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Existential orientation and adjustment to rheumatoid arthritis

Weiser-Horwitz, Sherri Robin, Ph.D.

City University of New York, 1989

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EXISTENTIAL ORIENTATION AND ADJUSTMENT TO
RHEUMATOID ARTHRITIS

by

SHERRI WEISER-HORWITZ

A dissertation submitted to the Graduate Faculty in
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Abstract

EXISTENTIAL ORIENTATION AND ADJUSTMENT
TO RHEUMATOID ARTHRITIS

by

Sherri Weiser-Horwitz

Advisor: Professor Suzanne Ouellette Kobasa

This study applied the principles of existential personality theory to the study of adjustment to rheumatoid arthritis. It was predicted that individuals who view life existentially would find transformational purpose in illness more frequently and participate in daily activities which were more meaningful to them than those without this orientation. It was also expected that an existential orientation toward illness and daily activities would result in less psychological distress than a nonexistential perspective.

Thirty women with seropositive rheumatoid arthritis were studied using both standardized questionnaires and an open-ended interview format. Significant others were also questioned regarding the patient's physical and psychological status. No relationship was found between a dispositional measure of hardiness and any of the study variables. However, the ability to find an existential meaning in illness, as revealed in open-ended interviews, was related to involvement in meaningful daily activities and both variables were associated with lower levels of

depression and anxiety. There were no differences between the patients self-reports and the responses of the significant others indicating that in general, the subjects viewed themselves in the same way as others did.

Results of the interviews suggest a more complex relationship between personality and meaning of illness than was hypothesized and calls the validity of the hardiness scale into question in this sample. For some subjects it appeared an existential view of illness may impact upon personality rather than personality determining illness meaning. These findings underscore the importance of combining quantitative and qualitative methodologies. Overall, it appears that existential personality theory offers a useful paradigm for understanding adjustment to illness. The implications of these findings are discussed and suggestions are made for practical application of these findings. Topics for further research are presented.

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TABLE OF CONTENTS

1. INTRODUCTION.....	1
Existential Psychology.....	20
Examples of Existential Principles in Health Research.....	27
General Statement of Purpose.....	33
A Methodology For Existential Psychology Research.....	34
Viewing Rheumatoid Arthritis From An Existential Perspective.....	39
Hypotheses.....	42
2. METHOD.....	47
Selection of Patient Sample.....	47
Instruments and Procedure.....	48
3. RESULTS.....	55
Demographic And Health Status Characteristics.....	55
Existential Orientation, Meaning of Illness And Personal Goals - Relationships Among Independent Variables.....	56
Hardiness Scale Results.....	56
The Meaning of Illness.....	57
The Relationship Between Hardiness and Meaning of Illness.....	60
Personal Projects Scale Results.....	60
The Relationship Between Hardiness and Personal Projects.....	63
The Relationship Between Meaning of Illness and Personal Projects.....	64
The Relationship Between Demographic Variables And The Study Variables.....	64
Existential Orientation and Psychological Status.....	67

Meaning Of Illness And Psychological Status.....	67
Personal Goals And Psychological Distress.....	68
Summery of Quantitative Results.....	69
Other Findings.....	69
Other Report and Self Report Measures of Psychological Distress.....	69
Results Of The Structured Interviews.....	71
Existential Principles At Work In Patient's Lives.....	78
When Illness Has Multiple Meanings.....	88
4.DISCUSSION.....	92
APPENDIX A -- Theoretical Model.....	133
APPENDIX B -- Interview Format.....	134
APPENDIX C -- Illness Meanings.....	135
APPENDIX D -- Personal Views Survey (Hardiness Scale)..	137
APPENDIX E -- Personal Projects Analysis (Checklist)...	139
APPENDIX F -- The Beck Depression Inventory.....	143
APPENDIX G -- The Arthritis Impact Measurement Scales..	146
APPENDIX H -- Self-Evaluation Questionnaire (Spielberger) State Anxiety Scale).....	156
APPENDIX I -- Interview Summary Format.....	157
REFERENCES.....	158

LIST OF TABLES

TABLE 1. Demographic Characteristics and Health Status Variables.....	115
TABLE 2. Hardiness Scale Properties.....	116
TABLE 3. Frequencies of Illness Meanings Chosen By Raters.....	117
TABLE 4. Personal Projects.....	118
TABLE 5. Intercorrelations Among Personal Projects Dimensions.....	120
TABLE 6. Personal Project's Checklist Mean Dimension Scores.....	124
TABLE 7. Correlations Among Demographic and Health Status Variables and Independent Measures.....	125
TABLE 8. Group Means For Outcome Scores.....	126
TABLE 9. Correlations Between Demographic and Independent Measures and Dependent Measures.....	127
TABLE 10. Responses to Structured Interview Question 2..	128
TABLE 11. Responses to Structured Interview Question 3..	129
TABLE 12. Responses to Structured Interview Question 4..	130
TABLE 13. Responses to Structured Interview Question 5..	131
TABLE 14. Responses to Structured Interview Question 6..	132

1. INTRODUCTION

The disease called arthritis takes over one hundred different forms. Despite this, when one hears the word "arthritis" an image of the rheumatoid arthritic comes to mind. Rheumatoid arthritis is the most common form of this disease, affecting anywhere from .1% (Anderson et al., 1985) to 5% (Lorig & Fries, 1980) of the population. It is also the most physically obvious type of arthritis, involving some degree of physical deformity. Rheumatoid arthritis strikes women three times as often as men. Though onset may occur at any time, it is usually detected between the ages of twenty and forty and is often insidious (Koerner & Dickinson, 1983).

Rheumatoid arthritis is a chronic systemic disease of the joints which is typically bilateral and polyarticular (involving many joints) and is sometimes presented with accompanying symptoms such as cardiac, pulmonary and eye disease (Koerner & Dickinson, 1983). It is characterized by swelling and pain which endure more than six weeks. Though the disease may jump from one joint to another the wrist and knuckles are almost always affected. The knees and the balls of the feet are also common sites for rheumatoid arthritis.

Lumps called "rheumatoid nodules" may appear beneath

the skin in advanced disease forms due to inflammation of small blood vessels. In severe forms, rheumatoid arthritis can lead to bone erosion, tendon ruptures and joint slippage. Dislocation of joints (subluxation) or fusion of joints (ankylosis) can cause deformities such as "swan neck" fingers and less frequently, crippling (Anderson et al., 1985).

The disease process underlying these clinical symptoms is well documented. Cells in the synovial membrane, which line the joints, divide and grow causing inflammation. The swelling and puffiness trigger increased blood flow to the joint which makes it feel warm. The cells further aggravate the joint space by releasing painful and irritating enzymes which eventually erode the bone (Loring & Fries, 1980). In addition, 80% of all rheumatoid arthritics eventually show positive rheumatoid factor thethers (antibodies to a certain protein) which are presumed to increase inflammation (Anderson et al., 1985).

The American Rheumatology Association categorizes arthritis levels by functional capacity. Class I (15%) consists of patients with complete functional capacity, Class II (40%) includes patients with functional capacity for normal activities despite discomfort or limited mobility of at least one joint, Class III (30%) consists of patients with the functional capacity to conduct only a few or no usual duties, and Class IV (15%) refers to

patients who are wholly incapacitated and bed or wheelchair ridden (Potts et al., 1984).

It is clear that most patients remain somewhat functional and complete crippling is rare. Total remissions are also unusual, but when they do occur, it is generally in the first two years of illness. Indicators of a good prognosis are acute onset, negative RF titers, low functional impairment, absence of nodules, intermittent episodes of acute disease responsive to initial drug therapy and being male (Anderson et al., 1985).

Although rheumatoid arthritis is pervasive and widely studied it remains "one of the most complicated and mysterious diseases known" (Lorig & Fries, 1980). Its course is unpredictable and no one is certain of its cause. Many theories, however, have been proposed. They include physiological, psychosocial and interactive perspectives.

One theory suggests that genetic factors may contribute to the development of arthritis. Genetic markers called HLA-DW4 and HLA-DR4 are found in 50% of the patients with rheumatoid arthritis. However, they are also found in a comparable percentage of normal people who never develop rheumatoid arthritis, so it is unlikely that they cause the disease (Koerner & Dickerson, 1983).

In the early part of the twentieth century, theories

regarding personality factors which predisposed individuals to developing arthritis were popular. It was thought that people who were depressed, dependent, perfectionistic, restricted in emotional expression, self-sacrificing, masochistic, conforming and athletic were the most likely candidates for the disease (Baum, 1982, Anderson et al., 1985).

The theory of the "Arthritic Personality" was based on clinic observations at a time when diagnostic criteria were poor (Baum, 1982). Controlled studies which have been conducted since 1960 show mixed results. However, these studies suffer from differences in assessment procedures, heterogeneity within the patient population, overemphasis of negative traits, and perhaps most importantly, retrospective design (Moos, 1964). These facts have caused researchers to dispute the idea of an arthritic personality type, and conclude that psychopathology is a by-product of the illness.

Investigators have sought a relationship between stress and the onset of rheumatoid arthritis. This body of work has been criticized for many of the same reasons as the personality research. Although rheumatoid arthritis is overrepresented in the lower classes, and many arthritics report family difficulties, no causal relationships have been found (Anderson et al, 1985).

The mechanism by which stress is supposed to result in arthritis symptoms has yet to be explicated. Increased

muscle tension produced by stress is believed to exacerbate flare-ups, but not necessarily to cause them (Acterberg-Lawlis, 1982). One field which promises to elucidate the pathways between stress and the rheumatoid arthritis disease process is psychoneuroimmunology. This refers to the study of how central nervous system responses affect the regulation of the immune system. Evidence shows suppression of cellular and humeral immune reaction following stressful stimuli. These responses may someday be linked to disease etiology (Anderson et al, 1985).

At present, arthritis is incurable. Therefore, its effects on the patient's quality of life are protracted and often severe. The prefix "rheum" refers to stiffness, fatigue and body aches. These physical sensations have been likened to a persistent flu (Lorig & Fries, 1980). The pain which accompanies these symptoms is a chief complaint of rheumatoid arthritis victims. Pain has been noted to account for the level of medication used and a good portion of functional and psychosocial disability (Anderson et al., 1985).

The amount of functional disability a patient reports is the single most important predictor of disease course. Since the development of the ARA classification system, more sensitive measures of activity impairment have been developed. The Arthritis Impact Measurement Scale (Meenan

et al., 1980) and the Health Assessment Questionnaire (Fries et al., 1980) are arthritis specific instruments. Areas such as mobility, selfgrooming, daily chores and leisure activities, which are observed to be curtailed by arthritis are reflected in both measures.

Recall that 85% of all rheumatoid arthritics report some functional impairment. In a recent study 79 rheumatoid patients were surveyed upon visiting a clinic (Deyo et al.,1982). As a group, their self-reported dysfunction in areas of work, recreation and household activities was substantial. Almost half of the subjects had difficulty walking, caring for themselves, working, engaging in leisure activities and sleeping. It is also informative, though not surprising, that a strong relationship was found between physical and psychosocial functioning.

The psychosocial impact of arthritis takes many forms. Many rheumatoids are unable to work. From interviews with 245 patients (mostly class II & III), one investigation showed that of the 59% who were working at the onset of illness, 74% were no longer able to (Meenan et al.,1981). Another 14% could only work part-time. Even those who continued to work earned, on the average, 50% of their income prior to illness. Most patients in this group did not have enough insurance to cover their losses.

Yelin (Yelin et al.,1979) also noted significant income loss for 50 class III patients. In general, their

income loss was three times as great as their medical expenses. Clearly, rheumatoid arthritis can eventuate in a decline in standard of living. This, plus the costs of health care can make the financial burden of the illness difficult to absorb.

Nonetheless, the psychosocial aspect of unemployment is reportedly worse than the financial strain. Yelin has equated a change in work status with a change in social and family status. Of Meenan's (Meenan et al., 1981) subjects, 18% were divorced or separated, a figure which is 7% higher than the national average. Though 85% of the patients reported changes in leisure activity, those who were unemployed reported the greatest psychosocial impairment. However, both marital problems and psychosocial impairment may alternately be explained by the patient's growing need for assistance from others.

Unemployment and dependency may not be the only sources of marital discord. For a multitude of reasons, many arthritics complain of sexual problems. Yoshino and Uchida (1981) studied 91 married females between 20 to 60 years of age. Sixty percent had sex less than three times a month and 10% had had no intercourse for more than one year. When asked to give as many reasons as they could for their limited sex lives, 50% claimed they had diminished sexual desires, 22% reported a fear of worsening their condition, and 50% reported joint pain

during intercourse.

In another study, 122 male and female rheumatoid patients were compared with patients with ankylosing spondylitis (another form of arthritis) and normals (Elst et al., 1984). Rheumatoid patients reported more aversion toward sex than the two other groups, and twice as many of them wanted sexual advice. Rheumatoids expressed the desire to reach a climax quickly, because prolonged sexual activity led to pain or fatigue. This was especially true for females.

Tantamount to these functional changes are the psychological effects of rheumatoid arthritis. One study compared 50 rheumatoids to 72 normals and found that the patient group showed less self-esteem (Earle et al, 1979). Self-esteem was also found to have an inverse relationship to activity level.

The unpredictable course which arthritis takes is another source of distress. Variability occurs with regard to progression, severity and area involvement. These factors were responsible for feelings of uncertainty in 21 arthritics studied by Weiner (1975). Unpredictability coupled with a progressive and incurable disease may result in feelings of helplessness and hopelessness (Nicassio et al., 1985).

Several studies have found a high prevalence of depression among rheumatoids using the MMPI (Anderson et al, 1985). However, investigators have found similar

levels of depression in other chronic illness populations (Spergel et al., 1978, Liang et al., 1984). Also Smyth (1984) has criticized the use of the MMPI on the grounds that many of the items relate to the somatic concerns of chronic illness which mimic the signs of depression.

Smyth's critique also applies to the Beck Depression Inventory (Smyth, 1984). With this in mind, another group of investigators removed the physical symptom items from this scale (Zaphiroparelos et al., 1974). They compared 26 rheumatoids to 32 controls and found more depression in the patient group. They theorize that distress may be due to the systemic nature of the disease, pain and disability and uncertainty.

Only one study compared rheumatoids to other chronically ill patients and controls simultaneously (Cassileth et al., 1984). They found no differences between the patient groups and the controls on anxiety, depression, positive affect, emotional ties, loss of control or global mental health. However, they did find that patients who were newly diagnosed had poorer mental health scores than those who had lived with their illness for longer periods, and that severity of illness is associated with psychological distress.

So far I have considered the general impact that rheumatoid arthritis has on its victims. The Casselith study underscores the importance of recognizing that

patient groups are heterogeneous and other factors besides the disease itself may account for psychosocial adjustment. Research aimed at identifying possible moderators between chronic illness and adjustment has been popular in the last few years. It has focused mainly on cognitive appraisal and coping, social support, and individual beliefs. To date, such research specific to arthritis is rare.

One prospective study of rheumatoids examined the effect of coping strategies and illness controllability on psychological adjustment in patients with four different chronic illnesses (Felton & Revenson, 1984). These authors chose information seeking and wishfulfilling fantasy to represent coping based on the Lazarus and Folkman (1984) typology. They hypothesized that information seeking would be more adaptive for those with "controllable" illness and wishfulfilling fantasy would benefit those with "uncontrollable" illness.

Subjects were 151 patients with either "controllable" illnesses: hypertension and diabetes, or "uncontrollable" illnesses: cancer and rheumatoid arthritis. Psychological adjustment was measured by an acceptance of illness scale and an affect balance scale.

Results showed that illness controllability had a marked effect on adjustment. Those with uncontrollable disease had less positive affect, more negative affect and were less accepting of their illness than the others.

Furthermore, controllability did not interact with coping strategy to determine adjustment. For all illnesses, information-seeking showed a small effect on outcome at time one, explaining 13% of the variance in positive affect alone. Wishfulfilling fantasy showed a stronger relationship to adjustment at time one, accounting for 12% of the negative affect and 27% of acceptance of illness.

Results at time two found coping to be a weak predictor of changes in adjustment over time, though the initial relationships between coping and adjustment remained. It appears that regardless of the illness, information seeking may enhance positive affect, while wishfulfilling fantasy may enhance negative affect and decrease acceptance of illness. It should be noted, however, that these relationships are weak.

Another analysis of the same data, using only rheumatoids, again uncovered modest support for the role of coping in predicting adjustment (Revenson & Felton, 1986). This time the investigators examined the relationship between disability and coping style, in addition to the mediating role coping may play between disability and adjustment. Forty-five patients who had completed a checklist of physical limitations, the Ways of Coping Checklist, and several indices of adaptation including mastery, self-esteem, acceptance of illness, and negative and positive affect were selected for study.

The authors found that cognitive restructuring, wish-fulfilling fantasy and threat minimization were used most frequently. There were no effects of disability on coping choice, however partial correlations revealed a relationship between change in disability for the worse and wishfulfilling fantasy.

Overall, increased disability was related to decreased acceptance of illness and to increased negative affect. Coping strategy was unrelated to all outcomes except for positive and negative affect. Information seeking related to increased positive affect and self-blame, emotional expression, and wish-fulfilling fantasy related to negative affect.

In conclusion the authors suggest that coping may affect adjustment by enhancing positive affect, while having no effect on the negative affect associated with rheumatoid arthritis. Overall, however, links between coping and adaptation are weak. At best they explain only one aspect of the complex, multidimensional concept of adjustment.

One study investigated the relationship between perceived stress (based on a daily hassles and uplifts scale) and coping ability adjustment separately and combined (Sawyer, 1983). Coping ability was assessed by the Self-Control Schedule. Self-control is defined as the ability to control emotional and physiologic responses, the application of problem solving strategies, the ability

to delay gratification and the perception of self-efficacy. Outcome was measured by the AIMS, red blood cell sedimentation rate, and patient and physician global ratings of health. Subjects were 45 female and 12 male arthritics whose average age was 49.7 years.

A significant relationship was found between perceived stress intensity and physician and patient combined ratings of disease activity (physical and psychosocial indicators). No relationships were found between coping and any indices of disease activity. These results are taken to suggest that the emotional arousal resulting from perceived stress is a moderator of disease activity. Because the data are cross-sectional, these conclusions are speculative.

It is difficult to evaluate the moderating effect of coping on arthritis at this early stage. None the less, it is possible to comment on the general trends of this work based upon similar research conducted on other chronic illnesses. For example, one study of chronic pain patients (Rosenstiel & Keefe, 1983) and another of herpes victims (Manne & Sandler, 1984) could not find any link between coping and good adjustment. They found, as did Felton and Revenson (1984), relationships between coping and poor adjustment only.

Studies of the relationship between coping and adjustment in cancer (Meyerowitz, 1980) and heart disease

(Krantz, 1980) have also been disappointing. For both illnesses, the use of denial is claimed to have variable effects on outcome. The question of at what stage and during what illness is denial preferable remains unresolved.

Another approach to psychological moderators of illness has addressed the patient's belief system. Beliefs that patients hold about themselves and their illnesses may impact upon their adjustment. Burkhardt (1985) compared psychological and physical variables to determine which were better able to predict outcome in 94 rheumatoid arthritics. Here adjustment is conceptualized as quality of life consisting of a life satisfaction and a domain satisfaction score.

Results indicate that psychological variables predicted the greatest portion of the variance in adjustment. Percentages were; self-esteem - 25%, internal locus of control - 20%, negative attitudes toward illness 15% and perceived support - 10%. Severity of impairment was the only disease variable to show a significant total effect. It explained 25% of the variance indirectly, through self-esteem and internal locus of control.

Recently, several investigators have become interested in arthritis-specific beliefs as moderators of illness. At Stanford University, a team of medical and social scientists have begun to explore the salubrious effect that self-efficacy has on illness outcome. Self-

efficacy is defined as a belief in the ability to exercise control over events by producing the necessary behaviors (Bandura, 1977). It has been applied to arthritics as the belief in the ability to manage the pain which accompanies arthritis (O'Leary et al, 1986).

In a retrospective analysis it was found that arthritics who benefited most from an education program were those who were high in self-efficacy (Lorig et al, 1986). Recent attempts have been made to teach self-efficacy to a group of female rheumatoids (O'Leary et al., 1986). Treatments such as cognitive-behavioral self-relaxation, coping strategies, goal setting and self-incentive strategy, are believed to increase self-efficacy. Self-efficacy enhancing strategies have tentatively been linked to decreased joint inflammation, disability and perceived stress. Controlled studies need to be done.

In a similar vein, feelings of helplessness surrounding arthritis may have a negative impact on adjustment. Helplessness may be construed as conceptually opposite from self-efficacy. It is the belief that one has no control over outcomes. The Arthritis Helplessness Index has been developed by Niccassio (Niccassio et al, 1985). Preliminary studies suggest a relationship between arthritis helplessness outcomes of depression and disease severity. As with self-efficacy, however, conclusive

results can not yet be claimed.

In general, the study of cognitive factors such as coping and beliefs in arthritis patients is gaining momentum. This literature offers insights into cognitive processes associated with adjustment. Despite flaws in the coping literature such as variable conceptualizations of coping as well as outcome, it is foreseeable that systematic longitudinal work in this area will eventually meet with success. That is, it may be possible to identify several coping strategies which will consistently predict good adjustment.

Perhaps the study of beliefs has enjoyed more initial success because belief systems are more fundamental and stable than coping techniques. It is likely that coping responses are determined in part, by beliefs (see Lazarus & Folkman, 1984; Leventhal et al., 1980). In this way beliefs like self-efficacy and helplessness may have direct and indirect effects on adjustment and account for a greater proportion of the variance than does coping.

None the less, research conducted in both areas to date has theoretical weaknesses. These pitfalls must be addressed if we, as psychologists wish to progress further and enhance our contribution to the field of health psychology.

One problem is that much of this work is variable based. Such a model presumes that a single variable is responsible for a major portion of outcome variance.

Kobasa (1985) offers two criticisms of this approach. First, it tends to place undue emphasis on measurement strategies at the expense of theory driven research. In the area of coping, for example, much activity is centered upon finding the best way to elicit a patient's coping repertoire and how to quantify it, rather than explaining what factors lead to specific coping responses and why some responses are more desirable than others under certain conditions. As a result conceptual clarification is compromised. We have accumulated a vast array of results, but we are not quite sure what to make of them.

Lack of conceptual clarification gives rise to another problem. When we ask patients how they are coping with their illness, we assume on their part, a homogenous understanding of their disease. In reality it is uncertain exactly what they are coping with. For example, one rheumatoid patient may view her disease in terms of pain and will discuss coping in relation to discomfort. Another patient, with the same type and severity of illness, may understand her illness as it relates to her limited mobility, and respond to a coping survey from this perspective. Unless what the patient is coping with is explicit, it is impossible to draw conclusions about which strategies are more adaptive.

Kobasa's second criticism is that univariate variable-based research perpetuates the belief that behavior is

reducible to a single dimension. Human behavior is complex and overdetermined. It is unlikely that one coping strategy or a trait such as self-efficacy alone will have a large amount of explanatory power across different groups or situations. Attempts to understand adjustment to illness as the result of a multitude of individual and environmental factors seems more propitious.

Another common shortcoming is the measurement of a variable at one point in time. Patients may experience gradual changes during the course of a chronic illness. The importance of beliefs, for instance, at one point in time may diminish at a later time (Lichtman et al., 1983). In addition, illnesses such as rheumatoid arthritis have variable and unpredictable patterns. Behavioral and emotional responses at each juncture may vary considerably (Mages & Mendelsohn, 1979).

A final drawback in the existing literature involves the notion that chronic illness is catastrophic. It is assumed to take priority in the patient's life above all else. This approach parcels out the illness experience as if it were occurring in a psychological vacuum, attacking the passive individual whose entire life now revolves around this insurmountable problem.

Such a scenario may be appropriate at the initial diagnosis of a life-threatening illness. It is also true that such behavior describes the chronic pain patient

(Sternbach, 1976; Fordyce, 1982), who is believed to achieve secondary gains from suffering. In a disease such as rheumatoid arthritis, however, such a view may be unwarranted.

It has been noted that many chronic illness victims do quite well overall (Mages & Mendelsohn, 1979, Meyerowitz, 1980). In all but extreme cases the patient learns to adjust to the impositions of illness and incorporate them into his or her life. It seems logical that while stricken with arthritis, individuals are still engaged in the business of life. Major life events such as marriage, divorce, promotions at work, and death of a loved one can impact upon a person's emotional status at any given point in time, regardless of disease status.

Therefore, before we begin to measure coping and adjustment we must accomplish a more fundamental task. We need to uncover the meaning that the illness has to the patient. For example, what implications does arthritis have for the other aspects of a patient's life, especially those which are important? How does the patient make sense of illness?

Once this is established we can determine the impact of arthritis as it is experienced through the filter of the totality of the individual's identity. As we have seen, such a task can not be met by the traditional methods of data collection and analysis but instead

requires a new way of looking at psychosocial mediators in a contextually bound manner. Existential psychology offers a more suitable paradigm.

Existential Psychology

Existential psychology owes its genesis to the philosophy of existentialism. In this school of thought the focus is on man's existence as the only thing real and concrete. Subjective experience alone is valid, all else is considered abstraction. Further, human existence is not static, but continually developing and changing. Transformation is achieved by the expressly human ability to make choices and act on them. This perspective counters mechanistic models of man which reduce him to individually analyzed parts, and view his life as irrational and socially, biologically or psychologically predetermined (Misiak & Sexton, 1973).

Martin Heidegger (1889-1976) is a celebrated proponent of existential thought. He contended that man's capacity for consciousness compels the awareness of inescapable death which accompanies his "being-in-the-world". The dread of this realization is avoided by the participation in a conventional life of "inauthenticity". This lifestyle limits freedom of choice in that one's mode of being is socially dictated. The resulting experience is pervasive guilt. Man can only be authentic and true to

himself if he confronts death and nothingness (Misiak & Sexton, 1973).

Jean-Paul Sartre (1905 - 1980) is an equally influential figure whose works reflect the tenets of existential thought. For Sartre, the hallmark of humanness is freedom and choice. If one accepts this challenge, one is perpetually developing into what one truly is and is not. Failure to exercise choice results in the anguish and despair of inauthenticity or, in Sartre's terms "bad faith" (Sartre, 1974).

Sartre believed that a person's value systems could be revealed by an analysis of behavior, since every action expresses choice. By examining a person's subjective life goals one can determine his or her overall life purpose which Sartre called the "fundamental project" (Kobasa & Maddi, 1977). Thus, it is only through a phenomenological perspective that one can truly understand another.

In the mid twentieth century, a growing dissatisfaction with traditional psychoanalysis and behaviorism was stirring among the psychological community. Though these two schools appear diametrically opposed, they share one common theme; the idea that man's fate was decided by a power outside his will (either biological or environmental).

There were those, however, who chose to view man as having the ability to direct his life through freedom

of choice. These psychologists focused on the here-and-now experiences of man, rather than on past experiences. This group was considered the humanist movement or the "third force" in psychology. Along with gestalt and self-actualization psychologies, existential psychology fell into this category.

Two of the men credited with bringing existentialism into the realm of psychology are Ludwig Binswanger (1881 - 1966) and Medard Boss (1903 - ?). Both men developed a mode of psychotherapy called Daseinsanalyse, which refers to man's ability to attribute meaning to existence. For Binswanger, the patient's underlying meaning structure or "existential a priori" allows him or her to endow events with meanings. These subjective meanings transcend the objectivity of any situation and determine choices and resulting behaviors (Kobasa & Maddi 1977).

Boss (1983) explains the difference between psychoanalysis and Daseinanalysis:

"... analysis of Dasein urges all those who deal with human beings to start seeing and thinking from the beginning so that they can remain with what they immediately perceive and do not get lost in 'scientific abstractions', derivations, explanations and calculations estranged from the immediate reality of the given phenomena. It is of paramount importance to realize from the

start that the fundamental difference which separates the natural sciences from the Daseinsanalytic or existential science of man is to be found right here" (Boss, 1963).

The goal of therapy for Binswanger and Boss was to guide the patient to become self-realized and authentic. Neurosis resulted from a failure for the patient to realize his or her potential (Misiak & Sexton, 1973).

At this juncture it is important to distinguish existential psychology from the self-actualization theories of Carl Rogers and Abraham Maslow. As Kobasa and Maddi (1977) point out, both perspectives value the notion of being true to one's self and authentic living. Self-actualization theory states that one needs only the proper environment to fulfill one's greatest potential. For Maslow (1950) it is the condition of sated biological and psychosocial needs. For Rogers (1961) it is unconditional positive regard. However, both these theorists assume that self-actualization is inevitable under optimal conditions.

In this way, self-actualization theories echo the deterministic perspective of psychoanalytic and behavioristic thought. Existentialism on the other hand, stresses the individual's responsibility for his or her actualization. In this view, achieving authenticity is an arduous task. It is undertaken by the courageousness of

one's own free will. According to existentialists, it is the legacy of the human beings to be able to transcend his or her conditioning regardless of external circumstances.

Most recently Rollo May (1950) and Victor Frankl (1956) have brought existential psychology into the mainstream in the United States. Frankl (1956), in his book Man's Search For Meaning, recounts his experiences in a Nazi concentration camp. He credits his survival to his ability to find meaning in his life despite conditions of extreme physical and psychological torture. He makes a convincing argument that the loss of hope preceded death for many of the prisoners when he states:

"The prisoner who had lost faith in the future - his future - was doomed. With his loss of belief in the future, he also lost his spiritual hold; he let himself decline and became subject to mental and physical decay ... He simply gave up."

(Frankl, 1959).

The few prisoners who did not suffer spiritual bankruptcy experienced a "fundamental change in their attitude toward life". Frankl explains;

"Once the meaning of suffering had been revealed to us, we refused to minimize or alleviate the camp's tortures by ignoring them or harboring false illusions and entertaining artificial optimism. Suffering had become a task on which we did not

want to turn our backs. We had realized its hidden opportunities for achievement ..." (Frankl, 1956). Frankl's technique of "Logotherapy" is intended to help the patient who suffers an existential void, find the purpose of life and maximize his or her human potential.

Kobasa and Maddi (1977) discuss the nine tacit assumptions which underlie existential psychology theory:

1. Personality is constructed through a person's attribution of meaning to self, others and the environment. Freedom is attained by way of recognition of these meanings.

2. Persons are characterized by symbolization, imagination and judgment which direct meaning.

3. Person's are characterized by participation in society. The need for contact with others and the mode in which this is expressed determines lifestyles.

4. Person's are characterized by their participation in a physical and biological environment.

5. Time is a necessary context for personality construction in that the extent of one's awareness of the finite quality of life is reflected in their way of being.

6. Human life is best understood as a series of choices. An analysis of many life choices of an individual can reveal his or her fundamental project.

7. Personality is a synthesis of facticity and possibility. To the extent that one accepts the

inevitable, one can gain greater perspective of what is possible for the future. 8. A person is always faced with either the future which promotes anxiety or the past which promotes guilt.

9. Courage facilitates choosing the future and requires faith in oneself as capable and conscious of choice.

These principles and the writings of other existentialists, suggest a certain way of being which allows an individual to maintain his or her self in the face of adversity. In other words, events which precipitate psychopathology in some people may not have such a marked effect on someone with an existential orientation toward life.

Maddi (1967) defines existential neurosis as "the belief that one's life is meaningless, by the affective tone of apathy and boredom, and by the absence of selectivity in actions.". According to him, this state is a result of premorbid vulnerability and a specific stressor which corresponds to the vulnerability.

The personality which gives rise to existential neurosis is one which believes his or her identity is determined by social roles and biological needs only. The notion of individual agency is absent in this self-concept. For heuristic purposes, Kobasa & Maddi (1977) refer to this type of personality as inauthentic. Stressors which force the individual to recognize his or

her limited self-perception precipitate psychopathology. Chronic illness provides such a stress in that it may severely limit the persons ability to participate in social roles and to fulfill all his or her biological functions adequately.

The existential perspective places the locus of responsibility for one's life within the person. Environmental or biological obstacles may be less troublesome for the authentic personality. Obstacles may also allow the individual an opportunity to express and develop his or her uniqueness through his or her original resolution of the problem.

Examples of Existential Principles in Health Research

To my knowledge, no one has of yet systematically applied the principles of existential psychology to health research, although several studies reflect aspects of the theory. So far, there is evidence that this is a worthwhile undertaking. For example, there has been work in the area of the human capacity to invest events with meaning through symbolization.

Both Skelton and Pennebaker (1982) and Leventhal and his colleagues (1980, 1983) present cognitive models of illness representations in which they contend that individuals automatically attribute meanings to physical symptoms which guide subsequent behaviors and emotions.

The Leventhal group for example, has demonstrated that hypertensives who symbolize their illness as acute are more likely to drop out of a treatment program, than are those who perceive the meaning of their illness as chronic (Leventhal et al., 1980).

One investigator noticed that children with juvenile chronic arthritis generally reported lower pain levels than adults with rheumatoid arthritis (Beales et al, 1983). Based on Melzack's theory that sensation and affective components of the brain are separate, and sensations are only unpleasant when affect is negative, he reasoned that the pain reports of arthritics may be due to the manner in which they are interpreted.

The degree and direction of affect may be modified by learning. The more a child associates sensations with internal pathology, which has consequences for activities and ambitions, the more they will experience them as painful. Since younger children are less aware of the implications of arthritis, they should report less pain.

This hypothesis was tested with 24 six to eleven year olds and 15 twelve to seventeen year olds. Measures were joint sensations, what the sensation represented (open-ended question), unpleasantness of sensation and severity of joint pain. Both groups reported similar sensations. For the six to eleven year olds, these sensations had no meaning. For the older group, they represented the

disease process. As expected, more unpleasantness and pain was reported in the older group.

In addition to studying the meaning of physical symptoms, there has been work on the patient's attempt to ascribe meaning to illness in general. Lipowski (1970) has provided an anecdotal account of the most prevalent meanings we assign to illness. They are illness as challenge, enemy, punishment, weakness, relief, strategy, irreparable loss or damage, or value. According to Lipowski, these meanings guide coping the patient's coping strategies.

In an empirical study, Liang et al. (1984) surveyed 76 lupus patients and 23 rheumatoid patients. They found that 50% of the total group reported a positive effect of illness. The illness provided them with an opportunity to reorganize priorities and identify what was truly meaningful in their lives. Many reported "being thankful for what I've got"

Similarly, White and Liddon (1972) found that half of the ten cardiac survivors they studied mentioned some form of transcendental redirection in their lives as a result of cardiac arrest. This took the form of either religious conversion or philosophical readjustment. Transcendental redirection was characterized by feelings of acceptance and absolution and a need to identify what's important in life.

Mann (1982) interviewed twenty patients with various

illness ranging in severity. Most subjects reported using illness to gain insight into themselves. Interestingly, those with internal locus of control showed more of a capacity to do this than those with external locus of control. This relates to the existential notion of choice and responsibility. People who feel control over their lives may experience illness differently than those who do not.

Thus it appears that for some, illness can provide a vehicle for finding meaning in life in much the same way as the concentration camp served those like Victor Frankl. This is congenial to existential theory in that traumatic events require readjustments which may cause one to question his or her general assumptions about life. A patient's ability to accept the facticity of illness and simultaneously perceive the possibilities of new life goals may be guided by his or her ability to find meaning in events.

Ultimately, this ability should be related to his or her level of existential orientation, since an existentially oriented person is continually changing and growing. For the person without an existential orientation, failure promotes psychopathology. Illness may be construed as a failure experience in the sense that the body is failing. Therefore, patients who are not existentially oriented should display greater difficulty

adjusting to illness than patients who exhibit an existential perspective.

One paper has directly linked adjustment to the ability of the patient to alter future goals. Adams and Lindeman (1974) relate the saga of two teen-age boys with similar pre-accident resources and interests who suffered almost identical injuries resulting in total paralysis. One adjusted poorly while the other did quite well.

The poorly adjusted patient remained at home unhappily, with "vague" goals and insisted he would walk again. Of him the authors comment "In terms of long range vocational planning, the patient repeatedly spoke of unrealistic physical activity. At one point, when the counselor stressed the necessity of a more realistic view, the patient became very upset and accused the counselor of telling him that he would never walk again". This attitude is a clear departure from an existential perspective.

In contrast, the other boy graduated from college and went on to teach. He even considered marriage. Originally, this patient had aspirations of becoming a physical education instructor. He was, however, able to alter his goals to accommodate his disability. As one would expect from an existential personality-type, he developed an new interest in history and pursued his interest in sports by coaching basketball from his wheelchair.

The ability to pursue important activities seems to be a critical piece in the health and illness puzzle. Herzlich (1973), in her descriptive analysis of perceptions of health and illness in France, duly noted that people were willing to be called "sick" at the point where their symptoms interfered with their daily routine. Beale's previously cited work on arthritic children contains a similar theme in that he alludes to impact of arthritis on the patient's "activities and ambitions" as a determinant of distress (Beales, 1983).

Another investigator in the area of rheumatoid arthritis, defines adjustment in these terms. Earle (Earle et al., 1979) states that adjustment is "the degree to which a patient perceives that he or she is capable of fulfilling obligations and responsibilities that constitute his or her roles...".

From a sociological perspective, Charmaz (1983) argues that the broader significance of psychological and physical suffering which accompanies chronic illness is actually the "loss of self". Illness is marked by a restricted lifestyle, social isolation, discreditation, and becoming a burden to others. This necessarily implies the relinquishing of former self-images, with limited opportunity to develop new and equally meaningful ones. Charmaz remarks that the various sources of loss "all lead to losses of control and action, the typical

foundations on which Americans construct their sense of self". The result is a diminished self-concept.

Charmaz's thesis is amenable to an existential analysis. Illness represents an obstacle to the freedom and choice which characterizes an existential orientation toward life. It thereby limits the individual's opportunities for varied experiences in which to actualize him or herself. To the extent that the patient views him or herself as a victim of illness with few life choices left, he or she will experience psychological distress.

General Statement of Purpose

The previously cited work which touches upon existential principles is drawn from psychological, sociological and medical literature alike. None of these authors claim to be operating within an existential framework. What I shall attempt to do is systematically apply the principles of existential psychology and existential personality theory to the study of health and illness.

It is my aim to provide a perspective which unites previously unrelated research and to demonstrate the hypothesis generating utility of this approach. By focusing on rheumatoid arthritics, I hope to provide a model within which to view other chronic illnesses.

A Methodology for Existential Psychology Research

Clearly, if one wishes to conduct research in health from an existential psychological perspective, one needs to adopt a methodology appropriate to the theory. This includes types of questions one would ask as well as the manner in which they would be posed.

Recently, a personality instrument has been constructed by Kobasa (1979), born out of her work with Maddi cited previously. The Hardiness Scale is a composite of three factors; commitment, challenge and control. Persons high in hardiness have a sense of commitment to life as opposed to feelings of alienation, view problems as a challenge rather than a threat and feel a sense of control over life instead of helplessness. These factors appear to be related to an existential perspective of life. So far, hardiness has been shown to buffer the effects of stress on health under certain conditions (Kobasa & Pucetti, 1983).

The above measure is useful for quantifying aspects of existential personality. However, in order to remain faithful to the core assumptions of existential psychology, this method must be used in tandem with a personological research approach of a more qualitative nature. In order to truly assess an individual's way of being-in-the-world, one must apply an open-ended format which allows idiosyncratic characteristics to surface.

Harre and Secord (1973) and, later, Harre (1980) make this point in their presentation of an "Anthropomorphic Model of Man". According to them, mechanistic models of man do not allow for human agency and the ability to endow events with meaning. Experimentation is invalid due to manipulative restrictions, conceptual naivete, demand characteristics, and the interaction between strangers (investigator and subject). The factors inhibit natural responses.

The anthropomorphic model assumes that individuals have some measure of autonomy and that actions are based on principles which have subjective meaning. The individual has freedom of will to decide whether or not to act upon plans, rules, impulses and feelings. Behavior then, is never the product of simple linear causality.

Harre and Secord's theory implies two rules for the study of human behavior. One is based on the "Open Souls Doctrine" and states that one must accept another's communication as authentic. The use of ordinary language, as opposed to providing words or ideas for the subject in a structured format, allows him or her to express concepts in their own terms. This can provide valuable insights that may have gone undetected. Secondly, the investigator must perform a diachronic analysis of behavior, which in common terms, is the study of change.

Recently psychologists who were also displeased with restrictive methodology have applied the free interview

format to the study of illness with encouraging results. Several studies of cancer patients use a person-centered approach (Mendelsohn, 1979, Mages & Mendelsohn, 1979, Mendelsohn et al., 1986). Mendelsohn (1979) explains that this design "takes the individual as the basic unit of study: it is the interrelationship, the distinctive patterning of variables within a single individual which is of interest".

The semi-structured interviews included questions about the history of illness, current status, patient's reactions both past and present, changes following cancer, social status, reactions of others, values and view of the future. This format allowed the author to draw general conclusions regarding these issues. In addition, a quantitative analysis was conducted via a Q-sort method.

Mendelsohn was able to show that cancer patients undergo major and enduring changes internally and externally. Usually, normal activities are reduced, the patient's self-concept is altered, and a new sense of what is important in life is gained. Also, in time, adjustment is quite good. In a later study of the same nature, comparing French and American women with breast cancer, Mendelsohn's original findings were confirmed (Mendelsohn et al., 1986). Mages and Mendelsohn (1979) have asserted that "adaption to cancer is best viewed as a process that unfolds through time and is influenced by its placement in

the developmental history of each patient".

Taylor's (Taylor et al., 1984) methodology also reflects this perspective. She used an interview format to study the effects of attributions and beliefs about control on adjustment to breast cancer. In this case, standard questionnaires were also included to establish the reliability of the interview and to augment the obtained information. Significant others were interviewed as well, to provide a well-rounded picture of the patient's experience. Taylor was able to conclude that attributions were unrelated to good adjustment, but different types of control (ie. cognitive vs. behavioral) had variable effects on adjustment.

Lichtman (Lichtman et al., 1983) makes a strong case for a mixed format in research design. She notes that open-ended questions provide rich, qualitative information, but may be difficult to code and draw inferences from. Conversely, closed-ended data is less unwieldy, but may conceal the essence of the patient's experiences. As a solution, Lichtman proposes that "when the focus of the research is on theory building, the mix might be weighted more heavily toward open-ended data. For more circumscribed theory testing, the more rigorous analyses call for the collection of more closed-ended data."

The above points notwithstanding, one newly developed methodology is particularly compatible with existential

theory. Brian Little (1983) has constructed a measure of "personal projects" which considers the spatial and temporal contexts within which personality forms and changes. The analysis of these projects allows insight into the "selective channeling of orientation and abilities in the course of an individual's progressive adaptations to the environment."

In existential terms, this method allows us to ask; What possibilities are sought in light of the facticities of the individual's life. It provides a way of systematically observing a person's way of being-in-the-world, revealing his or her existential orientation and fundamental project. Moreover, it assumes agency to decide on and direct life goals, and recognizes personality change as usual.

A personal project may be defined as "a set of interrelated acts extending over time, which is intended to maintain or attain a state of affairs foreseen by the individual". In contrast with other methods of personality assessment which reflect either cognitive, affective or behavioral aspects of personality, Little's approach is designed to reflect all three. As such, it boasts the potential to provide insight into important questions a personologist may wish to ask.

In order to complete the personal projects measure, subjects must list ten projects they are currently engaged

in. These may range from "cutting the grass" to "trying to clarify my religious beliefs." Then, each project is rated from zero to ten on seventeen dimensions such as importance, enjoyment and control. Subjects may also be asked questions such as "How will you be carrying out this project in the next week" and "why are you engaged in this project".

Theoretically, each dimension reflects an important project characteristic. Little explains that dimensions which are appropriate to specific subject groups may be added at the investigators discretion. One can use mean dimension scores in the same way one uses traditional personality scores. The advantage of Little's scale is that it assesses activities which are meaningful to the subjects. Therefore, this method has much to recommend it to the study of illness within an existential framework.

Viewing Rheumatoid Arthritis From an Existential Perspective

The implications of rheumatoid arthritis have already been addressed from functional, social and psychological perspectives. At this time, I wish to consider an existential interpretation of the illness process. When a diagnosis of rheumatoid arthritis is given, it is received by an individual with a pre-existing personality. This personality may fall anywhere on a continuum from

completely inauthentic to completely authentic to use Kobasa & Maddi's term. Where it falls may influence the imputed meaning of illness as well as subsequent behavior in relation to the illness.

It has been argued from an interactionist perspective, that personality is most likely to emerge under conditions of social ambiguity. Under extreme external conditions, it is assumed that the demands of the situation override individual predilections, and behavior is somewhat uniform. However, Victor Frankl's experience in the concentration camp contradicts this notion. He recounted that the torturous experience in the "death camps" allowed the true essence of the prisoner to surface: "Life in a concentration camp tore open the human soul and exposed its depths" (Frankl, 1956). It was as if the experience functioned as a test of inner strength.

It may well be that it is the catastrophes in life which force one to confront oneself and take a stand. For this reason, such circumstances are ideal for studying certain personality characteristics. This point has been eloquently argued by Kobasa (1985) with regard to illness. She emphasizes the importance of personality factors in accounting for variability of response to illness. Thus, insights into the patient's existential orientation may indeed be more accessible during illness encounters.

From the foregoing discussion, one may conclude that the present concept of existential orientation is highly

value-laden. Before proceeding further, perhaps an explanation of this perspective is in order. It is true that this thesis takes the position that an authentic personality facilitates adaptation to illness and life in general in a more satisfactory way than an inauthentic personality. Two points will be made in support of this assertion.

Firstly, if one is in the business of working with the chronically ill, it is necessary to make decisions about what factors enhance adjustment and what factors impede it. In an applied setting, value judgments have more than theoretical utility. They have clinical implications. Without these judgments it would be impossible to design plans to manage illness.

If one can document the value of an existential perspective toward illness, one can cull certain aspects of this viewpoint to help patients. In other words, it is proposed here that there are certain things someone with an authentic personality does which facilitate successful adjustment, that those with inauthentic orientations do not do. Specifically, patients with authentic personalities will continue to plan and pursue goals from which they maintain a strong sense of self and find meaning in life. Goal-setting, then, would be a reasonable intervention for patients who have abandoned future plans.

There is another reason why making value judgments about existential orientations may be less problematic than one may think. Existential personality suggests that it's best to actualize oneself to the greatest extent possible. Personality change is considered a normal part of life. Therefore, anyone may be capable of having an authentic personality, regardless of specific traits.

Therefore, when one makes an assessment of a patient as highly inauthentic, this is not a prelude to doom. Instead, it is an observation which may be useful in helping the patient gain control over his or her life. It should be added that it is not necessary that such a patient make tremendous gains to experience benefits. To the contrary, changes which appear slight to an outsider can have marked effects on the person who experiences them. As one rheumatoid arthritis patient remarked "...doing a simple chore can raise one's spirits to levels of supreme joy" (Wiener, 1975).

Hypotheses

Existential personality theory generates many interesting research questions and addresses issues other theories have for the most part neglected. Indeed, I hope to demonstrate that this approach will explain more of the variance in traditional outcome measures than other approaches have.

Existential theory applied to the study of illness

poses questions about the patient's level of responsibility, sense of choice, future orientation, the meaningfulness of goals and plans, degree of self-actualization and his or her ability to experience and express emotions. Because this area is vast, it would be impossible to test all aspects of the theory here. Instead I will select what I consider to be the most crucial questions as a preliminary effort to bring existential personality theory to the study of chronic illness. The variables I have chosen to study are meaning of illness, personality and life projects.

The first variable of interest is the meaning of illness. The notion of the individual actively constructing meaning in his or her life is at the core of existential thought. Therefore, one important question is what meaning does the patient find in his or her illness? Borrowing from Frankl's work on the value of suffering, it is proposed that patients who are able to find transformational meaning in their illness will have better psychosocial adjustment to illness than those who can not. The term "transformational meaning" is used here to connote the process of interpreting a negative event like illness, as one which has some positive consequences. This type of meaning may be considered existential in nature if it assists the personal growth of the patient.

The next variable I wish to discuss is personality.

The meaning of illness does not emerge in a vacuum. Instead it may be viewed as the product of individual factors and the illness itself. The individual variable most relevant to this study is the patient's existential orientation. The patient who feels a sense of choice and responsibility, is committed to self expression and is able to accept the facticities of life should be more likely to construe some transformational meaning in his or her illness.

Likewise, someone who feels helpless in the face of disease is less apt to appreciate the value of suffering. This person is likely to ascribe only a negative meaning to illness. While it is possible that illness can have multiple meanings, the present concern is the predominant meaning the illness has for the patient.

It is also necessary to determine the patient's life projects. One aspect of meaning is how important the illness is to the individual. This can be best understood in the context of other events the individual is currently coping with. From an existential perspective, these events must be subjectively defined by the patient. One way this can be done is by asking patients to describe the daily goals they are actively pursuing.

This inquiry can provide information about other things of importance in the patient's life. The Personal Projects Index allows one to examine an individual's activities in light of various existential dimensions.

Thus, it can be determined how meaningful all the patient's daily projects are. This information will reveal how salient other life issues besides the illness are to the subject. Patients who find existential meaning in illness should be involved in more projects and projects of a more meaningful nature than those with a nonexistential meaning of illness.

Another prediction regarding personal projects can be made. It has been previously argued that the Personal Projects Index is well suited to this study because it reflects aspects of daily activities which are existential in nature. Essentially, it is a way of measuring existential behavior. The index allows one to investigate the relationship between attitude and behavior. In other words, people who claim to be in control and are committed to life and the changes it brings, should be involved in activities which reflect this. Therefore, like meaning of illness, personal projects should be associated with a personality measure of existential orientation.

(See appendix A for theoretical model)

To summarize, the hypotheses proposed here are:

1. Personality is related to meaning. Patients with a high hardiness score will be more likely to find existential meaning in illness than those who are low in hardiness.
2. Personality is related to daily goals.

A) Patients with a high hardiness score will have a greater number of personal projects than those with a low hardiness score.

B) Patients with a high hardiness score will have a higher personal projects index score than those with low hardiness scores.

3. The meaning of illness is related to psychological adjustment. Patients who are able to assign an existential meaning to their illness will have less depression and anxiety than those who assign a nonexistential meaning to their illness.

4. Personal projects are related to adjustment.

A) Patients with high personal projects scores will show less depression and anxiety than patients with low personal projects scores.

B) Patients with a large number of personal projects will have better adjustment than patients with few personal projects.

5. Meaning of illness is related to personal projects.

A) Patients for whom illness has an existential meaning will have higher personal projects scores than those for whom illness has a nonexistential meaning.

B) Patients for whom illness has an existential meaning will have a greater number of personal projects than those for whom illness has a nonexistential meaning.

2. METHOD

Selection of Patient Sample

Thirty females with rheumatoid arthritis were selected for study upon their visit to the Hospital for Joint Diseases - Orthopaedic Institute. Patients were diagnosed for a least one year at a class II or III level of impairment and were between the ages of twenty and sixty-five. Only patients with a positive rheumatoid factor were included.

A list of all appropriate patients was provided by four rheumatologists affiliated with the hospital. Since this list was exhaustive, there was no possibility of the physicians exercising any sort of bias in patient selection. Patients were approached in person or telephoned by the investigator and asked to devote two hours to a private interview. The investigator informed prospective subjects that she was a psychologist at The Hospital For Joint Diseases and she was interested in understanding their feelings and attitudes towards their illness and in learning about how they cope with arthritis so that she may be able to help others with similar problems.

Only one patient refused to be interviewed stating that she was too busy at the present time. Of the thirty-four patients who consented to participate, one did not

have a positive rheumatoid factor, two were over sixty-five years of age, and one could not speak English well enough to complete the questionnaires. These four subjects were excluded.

Instruments and Procedures

Disease activity was measured by ARA classification, the number of affected joints and the current status of disease activity (active/inactive). The first part of the session involved a tape-recorded, semi-structured open-ended questionnaire much the same as those used by Mendelsohn (1979) and Taylor et al. (1984). The questions, in this case, were specifically designed to elicit the patient's interpretation of the meaning of her illness (see appendix B).

The structured questions were intended to provide guidelines for interviewing. However, patients were encouraged to tell their story in their own way. This was done to ensure that the obtained data reflected as much of the individual's unique experiences as possible. Responses were coded according to Lipowski's (1970) categorization of illness meanings.

According to Lipowski illness meanings may fall into eight different categories. Illness as challenge is a view in which illness is considered another life situation which requires mastery. Illness as enemy is a view where disease is seen as an invasion of the body and something

to be combated. Some patients see illness as either deserved or undeserved punishment. Still others regard illness as a weakness which indicates a loss of control.

For some patients, illness may be viewed as a relief from psychological or social demands placed upon them. Similarly, illness may be seen as a strategy to manipulate interpersonal relationships and get attention from others. Illness may also be viewed as irreparable loss or damage. Finally, some patients may view illness as value and believe that it has the potential to expand personality. (For more detailed definitions see appendix C.)

Two independent raters listened to the taped interviews and indicated which category or categories of meaning characterized each patient. The raters were then asked to come to an agreement about which category reflected the predominant meaning the illness had for each patient. These ratings indicate whether the patient viewed illness existentially, nonexistentially or as a combination of both.

Two meaning categories are clearly transformational from an existential perspective. These are illness as challenge and illness as value. Several other categories are clearly not transformational within this framework. These are illness as weakness, illness as relief, illness as strategy, and illness as irreparable loss or damage. It should be noted that a patient who views illness as a relief may speak about it in positive terms. Within the

an existential framework, this would not be considered a transformational appraisal.

Firstly, although such a patient may report little psychological distress, it is unlikely her social functioning would be good. Also, it is often the case that patients who use illness as a refuge from personal problems actually report high levels of depression and anxiety (Sternbach, 1968). Either they are unaware that they are using their illness as a relief or they are intent upon proving that they are worthy of the sick role by displaying psychological distress.

The remaining two categories, illness as enemy and illness as punishment, are more difficult to evaluate. Viewing illness as an enemy may be a useful way of rallying one's resources and taking control of one's disease. Therefore, a patient who considers illness the enemy may be adjusting well if she feels she is winning the battle. Likewise, a patient who considers illness a deserved punishment may welcome the opportunity to atone for her sins. She may also be adjusting well.

The problem is that neither of these conceptualizations is characteristic of existential thought. Viewing illness as an enemy may be associated with strong feelings of anger. This implies a lack of acceptance of one's biological being, an attitude that is incompatible with existential thought. Also, in this

case, it is hostility which is motivating the patient's behavior and not her desire to self-actualize.

Similarly, a patient who gets enjoyment out of what she considers a deserved punishment may be considered somewhat masochistic. The opportunity she seeks is absolution, not mastery of the situation for her own self-growth. For these reasons, I expected patients who assigned either one of these meanings to illness to have poorer psychosocial adjustment than those who saw illness as value or challenge.

Subjects were also given several standard questionnaires. First they completed the Hardiness Scale (Kobasa, 1982), a 50 item questionnaire which taps the respondent's sense of commitment, challenge and control (see appendix D). This scale provided a personality measure of existential orientation.

As a counterpart to the attitude scales, Little's (1983) Personal Projects Scale was administered (See appendix E). Relevant dimensions on this scale (i.e., importance of project, congruence with values) provided a combined score reflecting behavioral and dynamic aspects of existential orientation. The dimensions which were selected on the basis of their relevance to existential theory are indicated in appendix E. However, the scale was administered in its entirety to permit future comparisons with other populations.

Adjustment to illness was measured subjectively and

objectively. Depression and anxiety comprised subjective psychological outcome. Depression was measured by the Beck Depression Inventory (Beck, et al., 1961) (see appendix F) and the depression scale of the Arthritis Impact Measurement Scale (AIMS) (see appendix G). Anxiety was assessed by the Spielberger State Anxiety Scale (Spielberger, et al., 1970) (see appendix H) and the AIMS anxiety scale. The AIMS provides a measure of psychosocial disability as well as functional impairment. This measure was selected because it is easy to complete and provides a global measure of illness. Significant others, defined as "someone who you see often and who knows you very well", also completed the AIMS with the patient in mind. This was done to determine whether the subject's self-reports are similar to the reports of others.

The psychological variables were chosen because of their prevalence in the literature. It should be pointed out that research which attempts to demonstrate relationships between subjective measures of personality and subjective psychological status has been criticized. It is possible that both reflect the same underlying trait, negative affectivity for example (Watson & Clark, 1984). If so, discovering that personality is related to psychological status would be tautological. None the less, since depression and anxiety are common outcome

measures in studies like this one, it seems appropriate to include them, albeit cautiously.

In order to conduct a content analysis on the open-ended data two independent raters transferred the information from the tape-recordings to a contact summary sheet (see appendix I). The contact summary sheet, as described by Miles and Huberman (1984) is a single sheet containing a series of focusing questions about a particular contact. An overall summary of the data is presented as a systematic way of evaluating qualitative data.

First, raters were asked to describe briefly the main issues or themes which stood out from the interview. Then they were asked to summarize the information they got (or failed to get) on each question for each person in one or two sentences. They were further instructed to list anything else that struck them as salient, interesting, illuminating or important. This form also included the rater's determination of the meaning which the patient assigned to the illness. This method allowed for the comparison of rater's responses and an assessment of the similarities and differences among patients.

The information obtained from these sheets indicated the number of patients who found transcendental meaning in their illness. It also revealed the various meanings that illness is given and the frequencies of each meaning in this sample. The same information was reported for each

interview question. For example, it can be determined how many patients felt they changed from illness and how they experienced this change. These data provided the basis for studying how various characteristics worked in concert to determine meaning.

3. RESULTS

Demographic And Health Status Characteristics

The demographic and health status characteristics of the sample are summarized in Table 1. Of the original thirty patients that were interviewed, twenty-nine were included in the analyses. One patient was dropped from the study because her arthritis had been decidedly inactive recently, making it impossible to determine the effect that it had on her present life.

The age of the respondents ranged from 21 to 65, with a mean of 44.3 years. The mean number of years of education was 12.8. Although one subject had no formal education, 25 (86%) had completed high school and 15 (55%) reported at least some college. Approximately half (14) of the patients were private patients (indicating private insurance coverage or the ability to pay out-of-pocket for medical services) and half (15) were clinic patients (covered by medicaid or medicare). All were female. Thus, this sample represents a wide distribution of age, education and socioeconomic status.

With regard to their medical status, all subjects had been diagnosed as having sero-positive rheumatoid arthritis, which is distinct from rheumatoid arthritis for which rheumatoid factor is not found. At the time of the interview, subjects had been diagnosed as having

rheumatoid arthritis for 1.5 to 35 years with a mean of 10.8 years. In addition, this sample obtained a mean score of 2.1 on present disease activity level, where 1 indicates very active and 4 indicates not at all active.

Results of the AIMS physical activity scale showed impairment ranging from 1 to 8.6 out of 10, with a mean of 3.9. and a standard deviation of 1.9. These scores may be compared to the scores reported on a large group of rheumatoid arthritis patients by the authors of the scale which show a mean of 3.1 and a standard deviation of 1.9 (Mason, 1985). According to the author, a score of one half a standard deviation or more above the mean is significantly worse. It appears that the present sample is comparable to the normative sample in physical impairment.

Existential Orientation, Meaning of Illness and Personal Goals : Relationships Among the Independent Variables

Hardiness Scale Results

General existential orientation was measured by personality hardiness. Means, standard deviations and reliabilities for the hardiness scale and its components in the present sample are found in Table 2. Results from the 50 item hardiness scale revealed a mean score of 103.48 and a standard deviation of 17.75 for this sample. Although norms do not exist for hardiness in a chronically

ill population, the present findings may be compared to a sample of pregnant women coping with treatment for premature labor (Feldman, 1988). The pregnant sample had a mean hardiness score of 110, and a standard deviation of 13.5. These scores do not differ substantially from those of the arthritis sample.

Results of the Cronbach Alpha reliability check showed that the commitment and control components of the hardiness scale appear to be less reliable ($\alpha=.65$ and $.55$ respectively) than the whole scale ($\alpha=.86$) in this sample. However, these levels may still be considered acceptable.

The Meaning of Illness

It was hypothesized that existential orientation would be predictive of the meaning of illness, such that individuals with a high existential orientation would express an existential meaning of illness and those low on this variable would express a nonexistential meaning of illness. Before reporting this relationship, it is necessary to discuss the results obtained regarding the meaning of the illness.

Two independent raters, familiar with existential personality theory, reviewed the taped interviews for each of the 29 subjects. Both raters were asked to complete forms which summarized the salient information in the interview (see appendix I). From the responses to the questions and the tone of the interview, raters were

instructed to indicate, in order of importance, which meaning or meanings out of 9 the illness had for the subject. Raters were encouraged to select all the meanings gleaned from the interview.

The result of the meaning ratings are presented in Table 3. The number of meanings chosen by the raters ranged from 1 to 5 and spanned both existential and nonexistential categories. Although rater 1 chose several categories more often than rater 2, the raters showed a similar mean number of categories chosen (2.4 and 2.03). It is also notable that four meaning categories dominated both the rater's selections. Within the existential category, acceptance and challenge were chosen most frequently. Loss/damage and enemy were most often chosen within the nonexistential category. Other meanings were rarely selected, with relief and strategy omitted completely.

Theoretically, there should be no meaningful differences between illness meanings within the two categories existential and nonexistential. Therefore, all meanings previously defined as "existential" (challenge, value, and acceptance) were so labeled. Likewise, all other meanings (enemy, loss/damage, punishment, and weakness) were labeled "nonexistential".

In order to determine interrater reliability, the first two meanings selected by both raters were compared.

In 21 cases (72%) both raters were in complete agreement. In 2 cases (7%) the raters agreed about the first two meanings, but disagreed about the order of importance of the meanings. In other words, rater 1 selected a nonexistential meaning as number one and an existential meaning as number two and rater 2 did the opposite. Since both raters felt that the first two meanings were of equal importance, this discrepancy was considered insubstantial.

In order to resolve the remaining six cases (20%) where there was no agreement, raters met with the investigator to review the interviews. A consensus process similar to the one Brown used for his contextual measure of threat in a stressful life events study (Brown, 1981) was used to determine the remaining six cases. In other words, at least two of the three raters had to agree in order to assign a meaning to a subject.

Thirteen of the subjects were assigned an existential meaning (their first 2 meanings were existential), 10 received nonexistential assignments (their first two meanings were nonexistential) and 6 subjects were designated as having mixed meanings (one of the first two meanings was existential and the other was nonexistential). Due to the small size of the mixed meaning group, it was dropped from the quantitative analyses. However, the mixed meaning group is considered at length in the qualitative results section of this paper.

The Relationship Between Hardiness and Meaning of Illness

Student t-tests were performed to determine the difference in personality hardiness for existential meaning and nonexistential meaning groups. In addition t-tests were performed for the commitment, challenge and control components of hardiness, since each component is theoretically meaningful.

No differences in hardiness were found between the two groups ($t(20) = .69, p < .5$), indicating no relationship between existential orientation and the meaning the illness has to the subject. It may be noted, however, that the existential meaning group's mean hardiness score (105.7) is higher than the non-existential meaning group's mean (99.8). Additionally, the mean score of the former group falls above the total sample mean of 103.5, while the mean score of the later group falls below the group mean hardiness score.

The Personal Projects Scale Results

It was also hypothesized that existential orientation would affect daily goals in two ways. Subjects with higher existential orientations would have more personal goals and they would rate these goals higher along existential dimensions than would their lower existential orientation counterparts.

Personal goals were obtained using the Personal Projects Checklist. Subjects were asked to list up to 10

current projects and rate each on 18 dimensions (see appendix E). Table 4 provides a list of all the personal projects which were generated by the subjects. Similar projects among subjects were collapsed into one category, for a total of 93 projects. The activities in Table 4 vary from extremely concrete such as cleaning house, to more abstract projects such as learn to be more optimistic. Since no attempt was made to develop a priori categories of projects, the activities are not grouped together in any meaningful way. They are presented individually and in the same language that the subjects used.

Only the 11 dimensions which were previously selected as being theoretically relevant were used in the analysis. Mean scores for each dimension across projects were obtained and collapsed into a single scale. A Cronbach Alpha reliability analysis revealed an alpha of .76 for the 11 item personal projects scale. Intercorrelations for all dimensions are given in table 5.

This table shows that although some of the designated dimensions intercorrelate as expected, many do not show strong relationships to each other. For example, "visibility", which refers to the extent to which others are aware that the subject is engaged in a project, does not correlate with any other existential dimension. In addition some unexpected relationships were found. Challenge correlates negatively with control (another

existential dimension) and positively with stress and difficulty. Therefore despite the adequate reliability of the scale, these findings require a reconsideration of grouping the eleven existential dimensions into one category.

A recent study by Ruehlman et al. (1988) on 229 undergraduates found evidence for three factors within the 18 personal projects dimensions. While the arthritis sample results show no support for Ruehlman's first factor, project mastery, it does offer support for her last two factors. The label "project strain" was given to describe the interrelationships between challenge, difficulty and stress and "self-involvement" was used to describe the relationship between the control, self-initiated, value and self-identity dimensions. With the exception of the control dimension in the self-involvement factor, similar relationships were found in both samples.

In addition, Emmons (1986), in a study of personal strivings which is similar in concept to personal goals, studied the various properties of these strivings with 40 undergraduates. Although all of the four dimensions Emmons found can not be compared to the present findings, one factor "degree of striving" is relevant to this study. Degree of striving was composed of value, importance, commitment and past attainment. Interrelationships were found between the value, importance and absorption

dimensions in present sample as well.

Based on the findings of Ruehlman and Emmons, and additional analysis was done. This time the dimensions of challenge, difficulty and stress were combined to reflect Ruehlman's "project strain" factor and initiation, value and self-identity were combined to reflect Ruehlman's "Self-involvement" factor. Value, importance and absorption were chosen to comprise Emmon's "degree of striving" factor. Results of a Pearson Correlation revealed no relationships between the three factors and any of the outcome measures or the hardiness score.

The personal projects number is simply a count of the number of projects the subject reported. The average number of projects listed for this group was 6.2 out of 10. However, because the Personal Projects Checklist limits the number of projects which one can list to ten, it was decided that this was not an accurate way of obtaining the number of goals a subject really has. Subjects with more than ten projects were prevented from reporting all of them, while subjects with few projects may have tried to create more projects than they actually had in order to satisfy the investigator. Therefore, it was decided that the personal projects number should not be considered in the analysis.

The Relationship Between Hardiness and Personal Projects

The existential personal projects score for a subject is the average of all the subject's dimension scores

across the eleven existential dimensions. For this group, the mean was 7.5 out of 10 (see Table 6). Based on the results of a Pearson Correlation, no relationship was found between personality hardiness and the existential personal projects score ($r=-.058, p=.4$). The same was true for the three hardiness component scores. Therefore, in this sample, existential orientation as measured by personality hardiness is not related to the existential nature of the personal goals a subject reports.

The Relationship Between Meaning and Personal Projects

A student t-test was performed to determine the differences in the personal project index between existential meaning ($M=7.699$) and nonexistential ($M=6.79$) meaning groups. Results show significant differences between groups on the personal projects score $t(21)=2.16, p<.06$, in accordance with the theoretical model. Subjects who found existential meaning in illness had higher personal projects scores than those who did not.

The Relationship Between Demographic And Health Status Variables and The Study Variables

Pearson correlations revealed significant relationships between demographic and health status characteristics and the independent measures (see Table 7). Education was positively and strongly related to hardiness and the challenge component of hardiness

($r=.43, p=.009$ and $r=.60, p=.0001$) and negatively and strongly related to the personal projects score ($r=-.41, p=.03$). Age was negatively related to the challenge component of hardiness only ($r=-.39, p=.02$). T-tests performed on demographic differences between existential and nonexistential meaning groups yielded nonsignificant results. The two groups did not differ on any of the demographic measures .

Before turning to the relationship between demographic variables and outcome measures it is helpful to describe the outcome scores (see Table 8). Multiple measures were used for both depression and anxiety. Depression was measured using the Beck Depression Inventory and the depression scale of the Arthritis Impact Measurement Scale. Although they are both state measures, the BDI requires subjects to report their feelings at the present time, while the AIMS assesses feelings for the past month in relation to the physical symptoms of illness. Based on a recent study by Lorish and Maisiak (1986) seven items were dropped from the BDI because of their relationship to a physical illness such as arthritis (see appendix F for a description of these items).

The mean score on the BDI was 5.9. This may be compared to the finding of Lorish which was 5.1 for a comparable group. The mean AIMS depression score was 2.8, which is considerably less than the 4.0 reported by Mason (1988) on a large group of rheumatoid arthritics. This

may be because Mason failed to distinguish between arthritics with and without a positive rheumatoid factor. None the less, it may be concluded that this particular sample of arthritics were not notably depressed on this measure.

Anxiety was assessed with the Spielberger State Anxiety Scale and the Anxiety scale from the AIMS. The Spielberger differs from the AIMS in that subject's responses are based upon their present feelings. The mean score for the Spielberger scale was 33.9. This compares with norms reported for 110 medical patients of 44.3). The AIMS anxiety scale yielded a mean of 3.5 with is slightly higher than the 2.9 reported by Mason (1988). However, since the mean of the present population does not exceed one half the standard deviation of the normative population (1.9) the two samples may be considered similar on this variable.

Significant correlations were found between demographic and health status variables and all outcome measures (see Table 9). Education correlated .35 ($p=.03$) with the Spielberger anxiety measure. Present RA activity (negatively keyed) was negatively related to the BDI score ($r=-.35, p=.03$), AIMS depression ($r=-.46, p=.006$), and AIMS anxiety ($r=-.37, p=.03$). Finally, the AIMS physical impairment score was positively related to the BDI score ($r=.36, p=.03$) and the AIMS depression score ($r=.40, p=.02$).

Existential Orientation and Psychological Status

In order to control for the effect of a demographic variable on the relationship between an independent and dependent variable, partial correlations were done wherever a demographic variable correlated with both independent and outcome measures of interest. Such correlations were done to determine the relationship between personality hardiness and the psychological outcome measures. This procedure showed no relationship between hardiness and the BDI ($r=.08, p<.34$) or the AIMS depression scale ($r=-.2, p<.12$).

In addition there was no correlation between hardiness and The Spielberger anxiety measure ($r=.16, p<.2$) or the AIMS anxiety scale ($r=-.23, p<.12$). The commitment component of hardiness, however, was negatively related to the AIMS anxiety score ($r=-.39, p<.02$). This may indicate that respondents who are highly committed to others and to life report less anxiety than those who are less committed.

Meaning of Illness and Psychological Status

It was hypothesized that subjects for whom illness had an existential meaning would report less psychological distress than those for whom illness had a nonexistential meaning. Strong evidence was found in support of this hypothesis. Student t-tests revealed that the existential

group reported less depression on the BDI ($M=2.3$) and the AIMS ($M=2.13$), $t(20)=-3.58, p<.004$ and $t(19)=-2.23, p<.04$ respectively than the nonexistential group on the BDI ($M=9.1$) and the AIMS ($M=3.39$). The existential meaning group also reported less anxiety on the Spielberger ($M=29.33$ vs. $M=40$) $t(20)=, p<.04$) and on the AIMS ($M=2.427$ vs. $M=4.12$), $t(19)=-2.63, p<.02$.

Personal Goals and Psychological Distress

It was theorized that the higher the subject's personal projects score, the less psychological stress she would report. Partial correlations show that the personal projects score is significantly and negatively related to the BDI (par $r=-.41, p=.04$) and the Spielberger Anxiety Scale (par $r=-.41, p=.04$). Likewise, Ruehlman et al. (1988) found significant relationships between the three factors of the personal projects checklist and current measures of psychological distress. However, in Emmons study of personal strivings, only three dimensions (not factors) correlated with his negative affect measure.

There was no relationship between the personal projects score and the AIMS measures of depression and anxiety. It has been noted that subjects were instructed to respond to the Personal Projects Checklist in the present. Therefore, it appears that characteristics of current personal activities are related to present mood states, but not to measures of distress in the past month.

These findings in conjunction with those of Ruehlman et al. (1988) and Emmons (1986) illustrate the discrepancies found when different outcome scales are used.

Summary of Quantitative Results

It was found that personality hardiness was not significantly related to meaning of illness, personal goals or psychological distress. The relationship between meaning of illness and personal goals approached significance such that existential meaning was associated with a higher personal projects score. Meaning of illness was strongly related to all outcome measures. Subjects assigned to the existential meaning group reported lower levels of depression and anxiety on current and recent measures of distress than subjects assigned to the non-existential meaning group. Finally, the subject's personal projects score was significantly and negatively related to measures of current depression and anxiety only.

Other Findings

Other-report and Self-report Measures of Psychological Distress

As stated previously, the AIMS was completed by both the subject and her designated significant other. In the latter case, questions were reworded so that the significant other's responses reflected his or her perception of the patient. The purpose of this was to

provide an additional measure of psychological status in addition to the patient self-report measures. Therefore it is appropriate to inquire into the differences between the two groups on the AIMS scores.

Student t-tests were performed on the difference between the AIMS physical impairment scores, the AIMS depression scores and the AIMS anxiety scores for the subject and significant other groups. No differences were found on any of these variables. Moreover, moderate to strong correlations were found between the subject and the significant other on AIMS physical impairment ($r=.74, p=.0001$), AIMS depression ($r=.46, p=.007$) and AIMS anxiety ($r=.32, p=.055$). This indicates that subjects are responding to the AIMS with some veracity. At the very least, they perceive themselves the way others perceive them on selected measures.

Significant other's responses to the AIMS may also be considered an additional outcome measure. Of the health status variables, only present RA activity related to depression ($r=-.42, p=.02$) and anxiety ($r=-.42, p=.01$) as rated by significant others. Neither hardiness and its' components nor the personal projects index correlated with significant other's outcome measures. Once again, these relationships are consistent with the findings for the patient sample.

Results Of The Structured Interviews

While it is central to my thesis to discuss specific case materials, it is useful to begin by presenting aggregate responses to the interview questions. This will provide a framework within which qualitative results may be best understood. Subjects were first asked to discuss the history of their illness in a general way. The purpose of this question was to establish a relationship with the subject by allowing her to relate her story in her own way. Responses to the first question will be discussed in case examples later in this section.

Question 2 was "sometimes when people become ill they ask themselves 'why me'. Did you ever ask yourself this question and if so, what did you come up with?" Results are summarized in Table 10. Seven subjects (24%) claimed to have never asked the question. Of the remaining 22 (76%) subjects, 9 (33%) said they had asked themselves the question but never found an answer. The responses of the other 13 subjects (43%) were fairly evenly distributed among the following reasons: they felt they were being punished for an unknown reason, it was a random event "everybody gets something", they were biologically predisposed to it, there was a higher purpose for it, "God gave it to me because he knew I could take it", and it was the result of exogenous factors (a childhood operation).

These responses lend support to the contention of other investigators (ie. Taylor, 1984 and Bulman &

Wortman, 1977) that patients seek attributions for their illnesses. The majority in this sample did ask why me (67%). However, this number is small compared to the 95% of Taylor's breast cancer patients and all of Bulman and Wortman's spinal cord injury patients who had sought attributions for their physical problem. Seven arthritis patients did not seek an attribution for illness and of the 22 who did, 9 were unable to find one. Perhaps this is because there is no known cause of rheumatoid arthritis and physicians are very clear about relating this information to the patient.

Patients in both Taylor's study and the present study found a variety of reasons for their illness. However, these meanings differed between the two groups. For example, breast cancer patients cited more "controllable" causes such as stress, carcinogens and diet while the arthritis patients more often cited "uncontrollable" causes such as random event, genetics or the result of injury.

Only four of the arthritis patients seemed to feel responsible for their illness, and attributed illness as punishment for something they did. Many of the spinal cord injury victims also blamed themselves for their injury. Differences in attributions among the three groups may be attributed to actual differences in known causes for each disability as well as societal myths

involving each infirmity.

Question 3 consisted of two parts. First, subjects were asked how they changed (other than physically) since the advent of their illness. Results are shown in table 11. Only one person said that illness hadn't changed her at all and only one patient mentioned drastic financial changes. Most patients listed multiple changes.

Personality changes were cited most frequently. Twelve subjects reported prolonged increases in negative affect such as: more afraid, depressed, aggravated, dependent and moody. Eight subjects mentioned positive affective changes which included feelings of strength, less sensitivity to other's opinions, the ability to appreciate life and a greater sense of resourcefulness. Five subjects reported changes which appear to be related to a process whereby a serious illness forced them to face reality. Since their illness they claimed to be "less carefree, more serious, more responsible, more grown-up, and have less of a sense of humor".

Positive and negative interpersonal changes were reported by equal numbers of subjects (nine each). In the former category, 7 patients claimed that having arthritis has made them more sensitive to others. For example one woman, who was a nurse said that she is now more responsive to her patients. Another subject felt that being ill made her more outgoing since she tried to joke about her problem to make others more comfortable. One

person even reported an improved relationship with her husband.

The second part of this question was "what future plans did you have to change as a result of being ill?". These responses are given in table 11. The results are quite variable. Thirteen subjects said that arthritis has not interfered with any plans. Of the remaining 16 subjects, 7 discussed interrupted careers and the rest spoke of postponing events such as having children, traveling, owning one's own home and interruptions in education, personal achievements (such as athletics) and community activities.

It is clear from these findings that arthritis effects all spheres of a patient's life. Many patients found this adjustment quite difficult. However, 12 out of 29 patients (41%) claimed they had changed for the better. This indicates that a devastating event such as illness may provide the basis for valuable personal changes which may have otherwise not occurred.

For the fourth question, subjects were asked to think of themselves five years into the future. Results are shown in table 12. Here is what they saw: Two patients said they would be exactly the same as they are now and three felt they would get better. Four subjects didn't mention the illness at all and instead discussed such pursuits as owning one's own business and starting a

family. Nine of the subjects said that they didn't think about the future and gave such reasons as "I live one day at a time" and "I'm 65, I've already accomplished a lot".

The largest group of patients (11) expressed extreme fear about the future. Fears of dependency, illness progression, disfigurement and not being able to take care of their children plagued these women. These findings are not surprising considering that arthritis is progressive and its course is uncertain. It appears that anxiety about the future is a major source of distress for many arthritics.

Question 5 was "who has control over your arthritis?". Results are found in table 13. Eighteen (62%) of the patients said that only they had control over their illness. An additional 4 felt that they had control along with the physician. Two patients felt that only the doctor had control over their arthritis and one patient said that Jesus and the doctor were in control. Finally, 4 patients felt that no one had control over their illness.

The 22 patients who felt that they had some control over their illness were asked what they did to control their arthritis. Most patients did more than one thing. Ten subjects reported that their mental attitude affected their illness and they practiced emotional control. These patients practiced relaxation or tried to keep a positive mental attitude. One was reading Anatomy of an Illness

at the time of the interview.

Nine subjects claimed that taking care of themselves physically improved their condition. These patients exercised regularly, maintained strict diets and paced their activities. Four patients said they controlled their illness by following the doctors orders and taking medication and two said they practiced self-distraction techniques such as immersing themselves in their favorite hobby.

It is shown from these results that 76% of the subjects felt they had some control over their arthritis. This finding is particularly interesting considering the uncertain nature of this illness. However, it lends support to Taylor's notion that exaggerated perceptions of personal control are normal and may even contribute to well-being (Taylor et. al., 1988). Taylor proposes that this may be especially true in times of adversity, such as illness.

The final question refers to the subject's tendency to find something positive in the illness experience. The respondents were asked "has anything good come from having arthritis?". This question is similar to the third one regarding how the subjects have changed. Here however, they are asked to evaluate these changes and make a general statement about the effects of their disease.

Seventeen subjects (59%) answered yes and 12 (41%)

said no, indicating a fairly close division in the group. Table 14 reveals these results as well as what the subjects felt were good results of the illness. The responses varied widely, and again, most people gave multiple answers. As discovered in question 2, becoming more sensitive to others was a positive result for 8 subjects.

Other responses which differ from the results of the second question were: less concern with money, less self-destructive, more relaxed, less demanding and the opportunity to meet nice people (through arthritis related activities). Therefore, from this sample it appears that patients do differ in their ability to find positive meaning in illness. Even a devastating condition like arthritis need not be all bad. As one patient aptly put it "Out of evil came good".

Themes have emerged from the interviews such as the tendency to make attributions for illness, illness as a catalyst for life changes, fear of the future, feelings of control in a debilitating and frustrating situation and the tendency to find something good in the illness experience. Despite these trends the results from these questions show that rheumatoid arthritics are a diverse group with varying concerns and attributes. In order to address these individual differences and provide a more complete picture of the arthritis experience, I will present some case examples which

illustrate the application of my theoretical model.

Existential Principles at Work in Patient's Lives

The following examples will come from patients who are either low or high on existential characteristics based on the illness meanings which they were assigned. By showing how these characteristics emerged during the interviews I hope to clarify the processes by which existential orientation towards illness moderates the psychological effects of rheumatoid arthritis.

Despite the fact that general existential orientation, as measured by the Hardiness Scale, showed no relationship to psychological status, I maintain that many of the subjects exhibited "hardy" characteristics in their approach to life, while others did not. I believe that the following excerpts demonstrate how traits such as commitment, challenge and control operate to facilitate the process of adjustment to illness.

Ricky V. is a 59 year old Hispanic woman whose graduate education was cut short 14 years ago by a severe attack of arthritis. Up until then she had always been in charge of herself and her five children. Orphaned at an early age and raised by nuns, Ricky learned to be independent quickly.

Today she is wheelchair bound. She was forced to place 2 of her grandchildren in foster care. She feels

very guilty about this. She must rely on others to do her housework for her which always falls short of her fastidious standards. For Ricky "the worst part (of arthritis) is weakness".

When she taught school she received respect and admiration from her students. Now she feels that no one cares what she has to say anymore. Ricky claims that her illness has cost her all her friends. She relates "they were all professionals, now we have nothing in common". These problems have strained her relationships with others and she admits she is difficult at times.

Ricky is not optimistic about her future. She had many goals she believes she can not achieve such as owning a business and her own home. She searches for "something fulfilling so I can feel good about myself" like teaching, however she has been unable to define new goals for herself. In addition, she worries about her increasing dependence. While her family is very important to her, she feels like a burden to them.

The main themes to emerge from Ricky's story are loss, guilt, dependency and weakness. Instead of pursuing new goals, she mourns the ones she has had to give up. Instead of finding new friends, she dwells on friendships past. She seems to have lost her sense of commitment to life and regards herself as a weak person. Even though she remarked "I pray, I don't know why because we are really in charge of our own lives", she doesn't seem to be

taking charge of hers.

The story of Susan T. is mainly one of loss. At age 55, after 22 years of illness she still hopes her illness will "burn out". She is very dependent on her husband and her mother, who lives with them. She often spoke from the perspective of her husband: "My husband thinks I never learned to accept it (arthritis). That's why I used to buy shoes I could never wear. He thinks that's my problem. He thinks I dwell on it too much and that I'm too fearful of it".

Susan began to tear as she spoke of all the things she has given up. She had to quit her job. She can no longer "dress up" and entertain, which was very important to her. She is sensitive to people staring at her deformities (mainly in her hands). Susan had wanted to go to law school but felt the tension would be too great. She is constantly feeling apologetic, especially to her husband upon whom she has become so dependent.

Like Ricky, Susan believes "You control your own destiny" but she has been unable to accomplish what she had wanted to in life. She feels as if she's "always apologetic" and that she "can't live life to the fullest". To her, arthritis means loss.

Robin V. is a 30 year old housewife who has had arthritis for 12 years. She had just gotten married in 1980 and had hopes of being a successful accountant and

someday having children. It was then that her arthritis became problematic. She has undergone 2 joint replacements with the prospect of more. Although she has supportive friends and family, Robin was perhaps the most distressed of all the subjects.

It seems that Robin had a very happy childhood and thought that life was "like a T.V. show". She resents having to face the reality of her illness and bemoans the fact that "some things are out of your control". When it comes to arthritis, Robin feels that "you have to have courage to face it", and she is not sure that she does. She is very angry about being ill and views arthritis as an enemy in a battle she is losing.

Robin admits that she is very hard on herself in general. She is always afraid that people will judge her. These feelings are exacerbated by her illness. Robin remarked "I don't bother with new people anymore, it's (arthritis) too hard to explain". She feels that she can not live up to the "doctor's wife" image that others expect of her. Because of this she feels sorry for her husband.

Perhaps the most difficult aspect of her illness is that Robin feels useless; "I do nothing all day and then I blame myself for the things I can't do". When her life goals were interrupted, Robin lost a good deal of her self. Although she has financial, emotional and intellectual resources, she is unable to find a meaningful

purpose in her illness and she had lost interest in other people.

The following case is an example of "illness as punishment". Sally M. has had arthritis for 3 years. She is a 23 year old, intelligent and very attractive young woman who has secured a job in a brokerage firm. Although arthritis is a "huge" part of her life, she doesn't tell too many people about it because she doesn't want to be seen as a "complainer". She also admits to being embarrassed by having "an old person's disease".

When she was asked why she thought she became ill, this is what she said; "I don't think it's fair, I'm not a bad person, I don't deserve it". She regards illness as an evil force and finds nothing redeeming in it at all. Although she believes she has control over her illness through exercise and medications, she refused to comply with either regimen. It seems that Sally has yet to face the reality of arthritis.

Sally explained "maybe the reason I don't take my medications is that I dislike being dependent on them". Dependency appears to be a major source of conflict for her. She relies on others now a good deal more than she used to. "Not that I have to" she explains. Sally goes home to her overly sympathetic parents every weekend. She admits that her dependence is mostly psychological and would like to be less reliant on others. Sally was also

the only one to admit that sometimes she uses her illness as an excuse for not taking responsibility for herself. It seems like Sally is doing a good job of punishing herself.

These stories are certainly understandable given the grave implications of rheumatoid arthritis. However, it is illustrative to contrast these subjects with others who have found a way to transcend the limitations of their disease and have continued to live fulfilling lives in spite or because of it. I will turn now to the opposite end of the patient spectrum.

Some patients seem to simply accept their circumstance and are able to get on with their lives. Fran C. is one such person. An hispanic woman, now 65 years of age, Fran has had arthritis for 11 years. She had to stop working because of it. Arthritis was never hard for her to cope with even though she lives alone and must use a cane for mobility. She is only depressed when she's in pain.

Fran is happy to discuss her attitude toward illness; "I don't feel sorry for sick people because that doesn't help them", "If you think positive, you're gonna be positive ... people who are depressed, it's not the disease, it's personal problems". Clearly, Fran feels that illness alone is not reason for despair. Even when she refers to pain she says "Pain, so what - some people have pain worse then me. Why should I complain, it

doesn't change anything".

Her orientation toward life is best shown when asked about her lost income (she had been a seamstress). Fran responded "I miss the money, but I can get used to anything". She admits "sometimes I wake up and feel so bad I think I'll never get up....then I get out and talk to others. I don't stay shut-in and little by little, I feel better". Fran's ability to stay engaged socially may to be an important tool in her ability to cope with arthritis.

Bonnie B. is a black, 44 year old woman who was diagnosed with RA 7 years ago. About her arthritis she says "You have to accept it and try to build a lifestyle you enjoy around this thing". However, Bonnie didn't always feel this way. She says "I used to blame everything on my illness, but then I realized there were a lot of things I probably wouldn't do anyway".

It seems that Bonnie was able to face the truth about herself and take responsibility for her life. Arthritis no longer gets in her way. She realizes "As long as you can keep going you can keep the pain out of your mind". She pushes herself as hard as she can. Bonnie has also become a member of a hospital based support group called "The Old Arty Club". She enjoys interacting with other patients and claims that they always call her for advice. Bonnie's perspective on illness changed when she developed

a rewarding lifestyle inspite of arthritis.

Cindy V. is only 21 years old. When she first developed symptoms of arthritis 3 years ago she had no idea what was happening to her. Everyone on her hospital floor was "old and crippled". Cindy was scared. She was very active at the time and had to curtail all of her activities. She still admits to anxiety concerning the course of her illness but she realizes it's up to her to fight arthritis.

Cindy forces herself out of bed every morning by telling herself "it's (arthritis) not controlling me, I'm controlling it". This attitude has helped her decrease her medication intake. While Cindy once viewed illness as an enemy, she now most decidedly describes it as a challenge.

Most importantly, Cindy remarked that setting goals was a technique she used to maintain a positive outlook. Some of her goals are "going to work, going to night school, move out of the house, get married and have kids". While these sound typical for a healthy woman her age, they are much more difficult to accomplish for someone with arthritis. However, Cindy is certain she will achieve everything she wants for herself.

Wendy B. is a 40 year old nurse who has had RA for 5 years. One of the more articulate subjects, she had much to say about her adjustment to illness. She described arthritis as a "monster that came along and ruined

everything". She had been very active physically and socially. All her plans were shattered. Yet even then she felt that "something came along and gave me this challenge and I couldn't deal with it".

Wendy has found illness to be a learning experience, "it confronted me" she says. Out of this she had developed her "philosophy of life: Man has a purpose on earth. What kind of experience or knowledge would I have gained if I didn't get ill? Now that I have experienced the bitter anguish of life, it has made me a better person. It has helped me in my life in general...."

Now Wendy is more compassionate to her patients, she is more concerned with her own "self-preservation" and she believes that arthritis has made her more honest with people. When she met her husband of 3 years it was crucial to her to be completely clear about what might happen to her in the future. Wendy has definite plans to be working with the elderly soon and also showed a strong interest in the research she was participating in. More than just coping well with illness, Wendy seems to have gained more than she lost.

Beth K., a 48 year old arthritic for 20 years describes the challenge of illness this way: "I feel that I am fighting it every day of my life. Not an evil, but an obstacle to overcome. I have to defeat it or it will defeat me. For a while I let it take over. when I'm

fighting it, I feel more alive -it's more me. Doing something I didn't think I could do - it's a sense of accomplishment - I can do it".

Perhaps the clearest example of "illness as value" is found in the case of Nancy A.. Wheelchair bound since 1984, Nancy still "enjoys life, people and waking up every day" and says she's always been this way. Although she was once very active, she has not allowed illness to get in her way. About illness she says "This has slowed me down a bit, but it hasn't taken away my mind". She is still doing what she always loved; writing poetry, designing cloths and maintaining contacts with "lots of friends".

Spontaneously she discussed how illness has helped her to "stop and smell the flowers". She feels that her personality has changed for the better since she's been ill. She is more sensitive to others and tries to "lift their spirits" Her relationship with her husband has improved as a result of illness because they communicate better now.

Nancy is unable to have sex with her husband. Realizing his "needs" she suggested he find a "girlfriend". She describes their relationship like "brother and sister". This is particularly noteworthy since many of the marital relationships of these subjects suffered or dissolved as a result of arthritis. One person described it as "a third person in the

relationship". Nancy is unusual in her flexibility in adjusting to her circumstance.

According to Nancy, suffering is necessary in order to be fully human. She says "If you have never had pain, you'd never appreciate what you have... You know you're alive when you feel the pain". In her dreams she sees herself walking and believes that one day she will. Nancy has a good deal of inner strength, which, according to her "comes from the energy that surrounds me and the people that surround me".

When Illness Has Multiple Meanings - Case Examples

Six subjects in this study were not easily categorized in terms of the meaning their illness had to them. These people seemed to express both existential and nonexistential perceptions of illness. Tina G., a 28 year old black woman appeared to experience equal amounts of punishment and challenge in dealing with arthritis. She says "somebody handed me a wrong card". She feels like she's missed a lot. Like many other arthritics, she was very active before her illness. Now she claims "friends shy away because I can't do what they can do - No one really understands".

Feelings of isolation are apparent when Tina says "It's just me and my arthritis". Illness has caused her to grow up faster. As she puts it "I have to come to

terms with the fact that I can't have it all". Although she has faced the reality of the situation, she does not necessarily consider the confrontation a good one. She admits "I still haven't fully accepted it".

On the other hand, she is actively pursuing many goals such as finding a part-time job and returning to school. She acknowledges "arthritis made me look at myself and say I could do things if I try. I don't know if I would feel that way if I didn't have it". Upon reflection she said "I used to feel like it (arthritis) was punishment, but when I look around I feel like I've gained something....It's (arthritis) helped me more than I thought it had".

Karen C. experiences illness as many different things but according to her challenge and enemy are the two most powerful conceptualizations. Now married with one child, Karen at 38 has had what she considers a wonderful life and feels that arthritis may be punishment for so much happiness. She was an airline stewardess and a model; "looks were everything to me" she says. "I've had to give up so many things....at first I resented not being able to ski, now I just want to walk"(she had just undergone foot surgery).

She feels very guilty that she can't take care of her family the way she wants to. To compensate for this Karen tries to give of herself to the point of exhaustion. She explains "It's a family illness, they (her husband, child

and parents) have (a different kind of) pain too". She can not accept arthritis because she feels that is tantamount to giving up, but sometimes she says "It's too overpowering to fight". Karen believes she will die unfulfilled.

Despite this she is able to appreciate life to a greater extent than she could before she got ill. Karen also feels that her illness has given her daughter lessons in compassion and strength. She recognizes that it is important to her to feel that her life hasn't been "a waste". She is not entirely pessimistic about the future. Right now she puts her energy into her home and family and she hopes, someday apply what she's learned from her illness to working with juvenile arthritics.

Ann J. is another example of someone who finds a number of strong meanings in her illness. She is an unusually dedicated 38 year old woman with a highly demanding job in the social service field. She had many plans which were disrupted because of arthritis. Some were: to obtain a masters degree, to teach and write and become more politically active. She lost a personal relationship because her mate became scared when Ann had a particularly bad setback.

She is afraid to give up her job because she is supporting her sister who is also disabled and she feels she will eventually have to help her aging parents out

financially. In addition, she has medical coverage there and they are tolerant of her sporadic lateness due to illness. Some coworkers, however, have difficulty understanding her problem since she tries to minimize it. She is occasionally accused of using arthritis as an excuse. This is very frustrating to her.

Yet Ann understands that learning to deal with arthritis is "just a matter of changing perspective". About her illness she says "If it wasn't this it would be something else. I had to learn to cope with something". She claims that this philosophy has helped her advise those she works with who are in life and death situations. Ann explains that much of her coping with illness has to do with "mourning loss, once I accept it, I'll be o.k.". Right now she seems to vacillate between the two.

This concludes the presentation of case materials. A discussion of the conclusions drawn from these excerpts will be pursued in the section to follow. The implications of the "mixed meaning" category will be addressed as well.

4. DISCUSSION

The quantitative results of this study lend full or partial support to three of the five major hypotheses. By far, the strongest finding was the relationship between meaning of illness and psychological status. As predicted, patients who viewed their illness from an existential perspective showed less anxiety and depression than those who did not on all outcome measures. In addition, it was found that the personal projects score was related to measures of current depression and anxiety such that the more highly a subject rated her personal projects on existential dimensions, the less likely she was to report present feelings of psychological distress. The personal projects score showed no relationship however, to past month measures of anxiety and depression. Significant support was shown for the prediction that meaning of illness would be related to the personal projects score as well. Subjects who found an existential meaning in illness rated their daily goals more highly on existential dimensions than subjects with a nonexistential perspective of illness.

Finally, it was predicted that personality hardiness would be related to the meaning of illness and both personal projects measures. No support for either

hypothesis was found. Moreover, hardiness did not correlate with any psychological outcome measure. However, excerpts of the interviews suggest that hardiness traits such as commitment, challenge and control seem to be related to better adjustment to illness.

The lack of relationship between hardiness and the study variables is surprising. The explanation for this may lie in the properties of the scale. First the hardiness scale was designed for use with middle-class executives. The present sample consists of chronically ill woman, many of whom cannot work. Although the scale proved to be reliable in this sample, it may not be valid.

In order to adequately measure general existential orientation in this sample, it may be necessary to construct questions which reflect aspects of commitment, challenge and control in health related situations as well as everyday life. For example, one item on the hardiness scale refers to knowing when to ask for help at work. This could be changed to an item which taps the patients willingness to ask for physical assistance when needed.

In addition, because the present sample of chronically ill women are less educated than the group for which this measure was designed, some of the questions may be too sophisticated for them to understand, such as "I have no use for theories that are not closely tied to the facts. Indeed, many of the subjects in this study

required assistance in answering such items. It is recommended that revised items should be sensitive to the education level of the target population.

If however, the hardiness scale is indeed valid the lack of relationship between hardiness and meaning of illness may have positive implications for intervention. Since personality is considered relatively stable, it is unlikely that one would be able to change a patient's personality in an attempt to help her adjust to arthritis. On the other hand, the meaning that the illness has to the patient may be more responsive to environmental influences. During the structured interviews, many of the subjects discussed how the meaning of illness changed for them. In fact, the group of patients who had mixed meanings for illness may be most amenable to intervention since they are able to view arthritis existentially at times.

Although there was no relationship between the hardiness scale and meaning of illness, the results of the interviews provide additional insight into the link between general existential orientation and the patient's orientation toward illness. Excerpts from the interviews show that patients who have withstood the vicissitudes of illness appear to have existential qualities, such as a strong sense of control of life as well as a responsibility for it, and a strong sense of self and life priorities. In contrast, patients who considered illness

to be punishment, an enemy, loss or damage, or a personal weakness appear to feel controlled by their illness and have a diminished sense of self as a result of arthritis.

It is possible that for some patients, general existential orientation is not an antecedent of a person's ability to construe a transformational meaning in illness as was hypothesized. Perhaps illness is a unique experience which requires its victim to use resources otherwise untapped. If so, a person may view illness as being distinct from other life areas or may be forced to change perspectives on life as a result.

The interviews suggest that arthritis is a profound enough experience to change aspects of one's personality. Recall that in response to the interview question "How have you changed as a result of having arthritis", positive and negative personality changes were cited most frequently. This concurs with the findings of Liang et al. (1984) and White and Liddon (1972) who found that illness caused philosophical readjustment in half their samples. Similarly, Mendelsohn's personological study of cancer patients revealed marked and enduring personality changes and an altered perception of what is important to them.

If illness provides conditions for personality change then it may be that the dynamic experience of coping with illness impacts upon general existential orientation and

not vice versa as hypothesized. This appears to be true for some subjects. For example, the case of Robin V., the 30 year old housewife illustrates how arthritis transformed her from someone who was very goal oriented and in control of her life to someone who feels alienated and helpless. It seems as if she has permitted these feelings to generalize to all aspects of her life. In contrast, Wendy B., the 40 year old nurse found arthritis to be a learning experience from which she has developed her philosophy of life. She feels it has made her a better person and has helped her in other life areas.

While illness may alter general personality characteristics of some, this is clearly not the case for all. Other subjects seemed to bring their general existential orientation to the task of coping with arthritis. Susan T. is a 55 year old housewife who has always been dependent upon her husband. Her dependency carried over into her lack of ability to cope with arthritis. Likewise, a patient like Fran C. seems to always have had an existential perspective on life.

The direction of the causal relationship between general orientation and orientation toward illness remains unclear. However, the interviews suggest that relationships do exist, although they may be complex. Prospective studies are required to disentangle this relationship. Likewise a proper way of evaluated hardiness must be established. However, the discrepancy between the

results of the qualitative and quantitative analysis points to the importance of using population-appropriate measures along with a personological approach.

It was also surprising that the hardiness scale did not relate to the personal projects scores, especially since dimensions were chosen from the personal projects checklist which seemed to be existential in nature. It was expected that subjects who claimed to be more hardy would manifest this characteristic in their daily activities. In other words, they should feel committed to, challenged by, and in control of their goals. This was not the case in the present population.

Once again, the validity of the hardiness scale in this sample is questionable. If existential orientation was not adequately measured, any relationship between personality and behavior would have been obscured. Another reason for the lack of relationship between the hardiness scale and personal projects may be that the nature of the projects was not examined because the descriptions given by the patients were too brief to interpret accurately. It is possible that hardy individuals engage in different types of personal projects than others. However, this can not be determined on a post hoc basis.

Future research in this area may include a priori categories of projects based on the theoretical model such

as "projects which reflect the tendency for self-expression" or "projects which are other oriented". One way Little (1983) proposed categorization of projects is by morphological pattern. By this he means that projects may be grouped into missions, quests, routines, ploys, reconnaissance operations and vendettas. Some of these, such as missions or quests may be existential in nature and others, such as ploys or vendettas may be antithetical to an existential perspective. This idea may be explored in future studies.

Although the number of projects listed was omitted as a variable in this study, if assessed correctly, it may show a relationship to personality. Hardy subjects may, on the whole, be able to relay far more than ten personal projects. It is suggested that, in the future, there be no limit put on the number of projects a person can list.

Finally, it is also possible that personality has a different relationship with personal projects than the one proposed in this paper. Attitudes and behavior are not always related. Circumstances such as illness may temporarily prevent someone from engaging in activities which reflect his or her attitudes. The discrepancy between an individual's hardiness score and his or her personal projects score may be an additional source of psychological distress. This issue may be studied more thoroughly in the future.

If it is so that general existential orientation does

not predict one's orientation towards illness or the quality and number of one's daily goals, what does? In this study demographic variables showed no relationship to the meaning of illness. Education was the only demographic variable related to the personal projects score, and negatively so. Therefore, it is not age, socioeconomic status, duration of illness, disease activity, or physical disability which determines meaning of illness or the nature and number of daily goals one has. Instead it is possible that variables which were not studied may contribute to the constructs of interest.

Many patients spontaneously discussed the support of their families or others with arthritis as being instrumental in their ability to cope with illness. Perhaps some patients were able to emulate positive role models who have overcome the obstacles of arthritis with an existential outlook or by becoming highly active and engaged in life. The influence of social support and positive role models is a topic for future study.

It was expected that the personal projects score would be related to meaning of illness such that patients with existential meanings would rate their projects more highly than patients without this perspective. The rationale for this hypothesis was that patients who were able to accept their arthritis would not let it interfere with their personal goals, whereas patients who were

unable to accept illness would be too preoccupied to enjoy their personal projects or would be resigned to giving up certain activities. This hypothesis was confirmed at the .06 level.

Since the present population of patients was so small and a relationship between meaning and the personal projects score was found in the predicted direction, a significance level of .06 may be considered acceptable. If this finding is replicated in larger samples, than a case could be made that for patients who view arthritis existentially, illness does not prevent them from fully enjoying their life activities.

The personal projects score was negatively related to depression on Beck Scale and anxiety on the Spielberger scale. There was no relationship between the personal projects score and the depression and anxiety scale of the AIMS. The Beck and the Spielberger scales require that the subject report how she is feeling right now. As such, they are state measures. The AIMS scales, however, asks the subjects how she has felt in the past month. In this way they are not as anchored in the present as the other scales. The personal projects scale also asks the subject about present goals. Therefore, it is not surprising that the present activities one is engaged in is related to present psychological status and not to recent psychological status.

This finding may have important implications for

intervention. If one's current goals are related to one's current mood state, regardless of one's recent mood, then helping a patient cultivate meaningful daily goals may be one way of moderating psychological status. This model however, needs to be tested in a longitudinal manner.

A final word regarding the personal projects score is in order. Since the 11 dimensions of the scale did not all intercorrelate as expected, other ways of combining dimensions may be considered or new dimensions may be added and old ones changed to adequately reflect existential theory. For example, the definition of "challenge" given in the personal projects index is "to what extent is each project demanding and challenging to you?" This may be changed to a definition of challenge as and opportunity for self-growth. Although the creation of new factors in the present data, which were found by Ruehlman (1988) and Emmons (1986), did not clarify the relationship between personal projects and any other measures, future factor analyses on a much larger sample may reveal more meaningful ways of combining dimensions.

In this study, the meaning of illness is clearly the variable most strongly related to outcome. This relationship deserves further discussion. As existential personality theory predicts, patients who were able to accept their arthritis or find a way to meaningfully integrate it into their lives by considering it a

challenge or by finding value in it were less psychologically distressed than patients who did not find such meanings in illness.

This is reminiscent of Victor Frankl's analysis of concentration camp survivors who were able to find meaning in suffering. Essentially, in both cases, victims were able to transcend the situation by using their circumstances as an opportunity for self-reflection and growth. Such individuals became stronger as a result of their suffering. In the present study, many subjects remarked that illness has helped them cope with other life tragedies.

Determining the meaning illness has for the patient may be a useful heuristic in understanding her psychological adjustment to arthritis. The greater question then becomes; Can the meaning of illness be altered by an exogenous agent and how can this be done? The interviews revealed that for some, the meaning of illness did change over time. However, no one reported going from an existential meaning to a nonexistential one. Instead, some subjects began by viewing illness as a punishment or loss, for example, and eventually learned to view it existentially.

This suggests two things: first, patients do change their existential perspective on illness and second, the evolution from nonexistential to existential meaning is a sequential, irreversible progression. If so, once a

patient gains an existential perspective on illness she should be able to maintain it or at the very least, call upon it when necessary.

It would be instructive to ask patients what prompted a change in perspective. However, since this was not done in the present study, I offer suggestions regarding how one may elicit an existential perspective of illness in a patient. Frankl's logotherapy approach may be applicable here. He confronts the patient with the meaninglessness that characterizes his or her life and essentially confirms that the patient has no control over his or her fate. According to Frankl, this results in a reactive response whereby the patient is able to discover the true purpose of his or her existence.

A less intrusive approach was discovered while conducting the present study. It has been suggested that interviewing someone can be an intervention in and of itself by virtue of paying attention to the subject and by the truths which are revealed to the subject in the interview process (Sanford, 1982). In my experience, this appears to be true.

Many of the subjects reported that participating in the interview made them feel useful. They gained a sense of helping others. Others remarked that they learned something about themselves. For many, the interview was an emotional process in which they expressed grief and

pain. They were able to discuss aspects of illness no one may have asked them about before. This was particularly evident when they were asked "Has anything good come from having arthritis?" Some immediately answered "yes", others "no", but more than a few said they had never looked at it that way before. After some consideration they were able to identify some positive aspects of their illness.

Although it is not certain that the interview was a catalyst in changing a patient's orientation toward illness, it is the contention of this author that it paved the way for the change to begin. The posing of questions derived from existential theory may force the patient to begin thinking differently about her predicament. In future research, it would be interesting to assess the impact of the interview on the meaning the patient derives from her illness.

This study focused on patients who attached either existential or nonexistential meanings to illness. There is a third group, however, that deserves comment. Six of the 30 subjects fell into the mixed meaning category. Although this group is too small to include in the quantitative analysis it is sizable enough to consider in theoretical terms. Two explanations for this group are possible. One is that they simply hold stable dual meanings of illness and the other is that they are in the process of changing their orientation toward illness.

In the interview excerpts it was shown how some patients vacillated between viewing illness, for example, as a challenge and a loss. These patients may always hold dual perceptions of their illness. Which one they favor at any given time may be the result of a multitude of factors such as disease activity level or other major life events. In this case, their psychological status may depend upon which meaning is salient for them at the moment.

It is also plausible that a mixed meaning connotes a patient in the process of changing her orientation toward illness. While still expressing feelings of loss and helplessness, she is able to conceive of an existential perspective of illness which seems to emerge as a result of her effort to come to terms with arthritis. Thus, when evaluating an interview with this type of patient, a rater is likely to place her partially in both existential and nonexistential categories.

In this case, psychological adjustment may be harder to predict. On the one hand, since such a patient is capable of an existential outlook, one may expect her emotional status to fall somewhere between that of the existential and the nonexistential patient. On the other hand, since a patient in the process of change may be actively struggling with her feelings in relation to her illness she may be in a greater state of emotional

discomfort than the nonexistential patient. The implications of this state of change for adjustment remain an empirical question for future study.

When considering the mixed meaning group it seems likely that both explanations proposed here are viable depending upon the subject. In other words, some patients may hold dual meanings of illness which are resistant to change while others are in the process of change and therefore express meanings which characterize both existential and nonexistential perspectives. The latter scenario is compatible with the notion that illness provides a vehicle for personality change. This phenomenon may be elucidated through future research on this topic.

Watson and Clark (1984) have argued that when subjective independent and dependent measures are used, strong correlations may be the result of some underlying personality trait such as negative affectivity. Thus, a significant result may be an artifact of the method of measurement where people who report having a particular trait also report less psychological distress.

Hardiness showed no relationship to any of the psychological outcome measures. If a trait such as negative affect was contaminating the results, surely individuals that reported being low in hardiness would also report high levels of depression and anxiety. However, this analysis remains tentative due to the

dubious validity of the hardiness scale in this sample.

In order to avoid the problem of negative affectivity, future studies may include objective measures such as physiological data or physician's reports. While the aforementioned findings do lend support to part of the theoretical model, it is necessary to discuss the limitations of this study and when possible, how they can be avoided in future research. Four areas of the study deserve comment in this regard. They are; the sample, the time-frame, instrument validity, and the dependent variables.

The sample in this study consisted of 30 subjects, which is a relatively small number. This was due to an effort to obtain as homogeneous a sample as possible. All of the patients selected were diagnosed as having seropositive rheumatoid arthritis. It is the opinion of the experts who were consulted that this form of arthritis is distinct from other forms which are more ambiguous and difficult to diagnose accurately. Past studies have grouped seropositive rheumatoids together with seronegatives and with another form of arthritis called connective tissue disorder.

There is emerging evidence that sero-positive rheumatoids differ medically and psychologically from other types of rheumatoids (Lang, 1988). For one thing, sero-positive patients report lower levels of

psychological distress than sero-negative arthritics. Although combining this group with other forms of arthritis would have yielded a larger population, it is possible that the results may have been contaminated by the varying nature of illnesses. While a sample number of 30 may limit the generalizeability of this study to the general arthritis population, it succeeds in promoting greater generalizeability to the sero-positive rheumatoid group than prior studies have.

The small sample size also made it impossible to perform more sophisticated statistical procedures such as multiple regression and path analysis. It would have been interesting to study the additive effects of meaning and personal projects on outcome in a regression equation. Likewise, a path analysis would have helped to clarify the validity of the theoretical model. Unfortunately, this could not be done. In the future, it is recommended that at least twice as many patients be selected for study or that the study continue until equal numbers of patients are recruited in each of the three meaning of illness categories (existential, non-existential, mixed) for comparison purposes.

It should also be noted that this study focused on an urban or suburban east coast female population. Although they are in the minority, there are men who suffer from sero-positive rheumatoid arthritis. For gender related reasons the present results may not apply to them.

Likewise, geographic differences may distinguish this group from others elsewhere in the country. These factors should be considered when evaluating the generalizeability of this study.

Another limitation of this study is that it took place at one point in time. Central to the theory of existential personality is the human capacity for change. Although an effort was made to uncover changes which took place in the patient's life and personality since the illness, this was done retrospectively. As such, patients responses were subject to memory lapses and the tendency to reconstruct the past in a way that makes sense to them.

There are two reasons why a longitudinal model would be preferable in the future. Firstly, it would be interesting to discover how the meaning of illness is formed and what factors precede it. Secondly, a longitudinal study would provide a better test of the causal model proposed here. Current research suggests that mood may determine some cognitive processes (Gotlib & Cane, 1987, Miranda & Persons, 1988). If so, affective states such as depression and anxiety may influence self-report measures. For example, it is possible that subjects who felt depressed and anxious at the time of the interview also expressed cognitions about illness (in this case a nonexistential perspective) which were maladaptive. According to Miranda & Persons, individuals may have both

negative and positive attitudes. However, when they are depressed they are more likely to access dysfunctional attitudes. Thus, the direction of the causal relationships in the current model remain unclear.

A longitudinal model would shed some light on these issues. Ideally patients should be studied beginning one year from their first doctor visit (this is the usual time for accurate diagnosis) and followed up for at least five years, as an illness such as arthritis requires continuous readjustment.

A third limit of this research has already been mentioned. The measure used to determine general existential orientation (the hardiness scale) may have been inappropriate for this sample. One option for future research is to revise the hardiness scale so that it pertains to the chronically ill population. A method for this has been discussed previously.

An issue separate from the validity of the hardiness scale is whether or not hardy characteristics of commitment, challenge and control are sufficient to define existential orientation. The interview data revealed other aspects of an individual's personality which are crucial components of an existential perspective. These aspects include the way in which one responds to anxiety provoking situations, the individual's ability to feel and express emotions, and the tendency to engage in self-reflection. It may also be interesting to assess the

struggles which one has overcome in order to create a meaningful existence. The open-ended interview, originally intended to define existential orientation to illness, also provided insights into the subject's general existential perspective. In the future, a deeper analysis of the qualitative results may be used to define existential personality.

Alternately, another measure of existential orientation could be created. Perhaps it would be possible to create scenarios which require existential choices and rate subjects on their responses. Another option would be to devise an existential anxiety scale which would uncover an individual's attitudes towards anxiety provoking situations. The idea being that existentially oriented individuals would find them less objectionable than those without this perspective.

Finally, this study is limited to the extent that one is interested in other outcomes besides depression and anxiety. although these outcomes are frequently cited, there are other indicators of psychological adjustment which could be used in the future such as, self-esteem, self-efficacy, and arthritis helplessness. In addition, ways of measuring social health could be incorporated into future research.

It may be argued that depression and anxiety are not the appropriate outcome measures for this type of

research. Existentialists view struggle as an inevitable part of life. However, the measures in this study are used to define neurotic depression and anxiety, which would be uncharacteristic of one who feels in control and is able to construct a meaningful existence for oneself. It is more likely that neurotic psychological distress accompanies one's initial confrontation with the existential dilemma of life, but subsides when one consciously chooses to accept life's challenges. Perhaps it is necessary to construct measures which reflect "existential suffering", like the anxiety measure proposed above, in order to establish the difference between neurotic and "healthy" distress.

It is cautioned that rheumatoids have difficulty enduring a long testing process and may lose enthusiasm if they are given too many questionnaires. Therefore, all measures need to be selected carefully and appropriately and not just for the sake of collecting more data. None the less, the results of the present study are only applicable to adjustment defined in terms of depression and anxiety.

In conclusion, the present study has attempted to demonstrate the utility of existential personality theory in explaining psychological adjustment to rheumatoid arthritis. Unique aspects of this research were the attempt to study the illness in the context of the patient's lives, the awareness of the dynamic nature of

illness and the changes that result from it, the use of both personological and traditional methodology, and the search for positive effects of illness.

Although parts of the model were not confirmed, the results as a whole suggest that much of the prior research in this area may be subsumed under this paradigm. For example, work which attempts to show how the attribution of meaning to physical symptoms guides coping behaviors (Skelton & Pennebaker, 1982; Leventhal et al., 1980,1983; Beales et al., 1983) reflects one aspect of the meaning of illness. Liang (1984) and White and Liddon (1972) have focused on the transcendental meaning illness can acquire for certain patients. Mann (1982) discussed the benefits of feeling in control in adjusting to chronic illness and Adams and Lindeman (1974) emphasized the ability to alter future goals as being crucial to coming to terms with disability. Clearly, these topics may be interpreted within an existential framework.

The benefits of a theoretical model such as the one presented here is that it helps organize and explain much of the prior work that has been done in this area. For example, the finding that coping is weakly related to outcome (Felton & Revenson, 1984) may be explained in light of an existential model. What one does when one is ill may be important only in the context of the meaning the illness has to the patient. For example, information

seeking in and of itself may be unimportant if the patient accepts her illness.

Therefore, it is maintained that variable-based research offers limited utility in explaining adjustment to illness. The present results show how certain variables work in concert to determine the meaning of illness. Excerpts from the interviews have shown how many patients feel control in a largely uncontrollable situation, have the ability to find something positive in their illness, accept change as a normal part of illness, and remain committed to important personal goals despite their disability. All these factors may be understood within the context of the patient's existential orientation toward illness.

Although this study has several limitations, it has succeeded in providing the groundwork for future research into the application of existential personality theory to the study of chronic illness. Based on the present results, it has been shown that the meaning of illness and the ability to remain engaged in meaningful activities while faced with arthritis have important implications for psychological adjustment. It is maintained that these findings warrant further attention and that future work on this topic may yield important discoveries in understanding and treating individuals with rheumatoid arthritis and other chronic illnesses.

Table 1

Demographic Characteristics and Health Status Variables

<u>Variable</u>	<u>N</u>	<u>Mean</u>	<u>Standard Deviation</u>
Age	29	44.30	13.72
Years of Education	29	12.76	3.40
Duration of Disease	29	10.79	7.96
Disease Activity Level	29	2.10	.90
Physical Impairment	29	3.87	1.90

Note. For "Disease Activity Level" 2.1 is out of a 1-4 scale where 1 indicates very active and 4 indicates not active at all. and for "Physical Impairment" 3.87 is out of 10 where 1 indicates no impairment and 10 indicates total disability.

Table 2

Hardiness Scale Properties

<u>Scale</u>	<u>N</u>	<u>Mean</u>	<u>Standard Deviation</u>
Hardiness	29	103.48	17.75
commitment	29	35.55	6.15
challenge	29	27.97	8.82
control	29	36.97	5.72

Reliability Coefficients

<u>Scale</u>	<u>Number of Cases</u>	<u>Number of Items</u>	<u>Alpha</u>
Hardiness	29	50	.86
commitment	29	16	.65
challenge	29	17	.80
control	29	17	.55

Table 3

<u>Frequencies of Illness Meanings Chosen By Raters</u>		
<u>meaning</u>	<u>Rater 1</u>	<u>Rater 2</u>
Existential Meanings		
Accepted	19	15
Challenge	18	11
value	1	4
Nonexistential Meanings		
loss/damage	13	11
Enemy	15	10
Punishment	4	2
weakness	1	3
relief	0	0
strategy	0	0

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118-119

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Table 5

Intercorrelations Among Personal Projects Dimensions

	Importance	Enjoyment	Difficulty	Visibility	Control
Importance	1.00				
Enjoyment	.30	1.00			
Difficulty	.06	-.22	1.00		
Visibility	.27	.23	.04	1.00	
Control	-.02	.34*	-.37*	.20	1.00
Initiate	.43**	.5**	.03	.10	.08
Stress	.12	-.34*	.38*	-.17	-.46**
Time Adequacy	.32	.38*	-.21	.02	-.08
Outcome	.16	.40*	-.33*	.10	.46**
Self Identity	.30	.77***	-.03	.26	.29
Other's View	.29	-.09	-.16	.49**	.18
Value	.62***	-.07	.09	.46	-.03
Positive Impact	-.03	-.31	-.31	.16	.06
Negative Impact	-.12	.30	-.38	-.01	-.31
Progress	.19	.10	-.31	.15	.44**
Challenge	.13	-.11	.54**	.02	-.51**
Absorption	.50**	.46**	-.07	.31	.26
Impact	.55**	.30	.41*	-.05	-.04

*p <.05 (two-tailed test).

**p <.01 (two-tailed test).

***p <.001 (two-tailed test).

Table 5 continued

Intercorrelations Among Personal Projects Dimensions

Identity	Initiate	Stress	Time-Adequacy	Outcome	Self-
Initiate	1.00				
Stress	.17	1.00			
Time Adequacy	.25	-.16	1.00		
Outcome	.22	-.0001	.01	1.00	
Self Identity	.69***	-.26	.37	.32*	1.00
Other's View	.07	.08	.24	.36*	.11
Value	.46**	.40*	.21	.16	.07
Positive Impact	-.38	.10	-.22	.10	-.28
Negative Impact	-.72**	-.38	.02	.73	.05
Progress	.28	-.18	.26	.16	.26
Challenge	.16	.45**	.01	-.09	.04
Absorption	.37*	.06	.43**	.38*	.59***
Impact	.25	.23	.11	.36*	.53*

* $p < .05$ (two-tailed test).

** $p < .01$ (two-tailed test).

*** $p < .001$ (two-tailed test).

Table 5 continued

Intercorrelations Among Personal Projects Dimensions

	Other's view	Value	Positive Impact	Negative Impact
Other's View	1.00			
Value	.38*	1.00		
Positive Impact	.44*	-.02	1.00	
Negative Impact	.17	-.64*	.34	1.00
Progress	.44**	.34*	.24	-.70*
Challenge	-.02	.22	.07	-.38
Absorption	.59***	.25	.07	.35
Impact	.44*	.31	.09	.42

* $p < .05$ (two-tailed test).

** $p < .01$ (two-tailed test).

*** $p < .001$ (two-tailed test).

Table 5 continued

Intercorrelations Among Personal Projects Dimensions

	Progress	Challenge	Absorption	Impact
Progress	1.00			
Challenge	-.32	1.00		
Absorption	.30	.10	1.00	
Impact	.03	.51**	.72**	1.00

*p <.05 (two-tailed test).
 **p <.01 (two-tailed test).
 ***p <.001 (two-tailed test).

Table 6

Personal Project's Checklist Mean Dimension Scores

<u>Dimension</u>	<u>Mean</u>	<u>Standard Deviation</u>
Importance*	8.31	1.1
Enjoyment*	7.55	2.3
Difficulty	5.37	2.5
Visibility*	6.63	6.1
Control*	7.51	2.6
Initiation*	8.30	2.1
Stress	5.17	2.3
Time Adequacy	6.17	2.7
Outcome*	8.38	1.5
Self-Identity	8.07	2.1
Other's View	7.42	2.3
Value Congruency*	8.07	2.3
Positive Impact	6.34	7.8
Negative Impact	1.1	2.3
Progress*	5.17	2.5
Challenge*	6.78	2.7
Absorption*	7.77	1.6
General Impact*	6.33	3.1

Note.*indicates existential dimensions.

Table 7

Correlations among Demographic and Independent Measures

Measure	1	2	3	4	5	6	7
1.Age	--						
2.Years of Education	-.26	--					
3.Duration of Illness	.43**	.08	--				
4.Disease Activity Level	-.19	.21	.28	--			
5.AIMS Physical Impairment	.25	.09	.20	-.5**	--		
6.Hardiness	-.28	.43**	.04	.09	.11	--	
7.Project's Score	.35	-.41*	.05	.03	.08	-.06	--

*p <.05 (two-tailed test).
 **p <.01 (two-tailed test).
 ***p <.001 (two-tailed test).

Table 8

Group Means for Outcome Scores

<u>Measure</u>	<u>Mean</u>	<u>S.D.</u>
Depression		
Beck	5.9	5.1
AIMS	2.8	1.5
Anxiety		
Spielberger	33.9	11.8
AIMS	3.5	1.8

Table 9

Correlations between Demographic and Independent Measures and
Dependent Measures

Measure	<u>Depression</u>			<u>Anxiety</u>		
	Beck	AIMS	Other	Spielberger	AIMS	Other
Other						
1.Age	-.09	.14	.18	.01	.13	.42*
2.Years of Education	.12	-.19	.12	.35*	-.04	.05
3.Duration of Illness	-.23	-.06	-.19	-.15	-.19	.14
4.Disease Activity Level	-.35*	-.46**	-.41*	-.15	-.37*	-.42*
5.AIMS Physical Impairment	.36*	.40*	.19	.22	.31	.13
6.Hardiness	.08	-.20	-.10	.16	-.23	.03
7.Project's Score	-.36*	.1	-.21	-.38*	-.05	-.18

*p<.05 (two-tailed test).

**p<.01 (two-tailed test).

Table 10

Responses to Structured Interview Question 2: "Did you ever ask
"why me. If so, what answer did you come up with?"

<u>Response</u>	<u>N</u>	<u>% of total</u>
No	7	33
Yes	22	67

<u>Attributions</u>	<u>N</u>	<u>% of "yes" group</u>
Unable to find one	9	41
Punishment	4	18
Random event	3	14
Genetic	3	14
Higher purpose	2	9
Result of injury	1	4
Total	22	100%

Table 11

Responses to Structured Interview Question #3:How have you changed since you've been ill. How have your plans for the future changed

A. <u>What Changed?</u>	<u>N</u>
Nothing	1
Personality	
For the better	12
For the worse	13
Cognition (sense of reality)	5
Interpersonal Relations	
For the better	6
For the worse	7
Physical Activities	14
Financial Status	1
B. <u>What Plans Changed?</u>	<u>N</u>
None	13
Career	7
Education	4
Personal Achievement	3
Purchasing a home	2
Community activity	2
Travel	1
Starting a family	1

Table 12

Response to Structured Interview Question #4: Picture yourself 5 years from now, what do you see?

<u>Future View of Self</u>	<u>N</u>	<u>%</u>
Same as now	2	(7)
Better than now	3	(10)
Worse than now (fearful)	11	(38)
Subject doesn't think about it	9	(31)
Engaged in non-illness related pursuits	4	(14)
Total	29	(100)

Table 13

Responses to Structured Interview Question #5: Who controls your arthritis and if it's you, how?

<u>A. Who Controls Illness</u>	<u>N</u>	<u>%</u>
I do	18	(62)
My doctor does	2	(7)
My doctor and I	4	(14)
Jesus and my doctor	1	(3)
No one does	4	(14)
Total	29	(100)

<u>How do you control it?</u>	<u>N</u>
Mental attitude/emotional control	10
Taking care of myself physically	9
Self distraction	11
Following doctor's orders	4

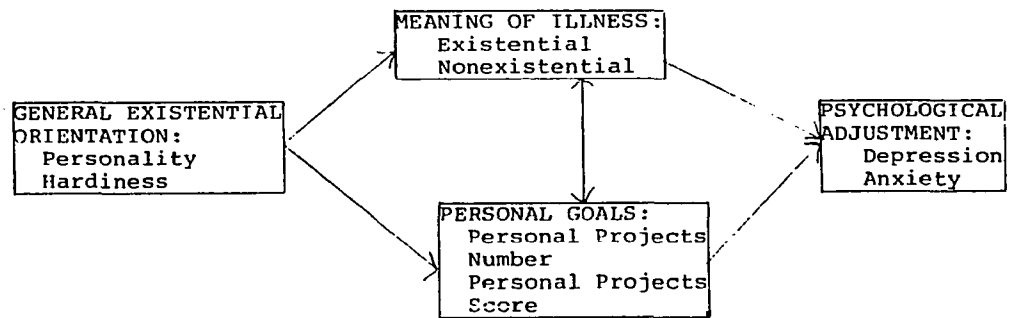
Table 14

Responses to Structured Interview Question #6: Has anything good come from having R.A.? If so, what?

<u>A. Response</u>	<u>N</u>
Yes	17
No	12
Total	29
<u>What good has come from having R.A.?</u>	<u>N</u>
Developed a greater appreciation for life	5
Became more sensitive to others	8
Became a better person	1
Became stronger	2
Became more relaxed	1
Became less demanding	1
Learned to cope better	1
Became less selfish	1
Improvement of marital relationship	1
Became less concerned with money	1
Met nice people	1
Became less self-destructive	1
Became more assertive	1
Became more patient	2
Developed a slower pace	1
Became a fighter	1

APPENDIX A

THEORETICAL MODEL



APPENDIX B

Interview Format

1) Tell me the history of your illness. Include when you first noticed the problem, what was happening in your life when it occurred, how long did you wait before going to the doctor, what were your initial thoughts about your symptoms, what was your reaction to the diagnosis of rheumatoid arthritis, what were the reactions of the people around you, etc.?

2) Sometimes, when people become ill they don't understand why and they ask themselves, "why me?". Sometimes they find an answer. Have you ever asked yourself that question? If so, what answer have you come up with?

3) What were you like before you got ill? How is that different from the way you are now? What were your long term plans before your illness, and have they changed because of your illness? How easy or difficult was it for you to deal with these changes?

4) Picture yourself 5 years from now. What do you see? Where does arthritis fit into this picture?

5) Do you think the course of your arthritis is something that you have control over? If so, how can you be controlled by someone or something other than you? If so, who or what? (Adapted from Taylor et al., 1984).

6) Overall, would you say that having arthritis has been a good or bad experience? If bad, how? Has anything good come of it? If good, how? Has anything bad come of it?

7) Is there anything we haven't talked about with regard to your illness that you think is important? If so, what?

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APPENDIX H

SELF-EVALUATION QUESTIONNAIRE

Developed by C. D. Spielberger, R. L. Gorsuch and R. Lushene

STAI FORM X-1

NAME _____ DATE _____

DIRECTIONS: A number of statements which people have used to describe themselves are given below. Read each statement and then blacken in the appropriate circle to the right of the statement to indicate how you *feel* right now, that is, *at this moment*. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feelings best.

	NOT AT ALL	SOMEWHAT	MODERATELY SO	VERY MUCH SO
1. I feel calm	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. I feel secure	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. I am tense	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. I am regretful	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. I feel at ease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. I feel upset	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. I am presently worrying over possible misfortunes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. I feel rested	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. I feel anxious	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. I feel comfortable	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. I feel self-confident	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. I feel nervous	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. I am jittery	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14. I feel "high strung"	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15. I am relaxed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16. I feel content	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17. I am worried	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
18. I feel over-excited and "rattled"	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
19. I feel joyful	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
20. I feel pleasant	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

APPENDIX I
INTERVIEW SUMMARY FORM

Rater: _____

Subject #: _____

1. What were the main issues or themes that struck you in this interview?

2. Summarize the information S.W. got (or failed to get) on each question.
 - A. History of illness (initial reactions of patient and others).

 - B. Have you ever asked "why me?" and what was your answer?

 - C. How have you changed since the illness, what long-term plans were altered?

 - D. How do you see yourself in the future?

 - E. Who has control over your arthritis?

 - F. Has anything good come from being ill?

 - G. Is there anything else you'd like to add?
3. List anything else that struck you as salient in this interview.

4. Indicate the meaning(s) you feel the illness has to the subject by placing a number next to the meaning(s) so that they are in order of importance to the subject.

___ Challenge	___ Weakness	___ Loss/Damage
___ Enemy	___ Relief	___ Value
___ Punishment	___ Strategy	___ Accepted

___ Other (please explain) _____

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