudes and beliefs held by various members of the social network, and how these norms are transmitted to the individual. Thus, the
Table 3

Post-Interaction Phase Variables

<table>
<thead>
<tr>
<th>Attitudes of Significant Others</th>
</tr>
</thead>
<tbody>
<tr>
<td>Use of Unorthodox Treatments</td>
</tr>
<tr>
<td>Problems with the Home Exercise Program</td>
</tr>
</tbody>
</table>
reactions of significant others to the treatment regimen are important because they can help to shape the response of the patient to his or her own treatment. From the point of view of the health care practitioner, families have the potential to reward good self-care behaviour, and to extinguish poor behaviour (Blackwell, 1979).

The last factor to be discussed is the use of unorthodox treatments. Although no studies could be found which identify use of alternative therapies as a cause of nonadherence, circumstantial evidence points to the possible connection between these two variables. Kronenfeld and Wasner (1982) indicate that many arthritis patients resort to alternative therapies because traditional medical treatments are often ineffectual on a long-term basis. As orthodox medicine does not have definitive answers, patients look for help elsewhere. Evidence for this phenomena comes from the Kronenfeld and Wasner (1982) study which showed that only 5% of the patients used alternative therapies prior to contacting a physician. This is in comparison to 83% of the patients who sought alternative therapies after being in a physician's care for more than one year. Although these findings are not directly related to nonadherence, it would seem plausible that nonadherence might increase as patients became more disillusioned with orthodox forms of treatment.

In summary, ten variables have been identified in the literature review as being related to nonadherence. By order
of occurrence in the Health Interaction Strategy Model these variables are as follows: demographics, the Health Beliefs Model, the patient's explanatory model, and nature of the illness (Pre-Interaction Phase); satisfaction with practitioner attributes, overall satisfaction, and shared responsibility (Interaction Phase); and problems with the home exercise program, attitudes of significant others, and use of unorthodox treatments (Post-Interaction Phase).

As each of these variables has been shown to be related to nonadherence in previous studies, it was felt that all should be given equal consideration as possible contributory factors to chronic nonadherence. They thus formed the basis of a structured, exploratory interview which was conducted with two populations of arthritis patients; a group of eight patients defined by the Arthritis Society as being chronic nonadherents, and a comparison group of seven randomly chosen arthritis patients.
METHODOLOGY

Subjects

Two populations were examined in this research study. The first was a small group of people who were identified by the Arthritis Society as being chronic, treatment nonadherents. As defined earlier, a chronic nonadherent is someone who exhibits a complete lack of adherence to at least one aspect of his or her therapeutic regimen for extended periods of time. The second population which was used as a comparison group had similar characteristics as the first population, except that treatment adherence behaviours were not known.

The chronic nonadherent population was hand-picked by key Arthritis Centre personnel according to the following criteria: male, living in Greater Vancouver, between the ages of 21 and 65, fluent in English, received physiotherapy at the Arthritis Centre within the past year, given a home exercise program by the physiotherapist, and by self-admission are nonadherent to the home exercise program. Fifteen patients were identified as meeting these criteria. Of these, four could not be located, and the fifth was a patient whom the Arthritis Society deemed ineligible because of additional medical complications. The remaining ten patients agreed to participate in the study. Unfortunately one of these participants was dropped from the study because he
consistently failed to meet with the interviewer, and the findings from a second participant were excluded from the results due to difficulties encountered by the respondent in understanding and answering questions. This left the chronic nonadherent group with eight respondents.

As previously indicated, assignment to the chronic nonadherent group was based on an assessment by the Arthritis Society. In order to check the validity of this assignment all respondents were asked for a self-report of their adherence behaviors.

A comparison group of 10 patients was randomly chosen from the total population of patients who are male, between the ages of 21 and 65, and living in the City of Vancouver. As this was the only information available from Arthritis Society records, an additional reserve sample pool of 20 patients was drawn in case original sample members were not fluent in English, had not received physiotherapy in the past year, had not received a home exercise program, or could not be located. After introductory telephone calls were made by an Arthritis Society staff member, ten patients were identified as meeting the aforementioned selection criteria. Of these, two patients refused to participate and one patient, although able to speak some English, was not sufficiently fluent to participate in the research study. This left the comparison group with seven respondents.
Procedures

Potential respondents in both the chronic nonadherent group, and the comparison group were originally called by a staff member at the Arthritis Society in order to notify these patients that they had been selected to participate in a research study. It was felt that the initial call should come from the Arthritis Society in order to maintain patient confidentiality, and to legitimize subsequent contacts from someone who was not an employee of the Arthritis Society.

This contact was followed by introductory letters which were sent to potential respondents explaining the details of the research study, and indicating that they would soon be receiving a second telephone call. This call was made by the researcher in order to answer any questions potential respondents might have had, and to ask for their participation in the study. Respondents who expressed interest in the study then participated in a 1½ hour, in-home, taped interview.

As part of this study a small amount of information was also required from the therapists in the physiotherapy department of the Arthritis Society. In order to obtain this information, contact was first made with the department head. The purpose of the study was explained to the manager of the department, and permission was then received to distribute a short questionnaire at the next physiotherapy staff meeting. At this meeting the therapists were given a brief explanation
of the study prior to their completion of the questionnaire. After completion questions were answered, and a more in-depth explanation of the study was provided.

**Measures**

The interview schedule for this study contained a mix of both qualitative and quantitative questions. The primary reason for using the two methodologies is as Glaser and Strauss (1967) state, that research is enriched when both types of methodology are used in unison. Together they provide different outlooks on the same data, and thus act together through a process of supplementation and mutual verification. Table 4 indicates the correspondence between study variables and interview schedule questions.

Insert Table 4 about here

The quantitative questions used in the interview schedule are a combination of items from pre-existing scales, and items which have been constructed specifically for this study. An attempt was made to find reliable, valid scales, but this was not always possible due to the specific nature of the information which was required. Interview items which were constructed for the study follow as closely as possible
Table 4

Correspondence Between Study Variables and Interview Schedule Questions

<table>
<thead>
<tr>
<th>Independent Variables</th>
<th>Relevant Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Demographics</td>
<td>(51)(52)(53)(54)(55)(56)(57)</td>
</tr>
<tr>
<td></td>
<td>(58)</td>
</tr>
<tr>
<td>Health Beliefs</td>
<td></td>
</tr>
<tr>
<td>Perceived Susceptibility</td>
<td>(2)(4)</td>
</tr>
<tr>
<td>Perceived Severity</td>
<td>(6)(11)(15)(17)</td>
</tr>
<tr>
<td>Perceived Barriers</td>
<td>(8)<em>(9)(13)</em>(14)*</td>
</tr>
<tr>
<td>Perceived Benefits</td>
<td>(7)*(10)(12)(16)</td>
</tr>
<tr>
<td></td>
<td>(28)(30)(31)</td>
</tr>
<tr>
<td>Nature of the Illness</td>
<td>(1)(3)(21)(22)*(23)</td>
</tr>
<tr>
<td>Satisfaction with Practitioner Attributes</td>
<td></td>
</tr>
<tr>
<td>Communication</td>
<td>(80)(83)(86)<em>(87)</em>(92)(93)*</td>
</tr>
<tr>
<td></td>
<td>(95)*</td>
</tr>
</tbody>
</table>

(table continues)
<table>
<thead>
<tr>
<th>Independent Variables</th>
<th>Relevant Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Affective Care</td>
<td><em>(79)</em>(81)(82)<em>(84)(85)(88)</em></td>
</tr>
<tr>
<td></td>
<td><em>(91)</em>(94)(96)*</td>
</tr>
<tr>
<td>Technical Competence</td>
<td><em>(89)</em>(90)(97)*</td>
</tr>
<tr>
<td>Shared Responsibility</td>
<td><em>(59) → (78)</em></td>
</tr>
<tr>
<td>Overall Satisfaction</td>
<td><em>(29)(32)(98)(99)</em> <em>(100)(101)</em></td>
</tr>
<tr>
<td></td>
<td><em>(102)</em>(103)(104)*</td>
</tr>
<tr>
<td>Attitudes of Significant Others</td>
<td><em>(46)(47)(48)</em></td>
</tr>
<tr>
<td>Use of Unorthodox Treatments</td>
<td><em>(49)</em>(50)*</td>
</tr>
<tr>
<td>Problems with the Home</td>
<td><em>(33)</em>(34)<em>(35)</em>(36)<em>(37)</em></td>
</tr>
<tr>
<td>Exercise Program</td>
<td><em>(38)</em>(39)*</td>
</tr>
<tr>
<td><strong>Dependent Variable</strong></td>
<td></td>
</tr>
<tr>
<td>Adherence</td>
<td><em>(40)(41)(42)(43)(44)(45)</em></td>
</tr>
</tbody>
</table>

* denotes questions which were reversed in scoring
variable definitions as provided by theorists in the field in order to enhance content validity. The complete interview schedule can be found in Appendix A.

Adherence

Adherence behaviours of both the chronic nonadherent group and the comparison group were measured in this study. The former measurements were taken in order to check the validity of the assignments made by the Arthritis Society. The latter measurements were taken as adherence behaviours of the comparison group were not previously known.

In order to measure adherence behaviours, a scale developed in a study carried out by Carpenter and Davis (1976) was utilized. Studying rheumatoid arthritis patients who had just been released from hospital, they used the scale to determine adherence to an exercise regime prescribed at the time of discharge. Carpenter and Davis defined adherence according to how well patients adhered to both exercise frequency and format.

No figures indicating reliability and validity are given by the authors, although they state that the validity of the adherence measure was tested by cross-checking the scale results with information obtained from three other sources. However, no indication is given by the authors as to how well the adherence scale performed in relation to these additional measures.
This particular measure was chosen for a number of reasons. First of all, it has been previously used to measure the same type of behaviour (adherence to a home exercise program), and with the same population (arthritis patients) as the current study. Secondly, the scale is short and easily understood. Lastly, the scale appears to have good face validity in that quantity and quality of exercise seem to be the two criteria which define proper exercise adherence.

The only changes which were made to this scale involved the addition and deletion of single questions, and a slight re-wording of existing questions. The added question asks the respondent to indicate the frequency with which they were told to do their exercises. This question has been added as patient files do not usually include this type of information.

As noted by many authors, adherence is a difficult variable to measure (Gordis, 1976; Hilbert, 1985). Measurement of outcome criteria is not usually possible because patients respond in different ways to treatment. As it is also not possible to watch patients complete their exercises, researchers are often forced to rely on self-report measures. The problem with this type of measure is that adherence is a socially desirable behaviour, and thus, respondents will tend to underestimate nonadherence behaviour (Gordis, 1976).

Because positive self-presentation (social desirability) occurs when a person feels threatened, a counteractive
strategy is to make questions seem less threatening (Bailey, 1982). This can be done by wording the question in such a way that an assumption is made that a majority of people already engage in the behaviour. For example, prior to the questions on adherence, a statement was included which read as follows: 'following the recommendations of one's physiotherapist is not always easy, and thus many people find it difficult to do their home exercises exactly as they were taught'. This statement attempted to give people permission to admit that they may have not been totally adherent, if this was indeed the case.

A further difficulty in distinguishing between adherent and nonadherent behaviour is that patients are often told to alter their exercise regime if excessive pain is experienced. Thus, it is difficult to determine whether a respondent who has made modifications to his or her exercise program is still adherent. In order to ascertain whether respondents who had made minor alterations to their exercise program should be classified as adherent or nonadherent, help was enlisted from the physiotherapy department. Working as a group, three physiotherapists were given the following patient information: diagnosis, type of home exercises given, frequency of exercise completion, and qualitative changes made to the exercise program. Using this information the physiotherapists were then asked to discuss the case and come up with a consensus as to whether respondents were exhibiting adherent or nonadherent
behaviours. Based on this decision, patients were then categorized as being adherent or nonadherent.

Demographics

This study asked respondents for information regarding their age, living situation, marital status, ethnic origin, level of education, income, and employment status.

The Health Beliefs Model

The Health Beliefs Model is a variable which has been measured using a scale developed by Given, Given, Gallin and Condon (1983). Although designed to measure the health beliefs of diabetic patients, the scale has been easily adapted to make it pertinent for use with an arthritis population. The scale was selected for this study because it addresses some of the criticisms which have been directed towards earlier measures. For example, previous scales have been criticized for using only one or two items to measure each concept (Champion, 1984). The Given et al. (1983) questionnaire uses numerous items for each of the subscales of perceived severity, perceived barriers, and perceived benefits. A second criticism mentioned by Champion (1984) is that previously concepts were operationalized at a nominal level, thereby limiting analysis to the use of elementary statistics. The Given et al. (1983) scale addresses this issue by using a large number of questions, and by scoring
items on a 5-point Likert scale. This allows for analysis appropriate to interval level data. One criticism mentioned by Champion (1984) which the Given et al. (1983) scale does not meet is that like earlier Health Belief scales, it has not been well-tested for validity or reliability. However, to the authors’ credit, they do discuss attempts to improve construct validity through the use of a three stage process to develop the questionnaire. These stages included: (1) a review and adaptation of previous instruments, (2) a review of patient education materials, and (3) in-depth interviews with 25 diabetic patients.

Changes which were made to this questionnaire in adapting it to the chronic nonadherence study included the deletion of a number of questions in order to pare the subscales down to four items each. This was done for the sake of brevity. Items which were kept were selected on the basis of high item-cluster correlation. These items were then reworded slightly to make them applicable to an arthritis population. Lastly, two items were added in order to measure a fourth concept, perceived susceptibility. Questions relating to susceptibility are not usually asked of patients with an acute or chronic illness as the presence of symptoms makes this question redundant. However, as certain types of arthritis may occasionally go into remission, it was felt that querying these patients regarding susceptibility would be appropriate. A sample of a couple of the items related to the Health
Beliefs Model includes; 'In general, the home exercises have helped my arthritis', and 'I worry when I think about how bad my arthritis may get in the future'.

Patient's Explanatory Model

This variable was measured using a number of qualitative questions developed by Kleinman (1980) to aid researchers and health care practitioners in eliciting patient's explanatory models. Although eight questions were developed for this purpose, only four of these were used in this study. Two questions were not included because they were asked elsewhere in the interview, and the last two questions were eliminated because they were felt to be extraneous to the subject of nonadherence. Two questions were added to find out whether patients had expectations of the Arthritis Society being able to control and/or cure their disease. Two of the questions which were included in the interview are as follows; 'what do you think has caused your arthritis?', and 'why do you think that was the cause?'

Nature of the Illness

As no standardized questions were found to measure this variable all questions were developed by the author. Elements of this variable which were felt to be important based on a review of the literature included current disease activity, current severity of the illness, perceived impact, and
perceived future duration of the disease. Each of these elements was measured with a single question. As an example, respondents were asked the following question, 'up to this point in time how much of an impact has your arthritis had on your life?'.

**Satisfaction with Practitioner Attributes**

The respondent's satisfaction with their practitioner's communication, affective care and technical competence was measured using a scale which was adapted by DiMatteo and Hays (1980) from two earlier measures. The scale was used by these two researchers to assess patients' satisfaction with their family physicians. In conducting this study on a sample of 329 patients, the researchers found that internal consistency tended to be higher than test-retest reliability. The exact figures being as follows: Cronbach's alpha = .92 (n=287), and test-retest reliability = .63 (n=22).

The adapted scale of DiMatteo and Hays (1980) was used in this study because of its qualities of brevity, being easily understood, and having high internal consistency. The only changes which were made to the scale involved dropping a five item subscale measuring general satisfaction, and the rewording of questions in order to change the orientation of the questions from physicians to physiotherapists. Two sample items from this scale are, 'the physiotherapist always seemed to know what she was doing', and 'the physiotherapist gave me
suggestions on what I could do to manage my arthritis better'.

Shared Responsibility

Shared responsibility is a variable which has been measured using a 20-item scale developed by Gleason, Karuza and Zevon (1981). This scale has been previously used to measure whether practitioner's choice of helping model is related to the age of the target population. Although information on validity is not available, the internal consistency of the scale is said to range anywhere from .6 to .8, depending on which of the helping models is being measured (J. Karuza Jr., personal communication, May 20, 1988).

Overall Satisfaction

Satisfaction is a variable which has been measured using an eight item client satisfaction questionnaire (CSQ-8) developed by Larsen, Attkisson, Hargreaves and Nguyen (1979). This questionnaire was selected for the chronic nonadherence study because of a number of advantages it holds over other measures. First of all, the scale has been used in a number of different settings that service different client types (Pascoe & Attkisson, 1983). Secondly, the questionnaire has been found to have repeatedly high values of internal consistency. Attkisson and Zwick (1982) indicate that previous studies have found internal consistency values of .93, .92, and .87. Thirdly, Attkisson and Zwick (1982) have
shown that the CSQ-8 also has a high degree of split-half reliability. The fourth benefit is that construct validity has been enhanced through a process of literature review and critiquing by a variety of health professionals and administrators (Nguyen, Attkisson & Stegner, 1983). Lastly, this scale has been shown to be significantly correlated with service utilization (Attkisson & Zwick, 1982).

One of the problems with this, or any satisfaction scale, is that studies using these scales repeatedly show unreasonably high levels of client satisfaction. In an attempt to limit the affects of social desirability, it was found that respondents reported a lower level of satisfaction when answering questions using a written mode versus an oral interview style. Conversely, the oral administration mode resulted in a significantly lower number of unanswered questions as compared to the written mode (Nguyen, Attkisson & Stegner, 1983). Thus, there are both advantages and disadvantages to using an interview-style format.

In adapting this scale to the chronic nonadherence study the only change made was to delete one question. This was done in order to make the satisfaction questionnaire equivalent to the questionnaire used in an earlier Arthritis Society study. This will allow comparison of satisfaction levels between both of these studies. One of the questions which was used to tap this variable was 'if a friend were in need of similar help, would you recommend your physiotherapist
Attitudes of Significant Others

This variable was measured with three questions, two of which were quantitative and one which was qualitative. These were developed by the author to determine how the advice or attitudes of significant others might affect adherence behaviours. For example, respondents were asked the following question, 'what were the reactions of family members to the treatments recommended by the physiotherapist?'. No information regarding validity and reliability is known for this variable.

Use of Alternative Treatments

The use of unorthodox therapies was measured with one qualitative question, and a single quantitative question. These questions sought to determine the numbers and types of alternative treatments which have been previously used by respondents.

It was felt by the author that respondents might be afraid of admitting the use of treatments which are frowned upon by the Arthritis Society. In order to counteract this effect, a technique was used which implies that the respondent engages in socially undesirable behaviour and leaves the responsibility up to the participant to deny that the behaviour is present (Bailey, 1982). For example, instead of
asking if respondents had tried unorthodox treatments, they were asked how many alternative treatments they had tried, with one of the available responses being 'none'. With the first form of the question, it is much easier for respondents to deny the behaviour, even if they have engaged in it at some previous point in time.

Problems with the Home Exercise Program

With this variable patients were asked to respond to six commonly cited problems associated with home exercise programs in order to determine the salience of each of these problems. As an example, respondents were asked to respond to the following statement, 'treatment made me feel worse afterwards'. A seventh question was added in order to discover whether respondents had any problems with their home exercise program in addition to the ones which had been previously mentioned.

As these questions were developed by the author, no information is available regarding validity or reliability.

Enhancement of Questionnaire Validity and Reliability

In order to improve validity for the whole questionnaire, data were gathered using an interview format. Bailey (1982) suggests that an interview format allows for access to the respondents non-verbal behaviour, as well as increasing respondent spontaneity. Access to non-verbal behaviour allows
the interviewer to estimate how truthful the respondent is being. The advantage of spontaneity refers to the fact that in answering questions, respondents are more likely to state the first thoughts which come to mind. Bailey feels that these first thoughts are more likely to be informative rather than normative. Or in other words, the first thoughts are more likely to reflect what the respondent really believes, as compared to what the respondent thinks the interviewer wants to hear.

One fear which respondents may have had is that word would get back to the Arthritis Society if they admitted to being nonadherent, dissatisfied, or otherwise engaged in some form of socially undesirable behaviour. In an attempt to assuage this fear, it was stressed at the beginning of the interview that all interview information was to be kept strictly confidential.

Miller (1986) states, "if a measure is valid (assesses what it is supposed to) it must also be reliable (relatively free of random error)" (p.59). Thus, the aforementioned techniques to improve validity should also have had a positive effect on the reliability of the interview schedule. In addition, one technique was used specifically to improve reliability. For the closed-ended questions, cards listing available responses were given to the respondents from which they could then choose their answer. By using cards all responses had an equal chance of being chosen; whereas, if the
answers were read aloud to the respondent, the first and last answers may have had a disproportionate chance of being chosen due to the primacy or recency effect.

Data Analysis

One of the difficulties associated with qualitative research is that the methodology is not standardized. In other words, analysis techniques are often applied in a variety of ways by different social scientists. Thus, in order for replication to occur it is not only important for future researchers to know the questions which were asked, but also the means by which the data was analyzed.

In this study the qualitative data have been primarily used as a supplement to the quantitative data analysis. This was carried out by coding the interview transcripts according to the various independent variables used in this study. For example, if any mention was made with respect to how aspects of the patient's illness affected adherence a notation was made. Similarly, notations were made in the interview transcripts if respondents made reference to any of the other variables being considered in this study. Quotations from the tape transcripts were then compiled categorically by variable. These quotations were then used to either verify or dispute the results of the quantitative data analysis. A sample interview transcript, prior to analysis, can be found in Appendix 2.
The quantitative data first underwent a process of univariate analysis whereby the frequencies, measures of central tendency, and measures of dispersion were determined for each variable. As the study was set up to ascertain factors associated with chronic nonadherence, t-test analysis was carried out in order to observe whether any differences were evident in the chronic nonadherent group and the comparison group. For variables which did not produce interval level data, median tests were carried out.

In measuring the actual adherence behaviours of group members it was found that some members of the chronic nonadherent group were, in fact, adherent, and some members of the comparison group were chronically nonadherent. Because of this finding, a second set of t-tests and median tests were conducted. For this second analysis respondents were rearranged into groups according to actual adherence behaviours. It was felt that this second set of analyses would provide a more accurate indication of the factors associated with adherence.
RESULTS

When the study was originally set up, the intention was to compare data between the chronic nonadherent group and the comparison group in order to determine the factors associated with chronic nonadherence. Once the data began to be analyzed, however, it was discovered that two of the eight respondents in the chronic nonadherent group were adherent to their home exercise programs. Similarly, two of the seven respondents in the comparison group were found to be nonadherent. Although this only represents a 25% error, it was felt that a second set of analyses should be carried out between those respondents who reported adherence to their home exercise program, and those who did not, regardless of the original Arthritis Society categorization. It is this second analysis which is of primary importance because it points to those factors that are actually related to patient adherence behaviours. Thus, it is this analysis which will be discussed on the following pages.

The first analysis which compares the data between the chronic nonadherent group as defined by the Arthritis Society, and the randomly chosen comparison group can be found in Appendix 3. A discussion which looks at deviant behaviour and the effects of labelling has been appended to this analysis.

Before presenting the results it is important to note the limits of the design in its ability to detect statistically
significant findings. This can be attributed to the fact that data analysis was carried out on a very small sample (N = 15). Thus, the analysis was prone to "Type Two Error"; the possibility of rejecting a finding which is, in fact, true. However, although statistically significant findings are lacking, the study did point to some interesting findings which ideally should be analyzed with a larger sample. In examining the mean differences between the two groups a significance level of .10 was chosen due to the exploratory nature of the study (Blalock, 1972).

**Analysis Using Self-Reported Measures of Adherence**

**Demographics**

Many of the demographic characteristics of the adherent and nonadherent group were shown to be similar. For example, both groups were well-matched with respect to living situation, and educational level. Factors which showed minor differences included age and marital status. With regard to age, nonadherents tended to be slightly older than the adherents. Thus, 62.5% of the nonadherents are 46 years of age or older, while only 42.9% of the adherents are in this same category (see Table 5). With respect to marital status, a lower percentage of nonadherents are married (37.5%) as compared to the patients who are adherents (57.1%).
As indicated in Table 5, factors that do show considerable differences are income and employment status. Nonadherents tended to be both low income earners and unemployed.

The Health Beliefs Model

Four variables are subsumed under the heading of health beliefs. These variables are perceived severity, perceived susceptibility, perceived barriers, and perceived benefits. Although each of these has been analyzed separately, they can be considered as various dimensions of a single unit, the individual's health beliefs model. As mentioned earlier, perceived susceptibility questions are not usually asked of patients with active symptomatology as the presence of symptoms makes the question redundant.

Of these variables, one which showed a significant difference in the scores of nonadherents and adherents was perceived severity (see Table 6).

In this instance the cross-tabulation indicates that adherents tended to have a stronger belief in the future
Table 5

Cross-Tabulations: Patient Demographic Characteristics by Adherence

<table>
<thead>
<tr>
<th>Demographic Characteristics</th>
<th>Nonadherents</th>
<th>Adherents</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No.</td>
<td>%</td>
</tr>
<tr>
<td></td>
<td>n = 8</td>
<td></td>
</tr>
</tbody>
</table>

**Age (Median = 46)**
- Under 46 years: 3 (37.5%) 4 (57.1%)
- 46 years and over: 5 (62.5%) 3 (42.9%)

**Living Situation**
- Alone: 3 (37.5%) 3 (42.9%)
- Other: 5 (62.5%) 4 (57.1%)

**Marital Status**
- Married: 3 (37.5%) 4 (57.1%)
- Other: 5 (62.5%) 3 (42.9%)

**Education**
- High School or less: 3 (37.5%) 3 (42.9%)
- Post-High School: 5 (62.5%) 4 (57.1%)

*(table continues)*
<table>
<thead>
<tr>
<th>Demographic Characteristics</th>
<th>Nonadherents</th>
<th>Adherents</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No.</td>
<td>%</td>
</tr>
<tr>
<td></td>
<td>n = 8</td>
<td></td>
</tr>
<tr>
<td>Income</td>
<td></td>
<td></td>
</tr>
<tr>
<td>under 20,000</td>
<td>6</td>
<td>85.7</td>
</tr>
<tr>
<td>20,000 and above</td>
<td>1</td>
<td>14.3</td>
</tr>
<tr>
<td>Employment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employed</td>
<td>2</td>
<td>25.0</td>
</tr>
<tr>
<td>Other</td>
<td>6</td>
<td>75.0</td>
</tr>
<tr>
<td>Perceived Severity</td>
<td>Mean*</td>
<td>SD</td>
</tr>
<tr>
<td>--------------------</td>
<td>-------</td>
<td>----</td>
</tr>
<tr>
<td>nonadherents</td>
<td>12.3</td>
<td>3.0</td>
</tr>
<tr>
<td>adherents</td>
<td>9.9</td>
<td>3.0</td>
</tr>
</tbody>
</table>

* Means were obtained by first summing the scores on the four items related to perceived severity. The mean thus represents the average total score of each respondent in each group.
severity of their disease than did nonadherents (see Table 7).

Patient's Explanatory Model

The Explanatory Model looks at the reasons people use to explain their illness. Analysis of the qualitative data showed that a majority of people felt that their disease was the result of a two-stage process. The first stage involves the existence of some type of factor which predisposes them to getting arthritis. Often mentioned factors in this light were heredity (50%), previous injuries (19%), and early life experiences (31%). Both heredity and previous injury are standard explanations espoused by the Arthritis Society as likely causes of rheumatic disease. As is evident, a large percentage of patients in this study had a belief in these standard explanations. A smaller percentage of patients believed in a combination of one of the standard explanations and early life experiences. These patients held to the notion that events in their early life somehow weakened them, thus making them more susceptible to the arthritis. Some examples of the early experiences referred to by respondents include previous diseases, poor food habits, improper clothing as a child, and for another individual improper clothing as an
Table 7

Cross-Tabulations: The Health Beliefs Model by Adherence

<table>
<thead>
<tr>
<th>Health Beliefs</th>
<th>Nonadherents</th>
<th>Adherents</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No.</td>
<td>%</td>
</tr>
<tr>
<td></td>
<td>n = 8</td>
<td></td>
</tr>
<tr>
<td>Perceived Severity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High</td>
<td>4</td>
<td>50.0</td>
</tr>
<tr>
<td>Low</td>
<td>4</td>
<td>50.0</td>
</tr>
<tr>
<td>(Median Split)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High</td>
<td>3</td>
<td>37.5</td>
</tr>
<tr>
<td>Low</td>
<td>5</td>
<td>62.5</td>
</tr>
</tbody>
</table>
adult. Only one respondent believed that an early life experience was the sole factor predisposing him to arthritis.

The second stage of the process requires the occurrence of some type of event which triggers development of the arthritis. Only two factors were mentioned by respondents as activating their disease. These were stress (58%) and illness (42%).

Not all respondents believed that their arthritis was the result of a two-stage process. Two patients (13%) had explanations as to why they were predisposed towards the disease, but were not aware of any events that might have activated the disease. Conversely, four patients (21%) were able to pinpoint factors which triggered the arthritis, but did not believe that they were somehow prone to getting arthritis. However, the majority of respondents (66%) felt that both factors were necessary. It is interesting to note that all four respondents listing a triggering factor as the sole cause of their arthritis were nonadherents.

A second part of the explanatory model explored with patients was treatment expectations. Treatment expectations refer to specific types of treatment patients remember that they were hoping to get from the Arthritis Society prior to the agency's involvement in their care. Types of treatment mentioned by patients were exercise (35%), other treatments (e.g. medication) (15%), and information (50%). With regards to these treatment expectations, adherents were much more
likely to have expected the procurement of information (100%), than were nonadherents (42.9%).

The second treatment expectation component was whether patients felt that cure and/or control of their disease was possible. No differences were evident between the two groups with respect to their belief in the ability of the Arthritis Society to cure or control their disease.

Nature of the Illness

The only factor related to the illness itself which had some relation to adherence was the presence of other medical problems. What the findings show is that nonadherents were more likely to have other medical problems (75.0%) than were adherents (42.9%) (see Table 8).

Table 9 lists other medical problems experienced by respondents in addition to their primary arthritis diagnosis.

Satisfaction with Practitioner Attributes

Table 10 indicates the relationship between satisfaction and adherence.
Table 8
Cross-Tabulation: Nature of the Illness by Adherence

<table>
<thead>
<tr>
<th>Presence of other Medical Problems</th>
<th>Nonadherents</th>
<th>Adherents</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No.</td>
<td>%</td>
</tr>
<tr>
<td></td>
<td>n = 8</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>6</td>
<td>75.0</td>
</tr>
<tr>
<td>No</td>
<td>2</td>
<td>25.0</td>
</tr>
</tbody>
</table>
Table 9

Other Medical Problems Reported by Study Respondents

<table>
<thead>
<tr>
<th>Medical Problem</th>
<th>Number of Patients Reporting Problem</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depression</td>
<td>3</td>
</tr>
<tr>
<td>Reiter's Syndrome*</td>
<td>2</td>
</tr>
<tr>
<td>Hypertension</td>
<td>2</td>
</tr>
<tr>
<td>Fibrositis*</td>
<td>1</td>
</tr>
<tr>
<td>Bronchial Asthma</td>
<td>1</td>
</tr>
<tr>
<td>Back Injury</td>
<td>1</td>
</tr>
<tr>
<td>Hiatus Hernia</td>
<td>1</td>
</tr>
<tr>
<td>Episcleritis*</td>
<td>1</td>
</tr>
</tbody>
</table>

* denotes medical problems that are a form of arthritis
As can be seen, the only factor which shows any degree of significance is affective care. Cross-tabulations (Table 11) point out that nonadherents were somewhat more unhappy with their physiotherapists level of affective care than were adherents.

Table 12 illustrates the cross-tabulations of the four shared responsibility models by adherence.

Table 13 illustrates the same data with median-split cross-tabulations. It was found with the first cross-tabulation that individual accumulated scores were tending to cluster at the low or high ends of the continuum, thus blurring the actual differences between the two groups. By carrying out the split-median cross-tabulation these differences were made
Table 10

T-Test Analysis of Patient Satisfaction with Practitioner Attributes with Adherence

<table>
<thead>
<tr>
<th>Affective Care</th>
<th>Mean*</th>
<th>SD</th>
<th>T</th>
<th>2-Tail Prob</th>
</tr>
</thead>
<tbody>
<tr>
<td>nonadherents</td>
<td>18.1</td>
<td>3.4</td>
<td>1.07</td>
<td>0.302</td>
</tr>
<tr>
<td>adherents</td>
<td>21.3</td>
<td>7.5</td>
<td>1.07</td>
<td>0.302</td>
</tr>
</tbody>
</table>

* Means were obtained by first summing the scores on the nine items related to affective care. The mean thus represents the average total score of each respondent in each of the two groups.
Table 11

Cross-Tabulations: Patient Satisfaction with Practitioner Attributes by Adherence

<table>
<thead>
<tr>
<th>Practitioner Attributes</th>
<th>Nonadherents</th>
<th>Adherents</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No.  %</td>
<td>No.  %</td>
</tr>
<tr>
<td></td>
<td>n = 8</td>
<td>n = 7</td>
</tr>
</tbody>
</table>

Affective Care

<table>
<thead>
<tr>
<th></th>
<th>Satisfied</th>
<th>Dissatisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>Satisfied</td>
<td>6 75.0</td>
<td>2 25.0</td>
</tr>
<tr>
<td>Dissatisfied</td>
<td>7 100.0</td>
<td>0 0.0</td>
</tr>
</tbody>
</table>

Affective Care (Median Split)

<table>
<thead>
<tr>
<th></th>
<th>Satisfied</th>
<th>Dissatisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>Satisfied</td>
<td>5 62.5</td>
<td>3 42.9</td>
</tr>
<tr>
<td>Dissatisfied</td>
<td>3 37.5</td>
<td>4 57.1</td>
</tr>
</tbody>
</table>
Table 12

Cross-Tabulations: Shared Responsibility Models by Adherence

<table>
<thead>
<tr>
<th>Shared Responsibility Model</th>
<th>Nonadherents</th>
<th>Adherents</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No.</td>
<td>%</td>
</tr>
<tr>
<td>Moral Model</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(High Blame/High Control)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>3</td>
<td>37.5</td>
</tr>
<tr>
<td>High</td>
<td>5</td>
<td>62.5</td>
</tr>
<tr>
<td>Medical Model</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Low Blame/Low Control)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>7</td>
<td>87.5</td>
</tr>
<tr>
<td>High</td>
<td>1</td>
<td>12.5</td>
</tr>
<tr>
<td>Compensatory Model</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Low Blame/High Control)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>High</td>
<td>8</td>
<td>100.0</td>
</tr>
<tr>
<td>Enlightenment Model</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(High Blame/Low Control)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>7</td>
<td>87.5</td>
</tr>
<tr>
<td>High</td>
<td>1</td>
<td>12.5</td>
</tr>
</tbody>
</table>
more distinct.

It can be seen that both nonadherents and adherents showed themselves to be solid proponents of the compensatory model (low blame/high control). However, one of the differences which is evident is that nonadherents were more uniform in their choice of adopted model, than the adherents. In addition to scoring high on the compensatory model, nonadherents also had low medical model (low blame/low control) and enlightenment (high blame/low control) model scores. In fact, the split median cross-tabulations indicate that the nonadherents had considerably lower scores than the adherents for these two models. This shows that although adherents and nonadherents were proponents of the compensatory model (low blame/high control), the nonadherents were more strongly uniform in rejecting other models which propound low levels of control.

According to theory, shared responsibility scores of the respondents should be paired with the shared responsibility scores of the physiotherapists in order to determine if there is a match between the two adopted models. As discussed in the literature review, adherence should be higher for patients who hold the same adopted model as the physiotherapist with whom they are working. Unfortunately for this study two
### Table 13

**Cross-Tabulations: Shared Responsibility Models by Adherence (Median Split)**

<table>
<thead>
<tr>
<th>Shared Responsibility Model</th>
<th>Nonadherents</th>
<th>Adherents</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No.</td>
<td>%</td>
</tr>
<tr>
<td>Moral Model (High Blame/High Control)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>5</td>
<td>62.5</td>
</tr>
<tr>
<td>High</td>
<td>3</td>
<td>37.5</td>
</tr>
<tr>
<td>Medical Model (Low Blame/Low Control)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>6</td>
<td>75.0</td>
</tr>
<tr>
<td>High</td>
<td>2</td>
<td>25.0</td>
</tr>
<tr>
<td>Compensatory Model (Low Blame/High Control)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>4</td>
<td>50.0</td>
</tr>
<tr>
<td>High</td>
<td>4</td>
<td>50.0</td>
</tr>
<tr>
<td>Enlightenment Model (High Blame/Low Control)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>5</td>
<td>62.5</td>
</tr>
<tr>
<td>High</td>
<td>3</td>
<td>37.5</td>
</tr>
</tbody>
</table>
factors prevented this pairing from taking place. Some of the patients have had more than one physiotherapist providing treatment, and thus it was impossible to decide which physiotherapist to choose for the comparison. Secondly, three physiotherapists who originally provided care for these patients were no longer at the Arthritis Society, and thus could not be tested. For the sake of interest, the adopted models of the nine physiotherapists who were tested were as follows: medical model (1), moral model (4), compensatory model (4). This suggests that, on the whole, physiotherapists at the Arthritis Society feel that it is important for their patients to have control. However, there are mixed feelings among these staff members as to the degree to which patients should be blamed for their problems.

Overall Satisfaction

T-test analysis indicates that few differences exist between the overall satisfaction of adherents and nonadherents.

Attitudes of Significant Others

No relationship was indicated between attitudes of significant others and adherence. However, it is interesting to note that advice from others will sometimes affect adherence. For example, one respondent states that he was previously adherent until he talked with a friend who had a
similar medical problem. Having had to endure a significant amount of pain as a result of exercising, his friend had stopped doing exercises. Upon hearing this news, the respondent decided to do the same, as he was also finding the exercises painful to carry out.

Use of Alternative Treatments

No differences were found between the use of alternative treatments by adherents and nonadherents.

Problems with the Home Exercise Program

When patients were asked to respond to a variety of problems previously found to be associated with the home exercise program, it was discovered from median test analysis that adherents had less problems with their exercises than did nonadherents (see Table 14). Analysis shows that 71.4% of adherents are equal to or below the median, while only 37.5% of the nonadherents are in the same position. A position below the median indicates relative freedom from exercise problems.

Insert Table 14 about here

One of the problems mentioned by respondents was that it is hard doing exercises on one's own. This was aptly described
Table 14

Median Test Analysis of Problems with the Home Exercise Program with Adherence

<table>
<thead>
<tr>
<th>Home Exercise Program Problems</th>
<th>Nonadherents</th>
<th>Adherents</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No.</td>
<td>%</td>
</tr>
<tr>
<td>Few (LE Median)</td>
<td>3</td>
<td>37.5</td>
</tr>
<tr>
<td>Many (GT Median)</td>
<td>5</td>
<td>62.5</td>
</tr>
</tbody>
</table>

Exact Probability .3147
by one person when he stated, "It's like having a skipping rope. You've got one, but if there is nobody else skipping rope around you just tend to forget about it". In making a reference to how painful exercises could be, another patient stated, "I think we used to go every week and after the first week I was too sore. Things were getting worse, and worse, and worse, and I just quit going". Other problems mentioned by respondents were the lack of improvement, the fact that exercises were uninteresting, and the frequent lack of energy needed to do the exercises.
Variables Related to Self-Reported Measures of Adherence

What the study shows is that there are three variables which show differences when comparison is made between adherents and nonadherents. These three are perceived severity, problems with the home exercise program, and nature of the illness.

As discussed previously, perceived severity is one of the two elements of the Health Beliefs Model which are felt to be motivating forces behind the initiation of health behaviours. In this situation the finding that adherents were more likely to perceive the future problematic nature of their disease was surprising, considering the fact that perceived susceptibility was also high across most respondents. This supports Rosenstock's (1974) contention that not only must perceived susceptibility be high through the presence of active symptoms, but patients must also perceive the future severity of their disease if it is left untreated. As Rosenstock (1974) suggests, perceived severity and susceptibility only provide the motivation for engaging in some type of health behaviour. The health behaviour which is chosen depends on the perceived risks and benefits of each of the alternatives. In this study, neither adherents or nonadherents showed much difference in their perceptions of risks and benefits of the home exercise program. However, what was evident was the
significance of a similar variable which asked participants to respond to a variety of problems patients normally experience with their home exercise programs. What the study found was that adherents reported less problems with their home exercises, than did nonadherents. This supports the veracity of the Health Beliefs Model which asserts that not only must a patient be motivated to engage in health behaviours, but they will only engage in those behaviours which have the least costs attached to them. One possible reason to explain why the perceived risks variable did not come up with the same findings as the other variable, is that the variable related to home exercise problems was much more specific, and was thus sensitive to particular problems patients might be having with their home exercise programs.

One question which is raised by these findings is that if nonadherents are forsaking their home exercises because of the problems which they are experiencing, what options are they choosing in its stead. In the hopes of answering this question, respondents were asked to remark on their use of alternative therapies. What was found was that 62.5% of nonadherents use unorthodox therapies, and 37.5% do not use any form of treatment whatsoever. Interestingly enough, it was found that little difference existed in the use of marginal therapies by either adherents or nonadherents. This might be explained by the fact that some of the patients were found to be using both traditional and nontraditional forms of
treatment in attempting to control their arthritis. Thus, the nonadherents who turned to alternative therapies after having a negative experience with their home exercises, were countered by adherents who also used alternative treatments, in addition to their home exercise program. This finding is echoed by Kronenfeld and Wasner (1982) who noticed that many participants in their study also made use of a combination of orthodox and unorthodox therapies.

The last variable is nature of the illness. As described in the previous section, it was found that nonadherents were more likely to have other medical problems, in addition to their primary arthritis diagnosis, than were adherents. What this may suggest is that the presence of other medical problems diminishes the importance attached to treating the arthritis. When an individual has a single illness, they are able to devote their full attention to its care. The occurrence of an additional medical problem may deflect attention from the first, if the second problem is perceived as being more serious. Even if it is not perceived as being more important, multiple medical problems means that attention has to be allotted between each of the illnesses. At this point in time these suggestions are speculative. Further research is necessary to determine how the presence of multiple medical problems increases the likelihood of nonadherence.

From the findings of this study it is apparent that the
Health Beliefs Model comes closest to explaining the nonadherence which was present in this sample of arthritis patients. As discussed earlier, once a cause for nonadherence is found, one can then begin efforts to rectify the situation. One intervention which is particularly apt for working with people's health beliefs is a process called contracting.

Limitations of the Study

Some of the shortcomings of this study mentioned in this section have been discussed at greater length elsewhere in this paper. For the sake of brevity they will be briefly reiterated.

The limitation of most importance in this study has been the lack of a large enough sample to ensure the detection of any significant findings that may have been present. As the situation now stands, findings of any statistical significance remain obscured from analysis. The weakened power of the analytic techniques is a direct result of the size of the sample. This is known as a Type Two Error. However, lack of statistical significance aside, the findings can still point to variables of potential significance that are deserving of further attention.

A second limitation of this study is the fact that it was retrospective in nature. This can be problematic due to respondents difficulties with memory recall. Bailey (1982) reporting on Kinsey's sex research findings, states that the
most difficulty people have with behaviour recall is in terms of frequency, and reporting when a behaviour first began. However, little difficulty seemed evident with respondents reporting types of behaviour they had engaged in. He goes on to state that two rules-of-thumb with respect to behaviour recall, are that the fallibility of memory increases as the salience of the behaviour to the individual decreases, and as the time period of the recall increases. Thus, a behaviour of little meaning, a short while ago, will be more difficult to remember than a behaviour of some import which took place a number of years ago.

The difficulty in transposing this information to the chronic nonadherence study is that the only questions which are behavioral in nature, are those which attempt to determine respondent's adherence behaviours. Instead most of the questions in the study are aimed at uncovering respondent beliefs, thoughts and feelings. Unfortunately no information could be found which addressed memory recall in these areas. With regard to adherence, Bailey would suggest that the salience of the event to the individual would govern the accuracy of his or her self-report. Since it is probable that each individual views his or her home exercise program with varying degrees of importance, it is difficult to assess the veridicality of any one respondent. In the future, use of a prospective design would decrease the variation in accuracy caused by variable memory recall.
A third limitation of this study was that it proved to be impossible to measure one of the more important variables in the study. As indicated in prior discussion, measurement of the shared responsibility variable required an accurate assessment of both the patient's and the practitioner's adopted model. Since complications interfered with the measurement of all the physiotherapist's adopted models, the necessary pairing of models could not be carried out. Thus, in actual fact, the findings are mute with respect to shared responsibility because of the inability of the design to successfully test this variable. With little information on shared responsibility, it was difficult to ascertain the role which control plays in patient nonadherence. As with respondent recall, a prospective design would help ensure an accurate measurement of the shared responsibility variable as both patient's and physiotherapist's models could be assessed concurrently.

The last shortcoming of this study was that there was a lack of a clear definition of chronic nonadherence prior to choosing the chronic nonadherent group. Thus, there is some confusion as to whether the nonadherence admitted to by respondents prior to their selection for the chronic nonadherent group is the same as the level of nonadherence which was later chosen to define this variable. For example, some members of the chronic nonadherent group may have based their admission of nonadherence on the fact that they
occasionally forgot to do their exercises. By the definition which was later chosen for the study, these patients would not be considered nonadherent.

Implications for Social Work Practice: The Contracting Process

Contracting is a multi-stage process which is meant to increase an individual's adherence to their therapeutic regimes by allowing greater self-responsibility for care. The three steps involved in this process are assessment, negotiation and contracting.

A useful place to begin an assessment is with the person's thoughts and feelings about his or her illness. Two theoretical formulations which help to examine these thoughts are the Health Beliefs Model and the patient's explanatory model. Both models have questions which the practitioner can use to determine the meaning that patients give their illness. Meanings are important for they form the basis of an individual's behaviour.

An interesting approach to the subject comes from Schwartz and Wiggins (1986) who look at meaning from the perspective of systems theory. From a systems approach an individual is seen as an open system which exchanges material between itself and its environment. Although these materials are essential for growth, it is necessary for the system to limit the quality and quantity of materials that are taken in.
For example, our body only needs certain amounts of protein, carbohydrates, sugars, minerals, and vitamins. In a similar manner, the body must also limit the exchange of information between itself and the environment. This is necessary in an environment which has much more information than is readily assimilable. The means to bring about this reduction is through the use of meaning-structures. As Schwartz and Wiggins (1986) state, "meaning-structures effect a reduction of complexity that is necessary for human existence because they unburden human life of a complexity which would otherwise remain overwhelming and unmanageable" (p.1216).

Meaning-structures refer to how we order the world, and they are formed through a combination of socialization and personal experiences. Green traffic lights mean go, yellow means caution, and red means stop. When one has a fever it means one should go to bed and get plenty of rest. When one's fever does not go away, one should see a doctor. These are examples of pieces of information which most people in our culture are familiar with, but which may be foreign to an adult living in a small village in India. Thus, meaning-structures act by ordering the world of experience into familiar and unfamiliar. Information with which we are familiar has a definite place in this structure. Information which does not make sense or fit into this structure is discarded or ignored. Denial as a common defense mechanism is an example of a method humans employ to disregard information
which does not fit.

This provides one explanation as to why practitioners need to assess the patient's health beliefs and explanatory model. As parts of the patient's meaning-structure, these two factors determine what information will be accepted, and what will be disregarded. This point is borne out in the case of Mr. 'Z', a gentleman in his late 40's who participated in this study. Mr. 'Z' has had osteoarthritis involvement in many of the major joints in his body for the past five to ten years. At the beginning of his illness he was a patient at the Arthritis Society, but he has now been identified as a chronic treatment nonadherent. This means that practitioners are hesitant to work with him because it is felt that he will not follow treatment recommendations. In talking with Mr. 'Z' it became apparent that he has two strong values with respect to his health. One of these is that it is very important for him to be active and independent. In fact, one of his big frustrations is that he does not feel that health practitioners understand his values. In referring to the exercise program that was given to him he states, "they thought I was supposed to just do their exercises and shrivel up and die. That was the opinion I got from them anyway". In his mind they were not understanding how important it was for him to remain active. The second value held by Mr. 'Z' is the importance of having information in order to cope with a situation. In the past Mr. 'Z' has found that it is difficult
getting accurate medical information from health practitioners, and thus he tends to be mistrustful of their recommendations. Because of this mistrust he has learned to trust his own body to tell him which treatments are effective and which are not. Thus, when he found that the physiotherapist was not understanding his need for activity, he went back to a method of self-reliance which he had found to work in the past. If the physiotherapist had assessed Mr. 'Z's health beliefs and explanatory model, she would have recognized these potential problems and could have tried to take them into consideration.

In the contracting process, once the practitioner is aware of the client's thoughts about his or her illness and how it should be treated, the practitioner can then comment on the validity of these thoughts based on current medical knowledge. The patient responds, and so begins a back and forth dialogue which concludes with some type of mutually agreed upon diagnostic and treatment plan. During this negotiation the patient is able to discuss potential problems with the treatment, and offer possible solutions (Becker & Maiman, 1980). Upon arriving at an agreement, the plan is written up and signed by the patient. Some research on the efficacy of contracting has also included the use of rewards for good adherence (Lowe & Lutzher, 1979; Mann, 1972). This is known as contingency contracting. This research has shown that the use of rewards or reinforcements has been effective
in modifying behaviour related to obesity, juvenile diabetes, cardiovascular disease, renal failure and drug abuse (Becker & Maiman, 1980). However, what does not seem to be known is the long term efficacy of the behaviour changes, or how one can move an individual from reliance on an external system of rewards, to personal responsibility for treatment adherence. For these reasons the contingency part of the contract process has been deleted from further discussions of this intervention strategy.

Using a process of negotiation as discussed above puts the practitioner-patient relationship on a more equal footing. Power is no longer held by the practitioner as it is recognized that both parties have an equal part to play in developing a treatment plan. Using negotiation with Mr. 'Z' would have allowed him the chance to voice his dissatisfaction with the exercise program he was originally given. He would then have been given a chance to state his own preferences for the treatment. The physiotherapist could then have responded to this, and so on, until an agreement had been worked out which was satisfactory to both. Mr. 'Z' would have left this interaction feeling that he had been heard, and that his needs were understood by the physiotherapist.

An example of contracting at work is given by Barofsky (1978) when he discusses a program set up at the Beth Israel Hospital in Boston. Designed to facilitate mutual problem-solving, decision-making, and education, the program works by
focussing on the patient's personal medical record. Prior to meeting with the physician, the patient jots down symptoms which s/he has been experiencing. In the ensuing interaction these symptoms are discussed, and a joint plan of action is decided upon. This plan is recorded by the patient and is then signed by both parties. As a result of this transaction both sides have negotiated a treatment plan. This is beneficial because the patient now has a clear record of his or her responsibilities, and the patient has also made a written commitment to follow the plan outlined in the medical record.

In summary, the benefits of engaging the patient in a contracting process are three-fold. The first benefit is that a discussion of treatment goals requires an explicit exchange of information as to what is required of the patient. As Garrity (1981) states, "the contracting process involves concrete discussions of specific behaviours that might be beneficial and how they must be carried out in order to fulfill the contract and claim any reward. From this perspective contingency contracting may be viewed as a highly precise approach to patient education" (p.217). The second benefit of contracting is that it provides the patient with a greater sense of control. The last benefit of the contracting process relates to the public commitment which is made by the patient. Levy (1976) states that studies have shown that adherence is more likely to occur if patients make
an overt commitment to a particular treatment regimen.

**Contracting - A Technique for Enhancing Control**

As just mentioned, the contracting process can result in an enhanced sense of patient responsibility and control. This potential growth can be better understood by looking at a number of control-enhancing interventions as outlined by Fiske and Taylor (1984). Of those mentioned, the ones most relevant to contracting are behaviour control, information control, and decision control.

Behaviour control can be defined as the ability to take active steps to end, reduce the likelihood, decrease the intensity, and/or alter the duration or timing of an aversive event (Fiske & Taylor, 1984). In the program described by Barofsky (1978), patients were given a number of opportunities to exercise behaviour control. First of all, patients were in charge of recording symptoms prior to visiting the physician. It was then presumed that patients would voice their opinions and ask questions during the interview. Additionally, patients were expected to follow the treatment plan which they themselves helped to create. This can be contrasted with the normal interaction in which the patient is told what to do, and is then expected to comply. What is lacking in the latter transaction is analogous to the deficiencies inherent in an assembly line method of production. The criticism of assembly lines is that workers have only one small part to fasten to
the car, and thus feel little attachment to the finished product. In the same manner, most patients have no part to play in the development of a treatment plan, and thus feel no attachment to the recommendations that have been given. On the other hand, in the Beth Israel Hospital program, patients have a part to play in every step of the process, and thus are able to take ownership of the treatment plan.

Decision control concerns the ability to make some type of choice regarding the aversive event (Fiske & Taylor, 1984). In the patient-physician relationship the physician is legally responsible for the patient's medical care, and thus the final decision ultimately rests with the practitioner. However, this still leaves ample room for the patient to make choices within this arrangement. What the practitioner may do is suggest to the patient a number of alternative treatments, informing them of the pros and cons of each, and then allow the patient to choose the treatment which they feel will be the easiest to follow. The benefits of decision control have been illustrated by Langer and Rodin (1976) in a study which was conducted at a nursing home. In this study one of the major differences between the experimental and control group was that the former were given a number of choices to make. They were allowed to be part of the decision-making process as to how complaints would be handled in the home, they were able to choose a plant to take care of, and they had a choice of which night they wanted to see movies. In the control group
these choices were already made for the residents. The outcome of these small tokens of control was that the experimental group respondents were rated by both themselves and by others as being significantly happier, more alert, and more active. However, one of the difficulties in attributing the improvements to changes in decision control is that there was a slight manipulation in the amount of behaviour control held by each group. Experimental group members were allowed to look after the plants they chose, while control group members had the plants they were arbitrarily given, cared for by one of the staff members. Nevertheless, in spite of this differentiation of types of control, this study is a powerful example of the improvements possible when people are in an environment in which they are powerless.

The last category, information control, simply refers to the importance of obtaining information about the aversive event. Based on the earlier discussion of meaning-structures, it is understandable how information helps patients to make sense of, and order, experiences with which they have been previously unfamiliar. As Fiske and Taylor state, "information control provides a schema for the event, that is, a general understanding of what will happen and why. Accordingly, when people face the event, they can make sense of each individual step, and they know when something signals a potential problem" (p.122)

In this study it was found that rather than going to the Arthritis Society for treatment or cure, many new patients were primarily seeking information regarding how their illness
works, and what they can do to cope with the arthritis.

Future Outlook

As the scope of this study has been very limited there is much that needs to be done in the future. Social work is very much of a "hands-on" profession, and thus social work research should have practical implications. In the case of nonadherence one practical outcome of research should be the development of interventions to enhance patient adherence. This study partially meets this obligation by pointing to possible causes of chronic nonadherence in a male arthritis population. However, it must be stressed that the results of this study are tentative. Lack of statistically significant findings invites prudence on the part of anyone reviewing this research.

Nevertheless, two major findings have developed from this study. One of the findings of this study is that the Health Beliefs Model seems to explain why nonadherence was occurring within this sample. The implication of this finding is that practitioners need to assess the health beliefs of their patients, prior to beginning treatment, in order to pinpoint and deal with potential causal factors before nonadherence occurs. In other words, practitioners need to adopt a proactive rather than a reactive stance. As this study of chronic nonadherence was conducted with a male population, future researchers should determine if this finding is also
valid with a female population.

The second finding (related to the analysis discussed in Appendix 3) is that some factor was at work which resulted in some patients being labelled inappropriately as chronic nonadherents. Numerous explanations were provided, but it was outside the scope of this research to ascertain which of these explanations was most correct. However, the implication of this finding is that a change needs to take place with respect to how practitioners view nonadherence. Rather than seeing it as deviant behaviour, it should be viewed as a sign that the therapeutic process is temporarily dysfunctional and needs to be assessed. This finding introduces a whole new area of study, that of labelling theory and the dispensation of therapeutics. It would be interesting for future researchers to identify the degree to which the labelling of deviant behaviour occurs in a medical setting, and to study the ramifications of the labelling process on patient and practitioner behaviour.

One intervention technique explicated in this paper has been the contracting process. The reason for choosing contracting is that it is well suited for dealing with voluntary nonadherence which has been the result of a patient's particular health beliefs. As little research has been carried out on this intervention, future researchers may be interested in determining whether contracting is a useful and efficacious technique.
102

BIBLIOGRAPHY


Hello. My name is Paul Adam. I am a graduate student at the University of British Columbia. I am hoping to learn more about how people react to arthritis. Therefore, I would like to talk to you about your experience with arthritis, your experience with the Arthritis Society, and your experience with the treatments you have received for the disease.

During this interview I am going to ask you a number of questions and then write down your answers. If you are unable to understand what is being asked of you, please let me know and I will repeat the question for you. Many of the questions seek to find out what your beliefs are, thus there are no right or wrong answers. All your answers will be kept strictly confidential.

Do you have any questions?

(1) What type of medical problem(s) do you have?

(2) Many people have difficulty believing the diagnosis which their doctor has given them. Do you believe that your diagnosis is correct?

  (a) strongly agree
  (b) agree
  (c) I don't know
  (d) disagree
(e) strongly disagree

For respondents with osteoarthritis, skip to Q.5

(3) Is your arthritis currently active?
   (a) yes
   (b) no
   if a, skip to Q. 5
   if b,

(4) Do you think it is likely that your arthritis will flare up again in the future?
   (a) strongly agree
   (b) agree
   (c) I don't know
   (d) disagree
   (e) strongly disagree

(5) How long ago were you diagnosed as having this type of arthritis?
   (a) less than 1 year
   (b) 1 - 5 years
   (c) 5 - 10 years
   (d) more than 10 years
   (e) I don't know

The following statements refer to various thoughts and feelings you may have about your arthritis and your home exercise program. For each statement let me know the extent to which you agree or disagree with the statement. Remember that these are your personal beliefs, and that there are no
right or wrong answers.

(6) I believe I will always need to do my home exercises.
(a) strongly agree
(b) agree
(c) I don't know
(d) disagree
(e) strongly disagree

(7) My exercises do not make me feel better
(a) strongly agree
(b) agree
(c) I don't know
(d) disagree
(e) strongly disagree

(8) Doing my exercises interferes with my normal daily work activities
(a) strongly agree
(b) agree
(c) I don't know
(d) disagree
(e) strongly disagree

(9) It has not been difficult following the exercise program that was given to me
(a) strongly agree
(b) agree
(c) I don't know
(d) disagree
(e) strongly disagree

(10) I believe that my exercises will control my arthritis
(a) strongly agree
(b) agree
(c) I don't know
(d) disagree
(e) strongly disagree

(11) My arthritis will cause me many problems in the future
(a) strongly agree
(b) agree
(c) I don't know
(d) disagree
(e) strongly disagree

(12) Doing exercises is something I must do no matter how hard it is
(a) strongly agree
(b) agree
(c) I don't know
(d) disagree
(e) strongly disagree

(13) It takes a lot of effort to do these exercises
(a) strongly agree
(b) agree
(c) I don't know
(d) disagree
(e) strongly disagree

(14) I would have to change too many habits to follow the exercise program which was given to me
(a) strongly agree
(b) agree
(c) I don't know
(d) disagree
(e) strongly disagree

(15) My arthritis will cause me to be sick a lot
(a) strongly agree
(b) agree
(c) I don't know
(d) disagree
(e) strongly disagree

(16) In general, the home exercises have helped my arthritis
(a) strongly agree
(b) agree
(c) I don't know
(d) disagree
(e) strongly disagree

(17) I worry when I think about how bad my arthritis may get in the future
(a) strongly agree
(b) agree
(c) I don't know
(d) disagree
(e) strongly disagree

(18) What do you think has caused your arthritis?
(19) Why do you think that was the cause?
(20) Why do you think your illness started when it did?
(21) How would you rate the severity of your arthritis at this point in time
   (a) 1 - no effect, whatsoever
   (b) 2
   (c) 3 - minimal
   (d) 4
   (e) 5 - average
   (f) 6
   (g) 7 - severe
   (h) 8
   (i) 9 - very severe

(22) How much longer do you think your arthritis is going to last?
   (a) the rest of your life
   (b) more than 5 years
   (c) 1 - 5 years
   (d) 6 months to 1 year
   (e) less than 6 months
   (f) I don't know

(23) Up to this point in time how much of an impact has your arthritis had on your life
(a) no impact
(b) minimal impact
(c) I don't know
(d) moderate impact
(e) great impact

(24) Before going to the Arthritis Society did you receive any treatments for the arthritis
(a) yes
(b) no
if no, skip to Q. 27
if yes,

(25) To what extent were these treatments effective in controlling your symptoms?
(a) very effective
(b) effective
(c) I don't know
(d) minimally ineffective
(e) totally ineffective

(26) What type of treatments did you receive before going to the Arthritis Society?

(27) What type of treatments were you hoping to get?

(28) What did you want this treatment to accomplish?

(29) Did you receive the type of treatments you were hoping to get?
(a) yes
(b) no
(30) Do you feel that treatments from the Arthritis Society can help to cure your arthritis?
(a) strongly disagree
(b) disagree
(c) I don't know
(d) agree
(e) strongly agree

(31) Do you feel that treatments from the Arthritis Society can help to control your arthritis?
(a) strongly disagree
(b) disagree
(c) I don't know
(d) agree
(e) strongly agree

(32) To what extent have you been satisfied with the effectiveness of the treatments you have received from the Arthritis Society?
(a) very satisfied
(b) mostly satisfied
(c) indifferent or unsure
(d) mildly dissatisfied
(e) mostly dissatisfied

A variety of reasons are often given as to why people are not happy with their home exercise program. Indicate the extent to which each of the following apply to you.

(33) Treatment was uncomfortable or painful
(a) strongly agree
(b) agree
(c) indifferent or unsure
(d) disagree
(e) strongly disagree

(34) treatment was too involved
(a) strongly agree
(b) agree
(c) indifferent or unsure
(d) disagree
(e) strongly disagree

(35) treatment made me feel worse afterwards
(a) strongly agree
(b) agree
(c) indifferent or unsure
(d) disagree
(e) strongly disagree

(36) treatments required too large of a change in my life
(a) strongly agree
(b) agree
(c) indifferent or unsure
(d) disagree
(e) strongly disagree

(37) treatment was going to last too long
(a) strongly agree
(b) agree
(c) indifferent or unsure
(d) disagree
(e) strongly disagree

(38) treatment did not seem effective
(a) strongly agree
(b) agree
(c) indifferent or unsure
(d) disagree
(e) strongly disagree

(39) other, please indicate
Following the recommendations of one's physiotherapist is not always easy, and thus some people find it difficult to do their home exercises exactly as they were taught.

(40) What exercises did your physiotherapist suggest that you do as part of your home exercise program?

(41) How often do you do each of these exercises?
(a) more than once daily
(b) daily
(c) 5 - 6 times/week
(d) 2 - 4 times/week
(e) weekly
(f) less than weekly

(42) How often did the physiotherapist recommend that you do your exercises?
(a) more than once daily
(b) daily
(c) 5 - 6 times/week
(d) 2 - 4 times/week
(e) weekly
(f) less than weekly

(43) Are you doing your exercises exactly as you were taught by the physiotherapist?
   (a) yes
   (b) no

(44) What changes have you made?

(45) Why did you make these changes?

(46) What were the reactions of family members to the treatments recommended by the physiotherapists?
   (a) very satisfied
   (b) mostly satisfied
   (c) indifferent
   (d) mildly dissatisfied
   (e) quite dissatisfied

(47) What were the reactions of friends to the treatments recommended by the physiotherapist?
   (a) very satisfied
   (b) mostly satisfied
   (c) indifferent
   (d) mildly dissatisfied
   (e) quite dissatisfied

(48) What advice did they give you about the exercises?

(49) Many people often try other types of treatment other
than what is recommended in the hopes of finding a cure for their disease. How many alternate therapies or treatments have you tried?

(a) more than 4
(b) 3 – 4
(c) 1 – 2
(d) none

if d, skip to Q. 51
if a – c

(50) What other types of treatment have you tried?

(51) What is your current living situation?

(a) living alone
(b) living with a partner
(c) living with children
(d) living with other family
(e) living with friends
(f) living with other than family or friends

(52) What is your marital status at this time?

(a) married
(b) commonlaw
(c) divorced
(d) separated
(e) widowed
(f) never married

(53) What is your ethnic origin?

if one country given, skip to Q. 55
if two or more countries,

(54) Which one of these countries do you most identify with?

(55) What is the highest level of education you have finished and received credit for?
   (a) professional or graduate school
   (b) completed university or college
   (c) some university or college
   (d) completed high school
   (e) some high school
   (f) less than 9 years of school

(56) What is your approximate personal income from all sources last year
   (a) under 10,000
   (b) 10,000 - 14,999
   (c) 15,000 - 19,999
   (d) 20,000 - 24,999
   (e) more than 25,000

(57) What is your approximate family income from all sources last year?
   (a) under 10,000
   (b) 10,000 - 19,999
   (c) 20,000 - 29,999
   (d) 30,000 - 39,999
   (e) more than 40,000

(58) What is your employment status?
   (a) employed, full time
(b) employed, part time
(c) unemployed
(d) receiving a disability pension
(e) student
(f) retired

I will read 20 statements that describe different ways we see ourselves, and our problems. For each statement please tell me how well it describes the way you generally feel when you face problems in your life. There are no right or wrong answers. Each person deals with problems in different ways.

In general, how well does each of the following four statements describe how you see the situation you find yourself in when you are confronted with a problem

(59) I bring the problems upon myself. My problems are my fault. The only person who can solve the problems I have is me. I alone am responsible for finding a solution to my problems by facing them head on.
(a) 1 - not at all
(b) 2
(c) 3 - a little bit
(d) 4
(e) 5 - moderately
(f) 6
(g) 7 - very much

(60) My problems are not my fault. I have no control over
the cause of my problems. I also can do nothing about solving them. I am dependent on others to solve them for me.

(a) 1 - not at all
(b) 2
(c) 3 - a little bit
(d) 4
(e) 5 - moderately
(f) 6
(g) 7 - very much

(61) My problems are not my fault. I am an innocent victim of circumstances, but I do play an important role in solving my problems. I can solve the problems for myself if other people work with me and give me a chance.

(a) 1 - not at all
(b) 2
(c) 3 - a little bit
(d) 4
(e) 5 - moderately
(f) 6
(g) 7 - very much

(62) My problems are my own fault. They are due to my own inability to control myself. I cannot solve the problems by myself. I need to devote myself to some higher goal or authority to find a solution and get the
In general, how well does each of the following four statements describe what kind of person you are when you face a problem.

(63) Lazy and stubborn. Someone who is sometimes inflexible and pig-headed but basically a strong person who can face problems head on by myself

(a) 1 - not at all
(b) 2
(c) 3 - a little bit
(d) 4
(e) 5 - moderately
(f) 6
(g) 7 - very much

(64) A weak person. Someone who is helpless and passive and often ill. One who is not to be blamed for my problems. Someone who often finds oneself dependent on others for many things

(a) 1 - not at all
An innocent victim. Someone who is basically a good person but has been given a raw deal, or just not given the opportunity to develop one's strengths. Someone who can learn and grow if others gave me a chance and worked with me.

A bad person. Someone who feels out of control. Someone who feels lost, alone, and ashamed and is searching. Someone who needs to submit to the authority, discipline, and support of others.
In general, how well does each of the following four statements describe what you should typically do to cope with your problems?

(67) Work harder to solve them. Pick myself up, admit I'm wrong, and get myself motivated to face the problems head on. Ultimately solve the problem for myself. Help myself - not rely on others.
(a) 1 - not at all
(b) 2
(c) 3 - a little bit
(d) 4
(e) 5 - moderately
(f) 6
(g) 7 - very much

(68) Depend on others who know what they're doing. Rely on them to do the things that need to be done. Don't take any chances on my own. Respect what others say and do. Let other people who know what they are doing take control.
(a) 1 - not at all
(b) 2
(c) 3 - a little bit
(d) 4
(e) 5 - moderately
(f) 6
(g) 7 - very much

(69) Work with others to find a solution. Use the chances others give me to the fullest. Develop my own competence and potentials. Be serious in finding a solution. Stand up for what is rightfully mine.
(a) 1 - not at all
(b) 2
(c) 3 - a little bit
(d) 4
(e) 5 - moderately
(f) 6

(70) Submit to the support and discipline of others. Develop a sense of belonging with others in the same boat as me. Admit that I'm bad and devote myself to something larger than me and my selfish desires.
(a) 1 - not at all
(b) 2
(c) 3 - a little bit
(d) 4
(e) 5 - moderately
(f) 6
(g) 7 - very much

In general, how well does each of the following four statements describe what other people should do to help you to
cope with your problems.

(71) Encourage and motivate me towards finding a solution for myself. Giving me a good kick in the pants to get me going. Give me a pat on the shoulder for a "job well done".

(a) 1 - not at all
(b) 2
(c) 3 - a little bit
(d) 4
(e) 5 - moderately
(f) 6
(g) 7 - very much

(72) Doing things for me that need to be done. Actively solving the problem for me and make me feel more comfortable. Taking charge of getting me out of the problem. Not blaming me for my limitations or expecting me to do what I can't do.

(a) 1 - not at all
(b) 2
(c) 3 - a little bit
(d) 4
(e) 5 - moderately
(f) 6
(g) 7 - very much

(73) Understanding where I'm coming from and be aware of the abilities I have. Giving me a chance to solve the
problems myself. Placing themselves at my service so I can develop my potentials. Teach me new skills that I could use in finding a solution myself.

(a) 1 - not at all
(b) 2
(c) 3 - a little bit
(d) 4
(e) 5 - moderately
(f) 6
(g) 7 - very much

(74) Being there and making me feel that I'm not alone but forcing me to see myself as I really am, a guilty person who is out of control. Shares with me the true way—the realization that there are more important things in life besides my selfish desires, and that my submission and obedience to higher ideals is necessary to control the problems I am guilty of.

(a) 1 - not at all
(b) 2
(c) 3 - a little bit
(d) 4
(e) 5 - moderately
(f) 6
(g) 7 - very much

In general, how well does each of the following four statements describe the basic strengths you must have to cope
with your problems.

(75) Having a sense of pride and being ambitious. Someone who isn't dependent on others. Feeling like a person of value and worth. Being self-assured, hard-working, and able to solve a problem by myself without others.
(a) 1 - not at all
(b) 2
(c) 3 - a little bit
(d) 4
(e) 5 - moderately
(f) 6
(g) 7 - very much

(76) Being careful and not making waves. Being cautious and not taking any risks on my own. Accepting the way things are now and the way they will be. Letting others do what has to be done.
(a) 1 - not at all
(b) 2
(c) 3 - a little bit
(d) 4
(e) 5 - moderately
(f) 6
(g) 7 - very much

(77) Effectively using the chances other people give me. Working well with others. Learning and using what they have to offer so I can develop and work out a solution
to my problems. Feeling competent and knowing I can achieve if I am only given a chance.

(a) 1 - not at all
(b) 2
(c) 3 - a little bit
(d) 4
(e) 5 - moderately
(f) 6
(g) 7 - very much

(78) Being able to accept support and discipline from others so I can take the right path. Accepting my guilty nature and not being afraid to dedicate myself to something larger than me. Being able to identify with others who need the same direction as me.

(a) 1 - not at all
(b) 2
(c) 3 - a little bit
(d) 4
(e) 5 - moderately
(f) 6
(g) 7 - very much

The next set of questions refer to your thoughts and feelings about your most recent physiotherapist.

(79) I feel the physiotherapist did not spend enough time with me

(a) strongly agree
(b) agree
(c) indifferent or unsure
(d) disagree
(e) strongly disagree

(80) The physiotherapist explained perfectly to me everything I could ever want to know about my medical condition
(a) strongly agree
(b) agree
(c) indifferent or unsure
(d) disagree
(e) strongly disagree

(81) The physiotherapist really cared about me as a person. I was not just part of their job
(a) strongly agree
(b) agree
(c) indifferent or unsure
(d) disagree
(e) strongly disagree

(82) The physiotherapist acted like I didn't have any feelings
(a) strongly agree
(b) agree
(c) indifferent or unsure
(d) disagree
(e) strongly disagree

(83) The physiotherapist gave me suggestions on what I could
do to manage my arthritis better
(a) strongly agree
(b) agree
(c) indifferent or unsure
(d) disagree
(e) strongly disagree

(84) The physiotherapist always treated me with a great deal of respect and never "talked down" to me
(a) strongly agree
(b) agree
(c) indifferent or unsure
(d) disagree
(e) strongly disagree

(85) The physiotherapist always relieved my worries about my medical condition
(a) strongly agree
(b) agree
(c) indifferent or unsure
(d) disagree
(e) strongly disagree

(86) During therapy, the physiotherapist hardly ever told me what she was doing
(a) strongly agree
(b) agree
(c) indifferent or unsure
(d) disagree
The physiotherapist did not give me a chance to say what was on my mind.

(a) strongly agree
(b) agree
(c) indifferent or unsure
(d) disagree
(e) strongly disagree

The physiotherapist did not act like I'm important as a person.

(a) strongly agree
(b) agree
(c) indifferent or unsure
(d) disagree
(e) strongly disagree

The physiotherapist always seemed to know what she was doing.

(a) strongly agree
(b) agree
(c) indifferent or unsure
(d) disagree
(e) strongly disagree

I have a great deal of confidence in the physiotherapist.

(a) strongly agree
(b) agree
(c) indifferent or unsure
(d) disagree
(e) strongly disagree

(91) I feel the physiotherapist did not take my problems very seriously
(a) strongly agree
(b) agree
(c) indifferent or unsure
(d) disagree
(e) strongly disagree

(92) The physiotherapist always listened to everything I had to say
(a) strongly agree
(b) agree
(c) indifferent or unsure
(d) disagree
(e) strongly disagree

(93) The physiotherapist did not tell me very much about her plans for me
(a) strongly agree
(b) agree
(c) indifferent or unsure
(d) disagree
(e) strongly disagree

(94) The physiotherapist was always very kind and considerate of my feelings
(a) strongly agree
(b) agree
(c) indifferent or unsure
(d) disagree
(e) strongly disagree

(95) When the physiotherapist gave me the exercises to do at home, she did not tell me as much as I would like to know about them
(a) strongly agree
(b) agree
(c) indifferent or unsure
(d) disagree
(e) strongly disagree

(96) The physiotherapist usually did not try to make me feel better when I was upset or worried
(a) strongly agree
(b) agree
(c) indifferent or unsure
(d) disagree
(e) strongly disagree

(97) I have some doubts about the ability of the physiotherapist
(a) strongly agree
(b) agree
(c) indifferent or unsure
(d) disagree
(e) strongly disagree
The next set of 7 questions also refer to your experiences with your last physiotherapist.

(98) How would you rate the quality of the service you have received?
   (a) excellent
   (b) good
   (c) fair
   (d) poor

(99) Did you get the kind of service you wanted?
   (a) no, definitely not
   (b) no, not really
   (c) yes, generally
   (d) yes, definitely

(100) To what extent did the physiotherapy program meet your needs?
   (a) almost all my needs have been met
   (b) most of my needs have been met
   (c) only a few of my needs have been met
   (d) none of my needs have been met

(101) If a friend were in need of similar help, would you recommend your physiotherapist to him or her?
   (a) no, definitely not
   (b) no, I don't think so
   (c) yes, I think so
   (d) yes, definitely

(102) How satisfied are you with the amount of help you have
received?
(a) quite dissatisfied
(b) indifferent or mildly dissatisfied
(c) mostly satisfied
(d) very satisfied

(103) Did the services you received help you to deal more effectively with your problems?
(a) yes, they helped a great deal
(b) yes, they helped somewhat
(c) no, they really didn't help
(d) no, they seemed to make things worse

(104) In an overall, general sense, how satisfied were you with the service you received?
(a) very satisfied
(b) mostly satisfied
(c) indifferent or mildly dissatisfied
(d) quite dissatisfied

(105) In reference to the whole interview, are there any questions which made you feel uncomfortable? Explain.
APPENDIX 2

Sample Interview Tape Transcript

I  What do you think has caused your ankylosing spondylitis?
R  What I know of ankylosing spondylitis is just that it is to some degree hereditary possibly, and other than that I don't know what it is. I went for ten years, going to chiropractors and stuff like that before I ever knew what it was. So it's a big relief to know what it is.

I  In your view, how do you think heredity is a cause?
R  I'm not even positive about that. I think I read something about that. I read a fair bit about it when I was first diagnosed, and then I really haven't kept up on it so much. So I'm a bit foggy about what it is. I believe there is some link, I can't even remember, but my mother has had back pain. But then they say that ankylosing spondylitis has mainly 90% male target groups. I don't know if she suffers from it or what. She's had other kinds of back trouble all her life. It's in the back of my mind.

I  Evidence that it might be heredity!
R  She lives up near ? . I don't see her very much. She's never followed through on why she's had that pain. She's one of those people who doesn't seek out answers. I tend to be that way, or up until this point I was anyway. Obviously for ten years with having this pain and not
knowing what was causing it.

I Do you have any idea why it might have happened when it did happen? Why it didn't affect you five years before, or why it didn't wait for five years from now.

R When I first started having, when I found out it was ankylosing spondylitis it was very apparent because they said that the age at which it usually comes out is around eighteen or nineteen, and that's exactly when I first started having problems. But you see, when I started having problems I had just moved to Toronto about that time, and I thought it was humidity related. In fact, in the back of my mind I was just thinking, 'well I don't know'. I never even pursued it as being arthritis. I just went to the chiropractor's and they fixed it temporarily, and then it would get bad again. I kept this up for a long time.

I There was nothing really going on in your life at the time which you think might have contributed to it all?

R No, it just came on really out of nowhere. It was so very rapid when I started having pain in a very short time.

I You said that you have to deal with your own motivation, and attaching cause to effect. What exactly, can you explain that a little bit.

R What I was, when I first started doing the exercises I had really marked results. It really felt good and
everything. And you see at the same time I did that, I got into quite a whole self-improvement thing. I lost weight and all this. I had always been overweight all my life.

I You sound like you were really motivated!

R I got very motivated. The two sort of went hand-in-hand you know. I got into really, uh, you know, not into like total physical fitness or anything like that, but I lost weight and that helps the back problem too. There was definitely a correlation there, but I let that, I'm one of those people who lets things like that slide. You know I've let the weight slide back to almost where it was. Now I've just got back on an upsurge of motivation. But as far as the exercises, what happened was that I had such good results. It took a long time. Like it's been about a year of doing them every sort of now and then. Sort of when I think of them, and sort of slap-dash way of doing them. Rather than, you know, all the time. I don't think in terms of preventive medicine.

I Okay, so it sounds like once they were so effective the pain went away. So therefore the pain wasn't -

R I gradually started decreasing them and then I forgot about them altogether. It's sort of like, like it's coming back to me in spades all of a sudden. Two weeks ago I just had the worst onset of pain ever. Prolonged, and you know I just went, 'this is ridiculous, I got to
get on to this and stay on it'. That is typical of what I do, so that's the angle of what I have to deal with. It's thinking every day I get up, cause I work evenings and nights in the clubs and stuff. I come home. I sleep in. I get up. I tend to get up and go out and do stuff that I have to do. I'm now trying to set aside an hour where I can get up. Really wake up properly. Feel like it, and then set aside half and hour to go do it.

I Do you think there is anything about the exercise program that they gave you that could have been different? That would have made it easier for you to keep at it?

R Not really, no. I, they're very simple. I haven't even looked at the chart of them in a year or two. I have them all memorized. Even a certain sequence that I like to do them in. It's quite easy to memorize. Even though I haven't done them that much I know them. In fact I just looked at the chart the other day to make sure there wasn't any I forgot, and I was doing all of them. The program itself is quite adequate I think. It's me that's the screw-up (laughs). One thing I've started doing just recently that helps my motivation is that I put on some music when I'm doing it, so it's not nearly so boring to be doing them. It sort of distracts the mind from the mechanics, the repetition of doing it.

I Are you doing the exercises exactly as you were taught by the physiotherapist?
R: I'm not sure. I don't recall. I reviewed them on the chart and with a couple of minor variations.

I: Can you think of any changes you have made to them?

R: No, not really off the top of my head.

I: It sounds like you really haven't made too much in the way of changes.

R: No, they're all pretty straightforward.

I: The sense I'm getting from you is that you were quite satisfied with the help you got there, but that once you found that the exercises were really quite effective, the pain was going away, and you had more flexibility, that it didn't become as important for you to do them. There was nothing that was pushing you to do them. Is there anything that could have been done here that might have prevented that somehow?

R: Let me just think for a second. As I recall, I'm sure that I was told that it would reoccur if I didn't keep it up. Again, whose job is it to be fire and brimstone with somebody. I think I must have understood what happened. But I'm like that with things in general, so I couldn't visualize anything that they could do to change me from being that way. They can't tell that I'm very lackadaisical about those kind of things. Possibly one thing I do with weight control, this is my own little personal regimentation, is that I print up little daily forms to follow a certain diet or do weight control
exercises or things like that. And I'm thinking of maybe even making a checklist and printing it. You see I just run it off on my computer, print them up. And that way I have a little clipboard there. It's sitting there. It's like a visual reminder for me. 'Hey, this things blank, you haven't done anything'.

I It's a little like a conscience.

R Exactly, that's exactly it. That's one thing I've come up with. I think I'm going to apply it to the arthritis exercises. Any little visual cue like that. That's the only thing that I can think of that works for me because it definitely prods the old guilt. Finding the time to do it. I'm one of the most unstructured people in the world as far as my own time. I've got to do whatever comes in my head to do. I usually get up and there is several things I have to do, but I can do them in any, it's like shuffling cards, in any order. I have to just put this card first everyday.
APPENDIX 3

Analysis using Arthritis Society categorization of a chronic nonadherent group

Demographic Factors

Table 15 illustrates the breakdown of patient demographic characteristics according to chronic nonadherent group and comparison group comparisons.

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Insert Table 15 about here

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With regard to age, the chronic nonadherent group tended to be younger than the comparison group. Thus, 62.5% of the chronic nonadherent group is under the median age of 46, whereas only 28.6% of the comparison group falls under the median. There is also a tendency for a larger percentage of the chronic nonadherents to be living alone as compared to the comparison group. Looking at the marital status, it can be seen that the chronic nonadherent group is much less inclined to be married (12.5%) than the comparison group (85.7%). With regard to education, the chronic nonadherent group has a much higher percentage of members with a high school education or less. Thus, 62.5% of the chronic nonadherent group have a high school education or less, while only 14.3% of the comparison group have been similarly educated. This same trend holds for income and employment. Members of the chronic
Table 15

Cross-Tabulations: Patient Demographic Characteristics by Arthritis Society Categorization

<table>
<thead>
<tr>
<th>Demographic Characteristics</th>
<th>Chronic</th>
<th>Comparison</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Nonadherent Group</td>
<td>Group</td>
</tr>
<tr>
<td></td>
<td>No.</td>
<td>%</td>
</tr>
<tr>
<td></td>
<td>n = 8</td>
<td></td>
</tr>
<tr>
<td>Age (Mdn = 46)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Under 46 years</td>
<td>5</td>
<td>62.5</td>
</tr>
<tr>
<td>46 years and older</td>
<td>3</td>
<td>37.5</td>
</tr>
<tr>
<td>Living Situation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>alone</td>
<td>4</td>
<td>50.0</td>
</tr>
<tr>
<td>other</td>
<td>4</td>
<td>50.0</td>
</tr>
<tr>
<td>Marital Status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>married</td>
<td>1</td>
<td>12.5</td>
</tr>
<tr>
<td>other</td>
<td>7</td>
<td>87.5</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
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<tr>
<td>high school or less</td>
<td>5</td>
<td>62.5</td>
</tr>
<tr>
<td>post-high school</td>
<td>3</td>
<td>37.5</td>
</tr>
</tbody>
</table>

(table continues)
<table>
<thead>
<tr>
<th>Demographic Characteristics</th>
<th>Chronic Nonadherent Group</th>
<th>Comparison Group</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No.</td>
<td>%</td>
</tr>
<tr>
<td></td>
<td>n = 8</td>
<td></td>
</tr>
<tr>
<td>Income</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;20,000</td>
<td>7</td>
<td>100.0</td>
</tr>
<tr>
<td>20,000 or above</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Employment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>employed</td>
<td>2</td>
<td>25.0</td>
</tr>
<tr>
<td>other</td>
<td>6</td>
<td>75.0</td>
</tr>
</tbody>
</table>
nonadherent group tend to receive lower incomes, and to not be employed. Thus, 100% of the chronic nonadherent group are receiving incomes of less than $20,000, whereas only 28.6% of the comparison group are in the same income category. Likewise, 25% of the chronic nonadherent group are employed, while 71.4% of the comparison group are in a similar position.

From these findings it can be seen that a member of the chronic nonadherent group is more likely to be younger, living alone, and not married. This person will also tend to have a lower education, a lower income, and to not be employed.

The Health Beliefs Model

One dimension of the Health Beliefs Model was shown to have a measurable difference between the two groups as a result of t-test analysis (see Table 16).

Curiously enough, the study pointed to the fact that the chronic nonadherent group felt there were fewer aspects of their home exercise program acting as barriers to exercise performance, than did the comparison group. This is odd considering the fact that it was expected that nonadherents would experience more rather than less barriers to exercise performance than the comparison group.
Table 16

T-Test Analysis of Health Beliefs Model by Arthritis Society Categorization

<table>
<thead>
<tr>
<th>Perceived Barriers</th>
<th>Mean*</th>
<th>SD</th>
<th>t</th>
<th>2-Tail Prob</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chronic Nonadherent Group</td>
<td>9.4</td>
<td>1.3</td>
<td>-1.26</td>
<td>0.228</td>
</tr>
<tr>
<td>Comparison Group</td>
<td>10.9</td>
<td>3.0</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* Means were obtained by first summing the scores on the four items related to perceived barriers. The mean thus represents the average total score of each respondent in each of the two groups.
Patient's Explanatory Model

Findings were much the same as those which were found when the data was analyzed according to self-reported measures of adherence. However, one difference was with respect to the treatment expectations held by patients. It was interesting to note that the three types of expectations (exercise, other treatments, and information) were similarly held by both the chronic nonadherent group and the comparison group. The second difference is that, unlike the first analysis, differences were evident between the chronic nonadherent group and the comparison group with respect to belief in the ability of the Arthritis Society to cure or control their disease. Cross-tabulation shows that the comparison group was more likely to feel that a cure was impossible (85.7%) than was the chronic nonadherent group (50.0%). Some responses which were received from the chronic nonadherent group illustrate the hope that these patients had, that the Arthritis Society could cure their disease. For example, one patient said that he wanted a cure for his disease, but had no clue as to how they would do this. Another patient stated that he wanted to walk right and be able to ride a bicycle again so that he could have a normal life. With respect to control, a similar breakdown of responses was evident in both groups.

Nature of the Illness

The nature of the illness is a variable which gets at the
effect of the disease itself on the patient's adherence behaviour. Two factors were shown to have mild association when compared across groups. These factors are the perception of current disease severity, and amount of time elapsed since diagnosis. Median test analysis indicates that chronic nonadherents tend to have known about their diagnosis for a shorter period of time (100% equal to or below median) than the comparison group (66.6% equal to or below median). As well, chronic nonadherents tend to feel that their disease is less severe (87.5% equal to or below median) than the comparison group (42.9% equal to or below median).

All respondents listed one of four different types of arthritis as their main medical problem. In order of occurrence, they were as follows: osteoarthritis (40.0%), ankylosing spondylitis (26.7%), rheumatoid arthritis (20.0%), and psoriatic arthritis (13.3%). No relationship was evident between diagnosis, and group category. A second illness factor which also did not show a relationship with group categorization was impact of the illness. Frequency distributions for this variable indicate that most respondents felt that, to date, their illness has had a great impact on their lives (66.7%). A smaller percentage (20.0%) felt that their illness has had a moderate impact, and only 13.3% felt that their arthritis has had a minimal impact on their lives.
Satisfaction with Practitioner Attributes

Although each of these variables are separate and distinct, they will be discussed as a group since previous research has shown that it is difficult for patients to distinguish between the technical and socioemotional aspects of their health practitioner's care (DiMatteo & Hays, 1980). Further evidence for the usefulness in grouping these variables together comes from a statement of one of the respondents interviewed in the study. According to this patient, the three factors that he respects in a practitioner are knowledge, the ability to make him feel comfortable, and the ability to communicate. In other words, he is referring to technical competence, affective care, and communication. Although, as stated earlier, no statistically significant findings were achieved, t-test analysis shows there was some degree of difference between the satisfaction held by the chronic nonadherent group and the comparison group (see Table 17).

---

Insert Table 17 about here

---

What seemed evident was that the chronic nonadherent group was somewhat more dissatisfied with their physiotherapists communication, affective care and technical competence than was the comparison group (see Table 18).
### Table 17

**T-Test Analysis of Satisfaction with Practitioner Attributes by Arthritis Society Categorization**

<table>
<thead>
<tr>
<th></th>
<th>Mean*</th>
<th>SD</th>
<th>t 2-Tail Prob</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Affective Care</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chronic Nonadherent Group</td>
<td>21.4</td>
<td>6.5</td>
<td>1.32</td>
</tr>
<tr>
<td>Comparison Group</td>
<td>17.6</td>
<td>4.3</td>
<td></td>
</tr>
</tbody>
</table>

| **Communication**        |       |     |               |
| Chronic Nonadherent Group| 17.1  | 6.0 | 1.08          | 0.300         |
| Comparison Group         | 14.0  | 5.2 |               |

| **Technical Competence** |       |     |               |
| Chronic Nonadherent Group| 5.5   | 2.3 | 1.08          | 0.300         |
| Comparison Group         | 4.4   | 1.3 |               |

* Means were obtained by separately summing the scores on the nine items related to affective care, the seven items related to communication, and the three items related to technical competence. The mean thus represents the average total score of each respondent in each of the two groups.
As one patient described it, "I had to have something to keep me mobile and at the same time to not do any more damage than was necessary. So I had to just figure it out myself". The reason he felt he had to figure it out himself was because the physiotherapists were not hearing his expressed need to do more exercises than what he had been given to do.

**Shared Responsibility**

Table 19 shows the condensed cross-tabulations of the four shared responsibility models according to Arthritis Society categorization.

Table 20 illustrates the same data with median-split cross-tabulations.

As a population, the chronic nonadherent group tended to
Table 18

**Cross-Tabulations: Patient Satisfaction with Practitioner Attributes by Arthritis Society Categorization**

<table>
<thead>
<tr>
<th>Practitioner Attributes</th>
<th>Chronic Nonadherent Group</th>
<th>Chronic Comparison Group</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No.</td>
<td>%</td>
</tr>
<tr>
<td></td>
<td>n = 8</td>
<td>n = 7</td>
</tr>
</tbody>
</table>

**Affective Care**

<table>
<thead>
<tr>
<th></th>
<th>Satisfied</th>
<th>6</th>
<th>75.0</th>
<th>7</th>
<th>100.0</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Dissatisfied</td>
<td>2</td>
<td>25.0</td>
<td>0</td>
<td>0.0</td>
</tr>
</tbody>
</table>

**Affective Care (Median Split)**

<table>
<thead>
<tr>
<th></th>
<th>Satisfied</th>
<th>3</th>
<th>37.5</th>
<th>4</th>
<th>57.1</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Dissatisfied</td>
<td>5</td>
<td>62.5</td>
<td>3</td>
<td>42.9</td>
</tr>
</tbody>
</table>

**Communication**

<table>
<thead>
<tr>
<th></th>
<th>Satisfied</th>
<th>6</th>
<th>75.0</th>
<th>7</th>
<th>100.0</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Dissatisfied</td>
<td>2</td>
<td>25.0</td>
<td>0</td>
<td>0.0</td>
</tr>
</tbody>
</table>

**Communication (Median Split)**

<table>
<thead>
<tr>
<th></th>
<th>Satisfied</th>
<th>4</th>
<th>50.0</th>
<th>4</th>
<th>57.1</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Dissatisfied</td>
<td>4</td>
<td>50.0</td>
<td>3</td>
<td>42.9</td>
</tr>
</tbody>
</table>

*(table continues)*
<table>
<thead>
<tr>
<th>Practitioner Attributes</th>
<th>Chronic Nonadherent Group</th>
<th>Comparison Group</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No.</td>
<td>%</td>
</tr>
<tr>
<td></td>
<td>n = 8</td>
<td></td>
</tr>
<tr>
<td>Technical Competence</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Satisfied</td>
<td>9</td>
<td>100.0</td>
</tr>
<tr>
<td>Dissatisfied</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>Technical Competence (Mdn Split)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Satisfied</td>
<td>3</td>
<td>37.5</td>
</tr>
<tr>
<td>Dissatisfied</td>
<td>5</td>
<td>62.5</td>
</tr>
</tbody>
</table>
Table 19
Cross-Tabulations: Shared Responsibility Models by Arthritis Society Categorization

<table>
<thead>
<tr>
<th>Shared Responsibility Model</th>
<th>Chronic Nonadherent Group</th>
<th>Comparison Group</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No.</td>
<td>%</td>
</tr>
<tr>
<td>Moral Model (High Blame/High Control)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>3</td>
<td>37.5</td>
</tr>
<tr>
<td>High</td>
<td>5</td>
<td>62.5</td>
</tr>
<tr>
<td>Medical Model (Low Blame/Low Control)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>6</td>
<td>75.0</td>
</tr>
<tr>
<td>High</td>
<td>2</td>
<td>25.0</td>
</tr>
<tr>
<td>Compensatory Model (Low Blame/High Control)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>0</td>
<td>0.0</td>
</tr>
<tr>
<td>High</td>
<td>8</td>
<td>100.0</td>
</tr>
</tbody>
</table>

(table continues)
<table>
<thead>
<tr>
<th>Shared Responsibility Model</th>
<th>Chronic Nonadherent Group</th>
<th>Comparison Group</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No.</td>
<td>%</td>
</tr>
<tr>
<td></td>
<td>n = 8</td>
<td></td>
</tr>
<tr>
<td>Enlightenment Model</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(High Blame/Low Control)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>6</td>
<td>75.0</td>
</tr>
<tr>
<td>High</td>
<td>2</td>
<td>25.0</td>
</tr>
</tbody>
</table>
Table 20

Cross-Tabulations: Shared Responsibility Models by Arthritis Society Categorization (Median Splits)

<table>
<thead>
<tr>
<th>Shared Responsibility Model</th>
<th>Chronic Nonadherent Group</th>
<th>Comparison Group</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No.</td>
<td>%</td>
</tr>
<tr>
<td></td>
<td>n = 8</td>
<td>n = 7</td>
</tr>
<tr>
<td>Moral Model</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(High Blame/High Control)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>5</td>
<td>62.5</td>
</tr>
<tr>
<td>High</td>
<td>3</td>
<td>37.5</td>
</tr>
<tr>
<td>Medical Model</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Low Blame/Low Control)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>5</td>
<td>62.5</td>
</tr>
<tr>
<td>High</td>
<td>3</td>
<td>37.5</td>
</tr>
<tr>
<td>Compensatory Model</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Low Blame/High Control)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>3</td>
<td>37.5</td>
</tr>
<tr>
<td>High</td>
<td>5</td>
<td>62.5</td>
</tr>
<tr>
<td>Enlightenment Model</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(High Blame/Low Control)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>4</td>
<td>50.0</td>
</tr>
<tr>
<td>High</td>
<td>4</td>
<td>50.0</td>
</tr>
</tbody>
</table>
be difficult to categorize. With all of the models, excepting
the compensatory model (low blame/high control), this group
tended to show a greater dispersion of scores than the
comparison group. While the comparison group scored high on
the moral (high blame/high control) and compensatory (low
blame/high control) models, and low on the medical (low
blame/low control) and enlightenment (high blame/low control)
models, the only area with which every member of the chronic
nonadherent group showed agreement was a high compensatory
(low blame/high control) score. What this indicates is that
the chronic nonadherent group tended to believe that they were
not to blame for their disease, and they should be in control
for dealing with it. On the other hand, the scores for the
comparison group signify that a high level of control was
important, regardless of the level of accompanying blame.

Overall Satisfaction

One of the criticisms which has been brought against
previous studies is that global measures of satisfaction often
obscure specific areas, with which a patient may be feeling
dissatisfaction (Pascoe & Attkisson, 1983). That is, it is
not sufficient to know whether someone is satisfied or
dissatisfied. In order for these results to have meaning it
is important to know which aspects of care are causing the
dissatisfaction.

In this study, t-test analysis indicated that some
differences were evident in the total level of satisfaction of the two groups (see Table 21) such that the chronic nonadherent group tended to be much more dissatisfied than the comparison group.

Insert Table 21 about here

In looking at specific satisfaction questions it was found that 40% of the total respondents felt that they did not get the kind of service they wanted, and 46.6% did not feel that many of their needs were being met. It was interesting to note that the dissatisfaction with the 'kind of service offered' was almost equally spread between both groups as cross-tabulation revealed that the chronic nonadherent group was only slightly more dissatisfied than the comparison group. This was not the case with the second element as chronic nonadherents were much more likely to feel that their needs were not getting met (62.5%) than were members of the comparison group (28.6%) (see Table 22 and Table 23).

Insert Table 22 about here
Table 21

T-Test Analysis of Overall Satisfaction by Arthritis Society Categorization

<table>
<thead>
<tr>
<th>Satisfaction</th>
<th>Mean*</th>
<th>SD</th>
<th>t</th>
<th>2-Tail Prob</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chronic Nonadherent Group</td>
<td>14.3</td>
<td>5.7</td>
<td>1.32</td>
<td>0.210</td>
</tr>
<tr>
<td>Comparison Group</td>
<td>11.0</td>
<td>3.5</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* Means were obtained by first summing the scores on the seven items related to satisfaction. The mean thus represents the average total score of each respondent in each group.
Table 22

Cross-Tabulation: Satisfaction with "Kind of Service Offered" by Arthritis Society Categorization

<table>
<thead>
<tr>
<th>Satisfaction</th>
<th>Chronic Nonadherent Group</th>
<th>Comparison Group</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No.</td>
<td>%</td>
</tr>
<tr>
<td></td>
<td>n = 8</td>
<td></td>
</tr>
<tr>
<td>Satisfied</td>
<td>4</td>
<td>50.0</td>
</tr>
<tr>
<td>Dissatisfied</td>
<td>4</td>
<td>50.0</td>
</tr>
</tbody>
</table>
Attitudes of Significant Others

The next variable to be discussed is the reactions of significant figures. No differences were evident between the two groups as most respondents reported that significant others were either satisfied with, or indifferent to their home exercise program.

Use of Alternative Treatments

The second last variable is the use of alternative treatments by patients. Alternative treatments refers to unorthodox therapies and medicines that are not recommended by the Arthritis Society, but which are used by patients in the hopes of finding a more effective cure for their disease. In looking at the results of the cross-tabulation it was found that chronic nonadherents are much more likely to use alternative treatments (87.5%) than are comparison group members (14.2%) (see Table 24). This was the only test carried out on this variable, therefore the strength of this relationship is not known.
Table 23

Cross-Tabulation: Satisfaction with "Having Needs Met" by Arthritis Society Categorization

<table>
<thead>
<tr>
<th>Satisfaction</th>
<th>Chronic Nonadherent Group</th>
<th>Chronic Comparison Group</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No.</td>
<td>%</td>
</tr>
<tr>
<td>Satisfied</td>
<td>3</td>
<td>37.5</td>
</tr>
<tr>
<td>Dissatisfied</td>
<td>5</td>
<td>62.5</td>
</tr>
</tbody>
</table>
Table 24

Cross-Tabulation: Use of Alternative Treatments by Arthritis Society Categorization

<table>
<thead>
<tr>
<th>Use of Alternative Treatments</th>
<th>Chronic Nonadherent Group</th>
<th>Comparison Group</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No.</td>
<td>%</td>
</tr>
<tr>
<td>None</td>
<td>1</td>
<td>12.5</td>
</tr>
<tr>
<td>1 or more</td>
<td>7</td>
<td>87.5</td>
</tr>
</tbody>
</table>
The various alternative therapies which were mentioned by respondents are as follows: diet (5), meditation (3), massage (2), relaxation (2), naturopathy (2), visualization (2), yoga (1), Chinese herbal teas (1), colonics (1), and Vitamin C (1). The number in brackets indicates the number of different respondents who used each type of treatment.

Problems with the Home Exercise Program

No differences were evident between the problems experienced by the chronic nonadherent group and the comparison group.
Possible Explanations for the Misidentification Phenomena

Upon looking at the findings one question which comes to mind is why are 25% of the chronic nonadherent group actually adherent. Or in other words, what causes someone to be identified as nonadherent when, in fact, this is not the case. Several explanations provide a possible answer to this question.

The first explanation is that since these results are based on a very small sample, research findings may be accounted for by an error in measurement. Because of the small sample size any error has the possibility of greatly altering the findings of the study.

Earlier it was stated that one of the selection criteria for the chronic nonadherent group was self-admission of nonadherence. A second explanation for what could be happening is that the definition of nonadherence used by some patients may be different from the definition used in this study. For example, some patients in the chronic nonadherent study may have felt that an occasional lapse of their exercise routine constituted nonadherence. Thus, by the definition of nonadherence used for this study, these patients would actually be considered adherent to their home exercise programs.

A third possibility is that the adherence behaviours of some of the chronic nonadherent group may have changed between the time of their self-admission of nonadherence, and when
adherence behaviours were measured for the study. Although no members of the chronic nonadherent group made mention of recent modifications, the fact that changes are possible is exemplified by one of the comparison group members. He stated that he only recently became adherent to his exercise program as a result of an onset of severe pain.

A fourth explanation is that the respondents in the chronic nonadherent group, identified in the study as being adherent, may have misrepresented their adherence behaviours to the interviewer. It seems reasonable to suggest that adherence is a socially desirable behaviour, and thus some of the respondents may have felt ashamed to admit that they engaged in a socially undesirable behaviour. Although possible, this explanation does not seem feasible considering that all of the respondents had freely admitted being nonadherent on other occasions. As well, the study incorporated techniques to counteract the effects of positive self-presentation. Thus, this explanation does not seem likely.

In order to assess the validity of these and other explanations it might be prudent to look at some of the other findings in the study. These may help to shed some light on the question of why some of the chronic nonadherent group are actually adherent. One clue to this puzzle may come from looking at the difference between variables associated with group membership, and those associated with adherence.
One difference which becomes apparent is that the chronic nonadherent group is relatively homogeneous, demographically speaking. Members of this group tend to be younger, living alone, and not married. As well, they are likely to have a lower education, to be unemployed, and to receive a lower income. This same degree of homogeneity was not found when adherents were compared to nonadherents.

In addition to perceiving their practitioner's as poor communicators, members of the chronic nonadherent group also tended to be more likely to express dissatisfaction with the quality of their physiotherapist's affective care and technical competence. This seems reasonable considering that these respondents also tended to be more dissatisfied, in an overall sense, in relation to the comparison group.

A third factor which seems important to mention is that chronic nonadherents make much more of an extensive use of alternative treatments than the comparison group. These are treatments which are normally frowned upon by the Arthritis Society because of their questionable therapeutic value.

What seems to be emerging is a picture of a chronic nonadherent group which has similar demographic characteristics, are more dissatisfied than a comparison group of arthritis patients, and who possibly express their dissatisfaction with conventional medicine by making use of unorthodox remedies.

Based on this information a possible fifth explanation is
that adherents were labelled by the Arthritis Society as deviants because they shared many of the same characteristics as the other nonadherents. That is, they tended to express dissatisfaction with the traditional medical practices espoused by the Arthritis Society, and instead vocalized support for more uncertain therapies. This might also explain why respondents in the comparison group, who turned out to be nonadherent, were not perceived as such. That this, they did not fit into the mold which would have identified them as nonadherents. Thus, they may have been demographically dissimilar, they may not have vocalized or been dissatisfied with the Arthritis Society, and/or they may not have expressed an interest in marginal remedies.

Unfortunately there is not enough information available to know decisively why some members of the chronic nonadherent group were adherent. Thus, to choose one of the aforementioned explanations as being most valid would be highly speculative and premature. For now it will have to suffice, to say that all explanations should be given equal consideration. However, since the notion of labelling and deviance has been brought up as a possible explanation, it may be beneficial to explore this subject in greater detail.

Labelling Deviant Behaviour

Gove (1980) states that people are often labelled as deviant because they either engage in deviant behaviour, or
have characteristics which make them appear deviant. As Schur (1980) states,

"the reference to the 'perceived' deviator is important because a person can be reacted to, even 'processed' as deviant, regardless of whether he or she actually committed the objectionable act. Here, as in the collective perception of threat, it is the perception that counts" (p. 12).

Thus, as Schur is saying, someone can be labelled and reacted to as deviant when, in reality, the truth of the matter can be much different.

Evidence for the current use of labelling in the health profession comes from Taylor (1979). She states that hospital patients are often categorized as 'good patients' or 'bad patients' based on their actions while hospitalized. According to Taylor (1979), "the 'good patient' is highly regarded by the staff because he or she is compliant, non-complaining, non-demanding, and generally passive" (p.168). Contrary to these behaviours, Taylor indicates that the bad patient complains excessively, is often angry, seeks attention inappropriately, and is frequently non-compliant.

Schur (1980) suggests that one of the reasons why labelling occurs is in order for a society to set and maintain some type of standards as to what constitutes appropriate behaviour. Certain activities are labelled as deviant in order to help contain or limit their proliferation. For example, by defining criminal behaviour as deviant, the hope is that the stigma attached to the label will prevent other people from undertaking criminal activities. Similarly, by
looking upon nonadherence as deviant behaviour, the intention is to encourage other patients to adhere to their therapeutic regimes. Although this would seem to have a beneficial role, labelling has many negative ramifications.

One of the outcomes of labelling mentioned by Schur is that people are treated as a category rather than as individuals. This process of depersonalization allows those who are doing the labelling to engage in collective discrimination. The discrimination is permitted because it is being directed towards labels and not people. Taylor (1979) points to the fact that difficult hospital patients are often discriminated against by staff members who ignore them, or give their complaints less than due attention. She also mentions other discriminatory practices which include over-medication, referral to psychiatric services, and premature discharge from hospital. By allowing the use of collective responses, labelling prevents problems from being dealt with on an individual basis. In other words, the label blocks the individual from being seen as they really are. In the case of the difficult patient described by Taylor, it is important to realize that the objectionable behaviour may be the result of the patient reacting to a loss of control. Likewise, previous discussion in this paper points to a number of possible causes of nonadherence. However, in both cases, labelling can prevent the practitioner from taking an in-depth look into the cause of that particular individual's deviant behaviour.
A second ramification of labelling is that it may lead to self-fulfilling behaviours. For example, someone labelled as a juvenile delinquent may intensify the activities which originally brought the label on in the first place. Instead of rectifying the situation, the process of labelling has resulted in the entrenchment of the deviant behaviour. Likewise, if someone has never exhibited deviant behaviour, but is unjustly labelled as such, they may begin to see themselves as deviant, and to act in a manner appropriate to the label.