

FACTORS CAUSING SOCIAL STRESS --

RHEUMATOID ARTHRITIS

by

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## ABSTRACT

**TITLE:** Factors Causing Social Stress--Rheumatoid Arthritis

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**OBJECTIVE AND METHOD:** To investigate the existence of factors in illness which precipitate or increase social stress. To determine the actual presence of 20 such factors in the specific illness, rheumatoid arthritis and the general types of social and emotional consequences precipitated by these factors. The case study method was used. Information on 15 cases was gathered through interviews. Findings from 10 additional patients interviewed by social service staff were added, bringing to 25 the total number of case studies. All patients were seen between October, 1953 and April, 1954. Interviews took place in the University of Wisconsin Hospitals or Out-patient Department.

**FINDINGS AND CONCLUSIONS:** The data gathered validated the objectives of the study. Almost all factors were found to be present and a substantial number of adverse consequences were precipitated. The majority of the patients tended to be most concerned with the unknown causal aspects of the disease and the overall expense for continued medical care and treatment. Some patients found hospitalization difficult to accept because it disrupted normal family life. A number of unanticipated consequences were found and these were mainly

related to fears and anxiety concerning the disease process. It is anticipated that this study will be useful for teaching purposes when it is incorporated into the larger research project, wherein, four disease entities will be investigated, compared, and analyzed. Observations made from this study of patient reactions indicate a need for more medical discussion with patients covering the etiology of the disease and more extensive use of vocational rehabilitation services.

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## CHAPTER I

### INTRODUCTION

The inter-relationship between physical, emotional and social aspects of illness has gained wide acceptance as a result of clinical observation and scientific investigation. In most instances, the investigation has been based on study of individual cases from which generalizations have been drawn. Each patient presents a clinical picture which varies from the "typical" and requires a differential approach in study and treatment. To make use of general knowledge without appropriate consideration of individual differences is acknowledged as unsound. However, to individualize each patient to the extent that general knowledge is excluded is equally against the best interests of the patient and the person responsible for his care.

Variations in the physiological aspect of disease cover a wide range. Even more complex are the variations in personality and social adjustment of the patient with the disease. Questions such as the following might then appropriately be raised--is there a "norm" which can be used as a basis for comparing individual social diagnostic findings as there is in medicine as represented by the "typical" or "classical" case? Is there a valid overall treatment regime which might

be modified to suit the variations in social and emotional patterns of the individual case as there is in treatment of the physiological aspect of the illness?

Answers to some of these questions are being sought and found. The psychosomtists are reaching tentative conclusions regarding the emotional causes of illness. Study is also proceeding to determine the social and emotional consequences of illnesses which do not appear to have emotional stress as a causative factor and much of our thinking regarding rehabilitation of the handicapped is based on such findings.

The history of medicine shows a consistent effort to group symptoms into disease entities and although disease may be defined broadly as a state of bodily malfunction, we usually think of it more especially as heart disease, asthma, etc. Restoration of the sick person to health or to as near normal functioning as possible involves for him acceptance of the process of medical examination, evaluation (diagnosis) and treatment. He must also adjust to his symptoms and deal with his own and the public's attitudes towards his specific disease.

In one sense, it is this total situation which creates many of his social and emotional problems. However, there are obviously some elements within disease and its treatment which are more threatening than others. Many of these elements or factors have been identified and considered in handling the ill person. That social dislocation results from confine-

ment in bed, physical deformity or need for special diet come quickly to mind. There are many additional factors which have received equal attention. About others, we have only impressions gained as a result of helping many patients who break down under the resultant stress. If disease and its treatment could be analyzed in terms of such factors, more complete consideration of them might routinely be included in medical and social treatment.

This study will attempt such an analysis and propose a roster of factors which appear to be involved in creating social stress. As teaching and treatment are most frequently done in terms of disease entities, an attempt will be made to determine whether these factors tend to present themselves in clusters which are characteristic of specific diseases. A further effort will be made to determine whether the factor may be considered as a source of stress in whatever context it may appear or whether its meaning is modified by the disease entity of which it is a part.

To proceed with this investigation four disease entities have been selected; diabetes mellitus, rheumatoid arthritis, epilepsy and rheumatic heart disease. These have been chosen because of their high incidence and because as chronic diseases, their duration can provide opportunity for the social and emotional problem to become apparent.

This segment of the total study will be concerned with the disease entity of rheumatoid arthritis and twenty-five

case studies will be made. Information will be gathered from individual interviews with the patients and in some instances, with their families. It will be supplemented with facts gathered from available medical records.

This information will be analyzed to determine whether the suggested illness "factor" can be considered as being a valid source of social stress, whether the anticipated stress factors appear in the disease under study, and what general types of problems (consequences) are precipitated or aggravated. The resultant data will then be incorporated in the larger study concerning the four disease entities of rheumatoid arthritis, epilepsy, rheumatic heart disease, and diabetes mellitus.

## CHAPTER II

### RHEUMATOID ARTHRITIS AND THE IDENTIFICATION OF THE FACTORS WHICH INCREASE SOCIAL STRESS

#### Introduction

The scope of the problem of physical disability, which might have been expected to diminish with improved medical care, has, paradoxically, pyramided to alarming magnitude. Even with better methods of prevention and care, survival of the chronically ill and longevity have increased to the point where the annual increment of the physically handicapped is constantly mounting. The problem has not been one of the emergence of new disease entities, but rather has resulted from the relative increase of disabled persons in our population. "The statistics alone tell only a small part of the story. The long-term toll of chronic illness in suffering, anxiety, and disrupted homes, constitutes the real tragedy of the situation. Moreover, the staggering cost of chronic disease to the community and the nation depletes our resources of manpower and money; and the loss of earning power of the incapacitated increases the total cost to billions of dollars annually."<sup>1</sup>

In a recent article on the treatment of rheumatoid arthritis, Dr. E. W. Boland stated that, "Most chronic diseases

serve as trying therapeutic problems but probably none has been more challenging than rheumatoid arthritis. Because the clinical pattern of the disease is variable and often unpredictable, and because response to treatment with measures used in the past has been slow, appraisal of newly recommended agents has been difficult. With an unknown pathogenesis and without the advantage of employing experimental animals to evaluate therapy, treatment has been almost entirely empirical. For no other disease have so many remedies been proposed, and although often heralded by extravagant claims, most have proved eventually to be of limited or no value."<sup>2</sup> It is felt, however, that the proper selection of certain time-tested measures has made it possible to afford varying degrees of comfort and often to prevent crippling. Thus, the results of these therapeutic efforts have been rewarded by partial or complete arrest of the disease.

#### Incidence and Classification

In 1952, the United States Public Health Service, did a study of the incidence of rheumatic diseases in this country which was based on a sample of some 25,000 households scattered in sixty-eight sample areas in forty-two states. The results of the study bore out earlier estimates, "and indicated that in 1951 approximately 10,104,000 persons 14 years of age and over in the U. S. believed they were victims of

arthritis or rheumatism and that in some 6,414,000 the diagnosis had been confirmed by a physician."<sup>3</sup> It was further indicated that about one-fourth of the 10,000,000 patients had made some significant change in the amount or type of their work as a result of their illness. "In respect to days lost from work, the rheumatic diseases were surpassed only by nervous and mental diseases....The estimated cost of medical care alone for the patients exceed one million dollars annually, but to this must be added untold amounts due to losses in production and education occasioned by disability among workers and students."<sup>4</sup>

Although the disease is extensive, "approximately one in each twenty of our population is affected,"<sup>5</sup> it has not, until recent years, stirred the interest of the physician and the public sufficiently to do anything about the problem. This attitude probably can be attributed to the fact that although rheumatic diseases make lifetime cripples, they do not kill. Certainly when one considers the fact that arthritic patients are often conspicuously crippled or deformed a discussion of public attitudes towards associating with persons suffering from this disease becomes an important factor for analysis.

"The term 'rheumatism' is as old as medicine and has been used for centuries to designate all forms of painful skeletal disturbances, whether joints, muscles, fibrous tissue or nerves were involved."<sup>6</sup> From a historical point of view,

the term rheumatism "was probably introduced by Galen in mediaeval times to designate pain which he believed to be caused by one of the four cardinal 'humours' which constituted the human organism being in faulty combination with the others, and being eliminated or discharged from the blood into one of the many cavities of the body."<sup>7</sup> The unlettered sufferers used the highly descriptive name of "the misery"<sup>8</sup> as they attempted to describe their discomforts; while the more learned individuals interchangeably used such terms as rheumatism or rheumatic fever or the gout to describe the various forms of chronic rheumatic arthritis.

There are a great many rheumatic and para-rheumatic diseases which affect most persons who complain primarily of pain in their muscles and joints. The classification of these diseases can not be entirely satisfactory while the cause of many of them remain unknown. In an attempt to avoid confusion in terminology, an eleven-point classification form has been officially adopted by both the American Rheumatism Assn. and the Standard Nomenclature of Disease. It has been found that "the majority of cases fall into eight important groups: (1) arthritis due to microbial agents, (2) rheumatic fever, (3) rheumatoid arthritis, (4) the 'collagen diseases', (5) degenerative joint disease, (6) arthritis due to direct trauma, (7) arthritis of gout, and (8) the nonarticular forms of rheumatism."<sup>9</sup>

Rheumatoid arthritis and rheumatic fever are the most

common types of the more severe forms of rheumatic diseases. Patients with rheumatoid arthritis form a great proportion of the population attending arthritic clinics because of the long duration and severity of the process. "Under the heading of rheumatoid arthritis are included certain diseases that are thought to be variants of classic rheumatoid arthritis, such as Still's disease, Marie-Strümpell disease or Ankylosing spondylitis, and the arthritis associated with psoriasis."<sup>10</sup> The classification of arthritis adopted by the American Rheumatism Assn. has done much to clarify the nomenclature of the rheumatic disease group. This study will be concerned only with rheumatoid arthritis and its variants.

### Etiology

Rheumatic arthritis is a disease of unknown cause. However, there are certain factors upon which general agreement is present. Rheumatoid arthritis is a disease of temperate climates. It may have a tendency to be familial, but this factor is difficult to trace genetically. The sex ratio is three females to one male, and 80% of the cases occur between the ages of twenty and fifty, the peak being thirty-five to forty years of age.<sup>11</sup> Additional investigations have shown that "rheumatoid arthritis is variously claimed to be (1) an infectious disease, (2) a metabolic disease, (3) a disease with an endocrinologic basis, (4) a disease of the peripheral circulatory apparatus, (5) a disease of the nervous system,

(6) a psychogenic disease, and (7) a disease of hypersensitivity. Such a list indicates how little actually is known about the cause of this disease."<sup>12</sup>

When one considers the social components of a chronic illness, the fact that little is known about the etiology might tend to cause the "unknown" aspect to become a source of considerable concern for the patient. In some cases the disease entity has been found in others of the same family group. Thus, it would seem that this situation would cause anxiety regarding the hereditary aspects of the disease. The factor of neglect in care, is also of importance for consideration, since proper treatment cannot be prescribed nor followed until a true and correct diagnosis has been established.

### Symptomatology

Rheumatoid arthritis is more than just a disease of the joints. "It is a general systemic disease with widespread pathologic changes in various organs and tissues throughout the body -- the joints may be the main scene but they are not the whole play."<sup>13</sup>

The onset of rheumatoid arthritis is frequently insidious. In many instances before the initial complaints regarding the symptomatology are made, the patient will generally complain of tiredness, general malaise, fatigue, exhaustion, lassitude, vasomotor disturbances, muscular stiffness, loss

of weight and general debility.

In the clinical picture of the rheumatoid arthritis patient, one finds that there is no single pattern in the development of the disease. The articular involvement is distributed symmetrically and the smaller joints of the hands are particularly prone to be affected, especially the proximal interphalangeal joints of the fingers. Muscular thickness and edema appear early along with thickening of the joints. As the disease process continues, the patient will complain of pain, swelling, stiffness after inactivity, and limitation of motion. Muscular weakness and atrophy, plus atrophy and pigmentation of the skin occurs. Laboratory observations show the development of hypochromic anemia that responds little, if at all to the oral administration of iron. In addition, these findings indicate an increase in the sedimentation rate of the blood and chemical changes in the synovial fluid in the joints.<sup>14</sup>

In discussing stressful factors in the symptomatology of rheumatic diseases, one must remember that rheumatoid arthritis is a chronic disease which leads to severe crippling. While it may become arrested or quiescent at any stage, the clinical pattern of the disease is variable and often unpredictable. Undue physical inactivity may promote muscle weakness and atrophy, thus too much rest may be detrimental. The typical rheumatic joints presents characteristic appearance. Usually there is swelling, persistent pain and limitation of movement or motion.<sup>15</sup>

### Treatment or "Management"

"Until the true etiology of rheumatoid arthritis is known, the treatment will remain empirical."<sup>16</sup> Because of the nature of the onset of the disease, it is frequently found that treatment is not secured until the disease is well or far advanced. However, in comparing the results of available therapy, there seems to be common agreement that the earlier the treatment is begun, the better the outcome.

Treatment directed to the joints alone is not enough, therefore, measures should be taken to combat the disease as a whole. Today, treatment measures are frequently spoken of as "management" of rheumatoid arthritis. Thus, the proper management of the disease would include the use of all the therapeutic agents which will ameliorate its symptoms. "These agents are: (1) properly balanced rest and activity, (2) salicylates and phenylbutazone (Butazolidin), (3) physical therapy, (4) psychotherapy, (5) measures to prevent or correct deformities, (6) treatment of the anemia with iron or transfusions, (7) attention to adequacy of diet and vitamin intake, (8) chrysotherapy, (9) cortisone, hydrocortisone, or adrenocorticotrophic hormone therapy, (10) roentgen therapy (of value only in rheumatic spondylitis), and (11) removal of proven intercurrent (focal) infections."<sup>17</sup> Years of clinical trial have indicated that "success in treating rheumatoid arthritis lies in the ability of the physician to use a combination

of the above agents."<sup>18</sup>

In approaching the problem of treatment for this disease, it is important to remember that a positive cure cannot be promised and that in all probability, treatment may require several years. Treatment planning should include the enlistment of the patient's own efforts to help himself. The patient with rheumatoid arthritis cannot just sit back and wait for the physician to produce a cure. He must be directed to plan his day to include proper exercises, balanced by adequate rest, various self-applied home physical-therapeutic measures, and other diversional activities, as well as simply taking prescribed medicines at the proper time. If possible, the patient should be "made an 'active partner' rather than a passive recipient of therapy."<sup>19</sup>

"Regardless of their placid and usually pleasant exteriors, most patients with rheumatoid arthritis tend to be irritable, fretful, and introspective. Even if no other significant emotional disturbances exist, arthritic patients have their own conditions to worry about. Eventually most of them harbor fears of being crippled . . . . These fears often lead prematurely to feelings of dependency, discouragement, and even hopelessness."<sup>20</sup> If the patient is given a full understanding of his disease as well as the limitations of therapeutic measures, much can be done to offset many of his fears.

Discussions with the arthritic patient should be aimed

at acquainting him with the fact that, "The objectives in rheumatoid arthritis (treatment) are to maintain the best possible functional range, to keep the degree of pain under control, and to preserve the strength and joints."<sup>21</sup> In order to accomplish these objectives, the patient must be aware of certain factors which will become a necessary part of his treatment. Regular medication and the use of appliances will be helpful in the control of pain. Occasional periods of hospitalization should be instrumental in maintaining the best possible functional range. Since it is essential for the arthritic patient to have an active program for the correction and the restoration of normal joint movement, painful treatment, either administered by themselves or by others, and required activities for continued mobility, become two additional factors regarding treatment to be considered. If the total therapeutic program is to be at all effective, then the patient must be responsive to the element of consistent medical supervision if any value is to be gained from the prolonged management of rheumatoid arthritis.

In regard to the prognosis of this disease, it is now felt that, "In spite of the vast amount of crippling and deformity to which rheumatoid arthritis leads, the prognosis is by no means as unfavorable as is generally supposed."<sup>22</sup> In most instances the disease does become arrested or quiescent during its course so that the patient can be taught to live and carry on an occupation with his arthritis without

great difficulty. Even though the prognosis now tends to be more favorable, it must be remembered that, "The patient with disabling rheumatoid arthritis has a lifetime problem with which to contend. He slowly and progressively sacrifices portions of his self-sufficiency and independence; and gradually becomes dependent upon others. The psychological impact of this process ultimately impairs will. Such a patient needs encouragement to continue treatment, and to refuse becoming dependent upon others."<sup>23</sup>

In the above discussion of the disease entity of rheumatoid arthritis, an attempt has been made to indicate the existence of certain factors or elements in this illness which would tend to precipitate or increase social and emotional stress. The following is a comprehensive listing of the complete group of factors which will be considered in this study.

- |     |   |                                   |
|-----|---|-----------------------------------|
| I   | Public Attitudes                            |                                   |
|     | 1. Social repulsion                         | 5. Persistent pain                |
|     |   | 6. Lack of mobility               |
| II  | Etiology                                    | 7. Low activity tolerance         |
|     | 1. Hereditary tendency                      |                                   |
|     | 2. Neglect in care                          | IV Treatment                      |
|     | 3. Unknown                                  | 1. Consistent medical supervision |
| III | Symptomatology                              | 2. Regular medication             |
|     | 1. Chronicity                               | 3. Painful treatment              |
|     | 2. Unpredictability of increase in symptoms | a. by self                        |
|     | 3. Progressive severity                     | b. by others                      |
|     | 4. Deformity                                | 4. Hospitalization                |
|     |   | 5. Required Activity              |
|     |   | 6. Use of Appliance               |

## Footnotes for Chapter II

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17. Ibid., 225.

18. Ibid., 226.
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## CHAPTER III

### METHODOLOGY

As previously stated, this study is one of the segments of a larger research project, regarding the social components of four chronic disease entities, which was begun in 1953 by the staff of the Medical Social Service Department of the University of Wisconsin Hospitals. The choice of rheumatoid arthritis for this segment of the study project was made because of the availability of the patients with this diagnosis in the hospital setting. Since much of the information desired for the study would be both introspective and subjective, it had been decided that the case study method of research would be used; interviewing responsibility to be shared between the writer and members of the professional social service staff.

To secure the sample of 25 cases a routine was established whereby a semi-weekly review of the two men's and the two women's medical wards was made to determine the number of appropriate patients in the hospital at that specific time. The wards were reviewed in rotation in order to insure a random sample. When two or more appropriate patients were found on the same ward at the same time, selection by alphabetical sequence was made. Because of a drop in appropriate

hospital admissions, it soon became apparent that this method alone, would not be adequate to provide the required number of cases within the time limits of the study. Therefore, arrangements were made to interview persons scheduled to be seen in the weekly arthritic out-patient clinic. Since we were also interested in including children, it was decided that patients admitted to the Children's Orthopedic Hospital would be included in the sample.

The criteria established for the suitability of the cases were as follows: (1) that the patient be between the age of three and sixty-five; (2) that the diagnosis be clearly established as rheumatoid arthritis or a variant; (3) that the patient's illness be uncomplicated by another disease which would interfere with our evaluation of the effects of the primary illness under study, and (4) that the patient be neither psychotic nor feebleminded. A few persons with a mild form of neurosis, were used in the study. In some instances it was necessary to reject some of the cases because they did not fit into the above categories. It might also be mentioned that some of the selected patients could not be seen because they were discharged before interviews could be arranged. Forty-two cases were screened before twenty-five appropriate ones could be found and interviewed.

The information for the study was obtained from interviews with the patients or with the parents if the patient was a young child. These interviews were, in the main,

conducted in privacy. However, some were carried out at the bedside with the patient's consent if he found it extremely difficult to get about, or in and out of bed. Because the majority of the patients to be seen were not local residents, but came from various sections of the state, and because the expected length of hospitalization was not easily determined, it was felt that a one interview type of contact would have to be made. In a few instances some individuals were seen for a second time because the patient had to restrict the length of the interview due to physical limitations.

Before the patients were interviewed, their medical records were reviewed in order to obtain supplementary medical and social information. When the person was contacted, the purpose of the interview and the study was explained to him as a research project being conducted in the hospital with patients having four different diseases. It was further explained that his participation was being solicited along with other patients, in order to give those persons working in the medical field a better understanding of the disease and its affect on individual patients. Most of the patients said they would be very willing to participate, especially if it was felt that their assistance would be helpful in treating other persons.

In the actual interview, neither a schedule nor a questionnaire was used. However, the interviews were focused on the medical-social factors which had been determined through

our reading and general knowledge of the disease and which have been described in Chapter II. All four general areas, those of public attitudes, etiology, symptomatology, and treatment were discussed with the patient whenever possible. In some cases, the degree of severity or the brevity of time since the onset of the disease made securing complete information during the interview somewhat difficult. It was necessary for the interviewer to be conscious of the patient's physical condition as well as the emotional reactions when certain areas were being discussed. Attempts were made not to ask direct questions, but to relate questions to general areas of concern. This method was found to be very useful and effective.

The patients, were all made aware of the fact that the information given would be confidential and recorded anonymously. In a few instances, it was felt that contact with the patient should be continued for casework services. When this occurred, the patient's permission was obtained to share with the doctors some of the information gathered for the study. A few of these patients were later referred for vocational rehabilitation.

In the following chapter will be found the case summaries of the twenty-five cases having a diagnosis of rheumatoid arthritis. The material presented there is pertinent information of a descriptive nature concerning each person interviewed. Additional data regarding the patient's responses

during the interview and the analysis of the consequences will be discussed later in Chapter V under the headings of the factors as they were listed in the previous chapter.

## CHAPTER IV

### CASE PRESENTATIONS

Case #1 - Mrs. L.

Age: 47

Church: Catholic

Sex: Female

Usual occupation: Housewife

#### Onset & Severity

The onset occurred about 16 years ago, beginning in the right index finger. The condition has spread to almost every joint in the patient's body. She is very concerned now that the involvement is starting in her knee again and in her back which is rapidly causing her to lose her ability to stand and to walk.

#### Emotional Stability

This patient seems to be a stable and mature person who is quite fearful of losing her independence.

#### Case Summary

Mrs. L. is an attractive 47 year old woman who does not appear to be acutely or chronically ill. After receiving

8 years of schooling, she worked in a factory until her marriage at the age of 19 years. She has 2 children, a boy and a girl, both of whom are married.

Mrs. L. speaks of herself as having been a very active club woman before developing this condition. She continued to carry on most of her social activities until she became severely crippled. She feels that the help and understanding received from her husband, who is a machinist, and her children have contributed greatly to the fact that she was able to maintain her role and status in her home for almost 16 years. Physical adjustments were made in some of the household furnishings in order to allow the patient to continue with her housework which she does from a sitting position. She has struggled very hard during this period to maintain her independence. Mrs. L. has developed the philosophy that, "Someone has to have this disease. There are other people who are worse off than I am."

Case #2 Mrs. K.

Age: 31

Church: Methodist

Sex: Female

Usual occupation: Housewife

### Onset and Severity

Onset occurred in 1948 when patient noticed some stiffness and joint pain of a migrating nature. This increased in severity until at the present time all extremities and patients jaw are involved. Patient walks with a slight limp and her hands are deformed.

### Emotional Stability

This patient appears to be a dependent person who has always been shy and withdrawn.

### Case Summary

Mrs. K. is a 31 year old woman who has been married for 11 years. She has three children, two boys and one girl, between 6 and 9 years of age. In speaking of her children in relation to her illness she says, "They are all very helpful. I guess they have to be because they have never really known me as being a well woman." Mr. K. operates his own trucking business. He moved his office into a wing of their home a few years ago when the patient's condition became severe.

Mrs. K. seems to have been able to work out comfortable solutions to most of the problems precipitated by her illness. Her husband attends to most of the meals and other household

duties with the assistance of a part time girl who helps, the neighbors who drop in every morning, and the relatives. From a sitting position, Mrs. K. does the dishes. She was told that the hot water was good for her hands. Social activities are centered around watching television and a weekly Friday night "movie and dinner date" with her husband.

The patient was described medically as being "resigned" to her illness and one who "never thinks of recovery". Her family is acclimated to her illness and help accordingly.

Case #3 - Mr. B.

Age: 18

Church: Lutheran

Sex: Male

Usual occupation: Student

#### Onset and Severity

Onset about  $1\frac{1}{2}$  years ago just before school opened. Involvement now in right elbow, wrist, ankle, and left knee. Limitation of movement confined to elbow and knee. Walks with a limp.

#### Emotional Stability

Patient appears to be a normal adolescent boy who is

very apprehensive about his illness.

### Case Summary

Mr. B. is an 18 yr. old high school senior who lives with his parents and two sisters, 10 and 21 years of age. He has a 25 year old married brother with whom he had considered working in a gasoline service station.

This student has, so far, been able to keep the true nature of his diagnosis from his schoolmates for he does not want them to think of him as a cripple. He has, however, informed his employer of his condition. He works in a grocery store for 4 hours per day comfortably but says, "I don't see how I stand the 8 hours on Saturday." His duties have been changed from unloading trucks to keeping the shelves stocked. This meant a relative amount of defeat to him, but he can tolerate the work situation because the group is understanding and accepting.

Mr. B. finds a differences in the attitudes of girls. "My first steady dropped me like a hot potato when I told her". He continues to be active in church and social groups, dates occasionally, and will only explain his limitations when he feels a girl is "really interested and not curious". His savings from  $2\frac{1}{2}$  years of work have been used for medical expenses. He had planned to use the money to supplement his income while taking a trade apprenticeship. This idea was

not encouraged medically. It was felt that the patient would benefit from vocational rehabilitation and a referral was made.

Case #4 - Mr. L.

Age: 55

Church: Protestant

Sex: Male

Usual occupation: Lithographer

#### Onset and Severity

Onset occurred about 8 years ago when patient felt a painful "catch" in his right hip. He received treatment and the condition disappeared for about 4 years. It recurred and the involvement is now in his knees, hands and wrist. Limitation of movement in these areas is sporadic.

#### Emotional Stability

Medically, this patient was described as being probably neurotic. He appeared in the interview to be unstable and flighty.

Case Summary

Mr. L. is a 55 year old married man who is of English descent. He has always lived in the midwest, completed the 8th grade, and was trained and has worked as an engraver. His wife and 80 year old mother have arthritis in their knees but he does not consider this as being an hereditary illness. He has one child, a 31 year old daughter who is married.

Mr. L. enjoys talking about and describing his illness. He has searched extensively for a cure and has been seen by medical doctors, osteopaths, and chiropractors. He has tended to give each one "a time limit to produce a cure" and this has been very expensive.

This patient worries about his future, however, feels that he is fortunate in having his present job. For when his fingers stiffen sporadically and he can not work for brief periods, he is able to make up the time later in the day. "It doesn't matter when, just so I eventually get the work out." It was difficult to interview Mr. L. for he was very preoccupied with describing the disease process from a physical point of view.

Case #5 - Mr. S.

Age: 54

Church: Lutheran

Sex: Male

Usual Occupation: Factory  
laborer

### Onset and Severity

Onset of this illness occurred in Jan. '54. Involvement is in his wrists, hands, shoulders, neck, and knees. The condition is presently described as being active and acute.

### Emotional Stability

Patient was rather emotionally upset because of the recent development of his illness, otherwise seemed to have been a stable person.

### Case Summary

Mr. S. is a 54 year old married man. He has six children between 12 and 30 years of age, and three of them are married. After completing six years of schooling, Mr. S. went to work in a creamery. Within a few years, he left this job and worked as a farm laborer. Ten years ago, he moved with his family to another section of the state and there obtained his present job as a "buffer" in a pressure cooker factory.

Mr. S. seems to be so preoccupied with his illness, his

wife's recent illness and hospitalization, and the family's financial situation that he is finding it difficult to comprehend, "just what has happened" to him in such a short period of time. He seems to have little awareness of the disease or its process in terms of long time treatment and possible incapacitation.

While Mr. S. was in the hospital, Mrs. S. applied for and received a partial general assistance grant. The patient is fearful that his family "is suffering now". The termination of sick benefits has helped to increase his anxiety. About two weeks ago, his thirty day leave of absence from his job was extended for an additional 30 day period. Because his physical condition has become generally weakened, Mr. S. doubts if he will be able to continue on his same job. He wonders if "an easier job will be available" for "it's hard to get a new job when a man is over 40".

Case #6 - Mr. L.

Age: 50

Church: Lutheran

Sex: Male

Usual Occupation: Farmer

### Onset and Severity

Onset about 15 years ago when patient noticed pain in right great toe occurring during spring planting. About 9½ years ago, he noticed joint pains affecting his feet, ankles, knees, and hands. Increasingly the episodes became more frequent. Now almost all joints in the body are involved. Patient can only walk and stand with great difficulty.

### Emotional Stability

Patient's history indicates that he tends to be a dependent and somewhat immature person.

### Case Summary

Mr. L. is a 50 year old man of German descent who was educated through the 8th grade. He has two daughters, 23 and 19 years old, both of whom are married.

Mr. L. had been a farmer all his life until 5 years ago when he decided to sell his farm because of his physical condition. Most of the money received from the sale of the farm has gone towards the expense of the patient's medical care. For the last 5 years, Mrs. L. and her 19 year old daughter, who still lives in the home, have been employed. In order to be helpful in this situation, Mr. L., who is still able to drive a car, calls for his wife and daughter daily after work and brings them home.

He is not able to arrange similar transportation in the mornings because he is too "stiff". Thus he arises around 10 A.M., prepares his breakfast, and does some household activities. Since standing has become very difficult, he sits while performing these duties. During the afternoon, he reads, works on his crocheted rugs, takes a nap, or visits with a few friends who come to see him, however, most of the time he feels "all alone and like a hermit."

Towards evening the patient's pains become worse. Therefore, he and his wife generally "spend quiet evenings at home listening to the radio". When referring to his total situation in relation to his wife and children he said, "It's not as hard for them as it is for me. For they can still get around when they want to and I can't."

Case #7 - Mr. W.

Age: 22

Church: Methodist

Sex: Male

Usual Occupation: Univ. Student

#### Onset and Severity

In 1947, the patient became ill and he was told he had

rheumatic fever; treatment recommended was for modified bed-rest. During the winter of that year, the pain increased as the hands and knees became more involved. This time he was told that he had arthritis. In 1950, he had marked deformities of both hands, but had no limitation of motion. His condition remains relatively the same at the present time.

#### Emotional Stability

Seems to be a stable individual, but history indicates a tendency to be dependent.

#### Case Summary

Mr. W. is a single young man who looks older than his 22 years of age. He is presently a student in agricultural engineering. He lives with his parents; his mother is an employed registered nurse and his father, a former farmer, is temporarily unemployed due to a back injury sustained last fall. The patient also has a married sister who is one year his senior.

Mr. W. feels that "small things are beginning to irritate me now" such as the dirty dishes around the house which are not done until his mother returns from work. For the last  $1\frac{1}{2}$  years, he has been going steady "with a nice girl" who is aware of his physical condition. He is now very jealous of her "because of extremely small things," thus, he is fearful

of losing her.

This patient is also concerned about his future vocation and employment opportunities which would be suitable for him. For the last few summers he has worked for either the Highway Commission or the Conservation Dept. He feels that he can fit better in the latter program since "walking and standing is better than sitting for me." If this does not work out for him the patient feels that with "a little additional training" he could change his occupation to a "desk job in a warm climate which might be more appropriate."

Case #8 - Mrs. R.

Age: 59

Church: Presb.

Sex: Female

Usual occupation: Housewife

#### Onset and Severity

The onset of the rheumatoid arthritis occurred about 24 years ago when the patient was 35 years old. The involvement has been progressive especially in the hands, knees, and neck. At the present time there are considerable deformities in the finger joints and restricted motion in all the joints.

Mrs. R. was able to get about with very little or no assistance until 4 weeks before this period of hospitalization.

### Emotional Stability

Patient appears to have been a mature and well adjusted person who has struggled desperately to maintain her independence. She feels that she is a "worry-wart" and finds it extremely difficult to accept the fact that she is becoming a "burden" to her family.

### Case Summary

Mrs. R. is a 59 year old married woman who has three children, 2 girls and one boy, all of whom are married. Mrs. R. is of Norwegian descent and had 9 years of schooling. Mr. R. is described as being a heavy drinker especially since he received, about 10 years ago, a big disappointment in job opportunities. His employment had been steady and he worked mainly as a laborer in various factories and foundries. He retired about three years ago because of his own physical condition and Mrs. R's. Their present income of \$127.00 comes from Mr. R's social security pension and a private pension fund.

Mrs. R. feels that her husband and children have been understanding, helpful and considerate of her since she developed rheumatoid arthritis. Until about 5 years ago, she

was able to maintain and manage her home. Since then they have moved to a small furnished apartment, and Mr. R. has gradually taken over the housework. About four weeks ago she "had to take to the wheelchair." This meant the complete loss of independence and it has been very difficult for her to accept. Mr. R. makes her "nervous and irritable" because he is extremely thorough and "is at home almost 24 hours a day."

For years she has looked for and used many forms of "cures and advices". She has some guilt feelings about passing on her disease to her children since 2 of the 3 children are developing many of the symptoms of rheumatoid arthritis while still in their 30's as she did 24 years ago.

Case #9 - Mrs. D.

Age: 29

Church: Lutheran

Sex: Female

Usual Occupation: Housewife

#### Onset and Severity

Patient believes she has had "arthritis" since she was 10 years old. At that time she had appendicitis with gangrene.

Several months after the surgery, she noticed stiffness in her joints. Since then she has had a tonsilectomy and all teeth extracted. Rheumatic involvement is present in all joints now including hip and spine. Limitation is extensive. Patient walks only with great difficulty.

#### Emotional Stability

Seems to be a controlling person who is embittered because of her condition.

#### Case Summary

Mrs. D. states that she is the second youngest child in a family of 10 children. Her father died of "a nervous breakdown" when the patient was 8 years old. Her mother continued to operate the farm and the patient helped until she became too ill. She completed grade school and then took a job doing housework. Mrs. D. married when she was 18 years old following a one year courtship period. She has two children, a girl 10 and a boy 3 years old. Mr. D. tried farming for a few years then "gave up" and took a job in a creamery.

When Mrs. D. was admitted, she said she was "scared to death of the hospital." She seemed to have many feelings of hostility toward the hospital personnel. She said she was going to refuse to answer another question as she was sick and tired of people questioning and examining her. It was

felt that this might have been a defense the patient wanted to use for when given the opportunity to ask the interviewer a question, she talked for half an hour about her condition. This attitude might be attributed to the fact that she has been "doctoring for 20 years and it looks like its just the beginning." A structured interview was not possible with this patient because of her deep feelings regarding her condition and appearance.

Case #10 - Mr. L.

Age: 38

Church: Protestant

Sex: Male

Usual Occupation: Univ. Student

#### Onset and Severity

The onset occurred in Feb. of 1954. The disease process started with swollen painful ankles. Treatment was started in March of this year. The residual affects are few and not severe. There is no limitation of motion or movement.

#### Emotional Stability

This patient appears to be an apprehensive individual

who is anxious now to learn more about this disease. His history indicated some degree of instability.

### Case Summary

Mr. L. is a 38 year old special student who is interested in journalism. He came to this country from Denmark in July of 1953. His present marriage is his second and is of three years duration. Mr. L. has a 2 year old daughter; both wife and child remained in Denmark.

Mr. L. feels that the fact that he has rheumatoid arthritis will make a number of changes in his life, especially the factor of chronicity. He was told not to over work and to stay off of his feet as much as possible. He has interpreted this as being the loss of his freedom and speed, for one of his great pleasures in life had formerly been to spend many hours walking in the spring time. He feels very annoyed by this and regarding it he said, "It's a small handicap, but it has slowed me down tremendously."

The patient doesn't mind the expense of regular medication (aspirins), but the regularity par se, makes him irritable. "It's not the work of taking the pills, its psychological. The interval is too too short." Mr. L. feels that it will be difficult to remember to take the medication 3 or 4 times per day, but he will try to do so since it was medically advised.

Case #11 - Mrs. G.

Age: 64

Church: Protestant

Sex: Female

Usual Occupation: Housewife and  
Janitress

#### Onset and Severity

The onset of this disease occurred in 1946 starting with pain and swelling of the knees and ankles. In 1949 she was hospitalized and the condition subsided. In June 1953, she had an acute attack involving all joints of both extremities. Patient now walks with a cane and limitation of movement is in the left knee only.

#### Emotional Stability

This appears to be a stable and mature individual who has done extensive reading on the subject of arthritis in order to get a better understanding of her physical condition.

#### Case Summary

Mrs. G. is a 64 year old Negro woman who looks young for

her age. She is married and has 2 children, a daughter and a son, both of whom have been married. She had 6 years of schooling and has worked for many years in a factory as a janitress. This patient developed a malignancy condition for which she had surgery in April 1953. She has not worked since that time. Mr. G. is also a factory worker; his responsibilities are limited because of the partial loss of his eyesight.

Following the surgery and adherence to the prescribed amount of rest, Mrs. G.'s arthritis became worse. She feels that the severe attack which occurred in June resulted directly from the "lack of activity and exercise."

She feels that the progressive course of the disease has caused her the most concern and anxiety. Because of this factor she has been forced to discontinue almost all of her social activities in her church, her social clubs, and with her husband, with whom she frequently went out to social functions and the movies. Regarding this she said, "That's the thing that I really miss."

Mrs. G. rejects the idea of regular medication and will not take any medication for a long period of time unless it quickly benefits her condition. She said that she refused to take cortisone when it was prescribed because of the regularity of having to take this particular medication. She stated that, "I don't like the idea of taking pills and becoming dependent on them. Once I stopped taking everything

and I felt wonderful. Finally I did start with the aspirins again."

Case #12 - Mrs. S.

Age: 31

Church: Lutheran

Sex: Female

Usual Occupation: Housewife

#### Onset and Severity

Onset occurred in Jan. 1952 with swelling and pain in her wrist, right elbow, knees, shoulders and a few of her fingers. The duration of this severe episode was brief, only about 4 months. Limitation now in 2 fingers.

#### Emotional Stability

An emotionally mature and controlling person. Seemed to have been a determined person who decided that she would not be ill and "fought hard to recover."

#### Case Summary

Mrs. S. is a 31 year old female of Norwegian and German extraction. She is married and has 2 sons, age 9 and 12 years.

She is a housewife and has worked during 2 brief periods since being married. Mr. S. works as a "dairy field man."

Mrs. S.'s experiences with the severe aspects of this disease was of short duration. She describes herself as being "one of the lucky ones. The cortisone and A.C.T.H. worked with me. Before I took it, I could hardly move." She felt that she did have "some side affects, I was sad and moody and have additional body hair," but she would take it again if it were prescribed.

At first she felt that her condition was hopeless. Now following her recovery, her doctor has sent many people to visit her to discuss the disease process. She feels that she was instrumental in getting 2 persons to accept hospitalization as a part of their treatment. She says, "It makes me feel good when the people come to see me now." Mrs. S. feels that her discussions must be of value since she considers her own period of hospitalization as being unfavorable. She states that the diagnosis was bluntly given to her and that the prognosis was that of being a cripple. "It was then that I decided to fight for recovery. I stopped worrying about the trivial things such as the unmade beds and unwashed dishes, and decided that I would get better and not be dependent on or a burden on anyone."

Case #13 - Mr. P.

Age: 44

Church: Lutheran

Sex: Male

Usual Occupation: Brewery Worker

### Onset and Severity

About  $4\frac{1}{2}$  years ago, the onset suddenly began with a fever while the patient was at work. The next morning he awoke with swollen and painful joints. Since then, recurrences have been sporadic. One month ago the patient was hospitalized and diagnosis was made. He now has some limitation of motion and deformity in his hands. The other joints function fairly well.

### Emotional Stability

History indicates what seems to be a dependent and immature person. Although the condition and pain appear to be minimal, the patient has not worked for the last four years.

### Case Summary

Mr. P., who is of German descent, is a 44 year old married man. He has one son, age 18, and two step-daughters, 21 and 22 years old. One step-daughter is married and out

of the home. Mr. P. worked for many years as a driver's helper and most recently has worked as a bottler in a brewery. Both patient's parents are living, and his mother has some form of arthritis in her hands, but the patient does not consider the condition as being hereditary.

Since becoming ill, Mr. P. has attempted to keep busy around the house and to find a suitable occupation for himself. However, since most of the involvement is in his hands he feels that almost any job requiring the use of his hands would not be satisfactory. He attempted to return to a former occupation of house painting but found that the factor of unpredictability kept him from doing an adequate job. He said, "It's sad -- one day you're O K and the next day you can't move. I feel like a caged animal.

The family is now solely dependent on Mrs. P.'s income. She works in a cleaning establishment and her wages are low. So far, they have been able to manage but Mr. P. is now fearful that they may have to ask for public assistance since, "her health too is beginning to get bad."

Mr. P. was in the hospital for a 10 day medical evaluation in compliance with the Vocational Rehabilitation Program. It took his wife and sister two years to interest him in this program. Now he feels that they are moving too slowly for him. He said, "I've worked since I was 14 years old and now it's hard for me to ask people to do things for me." He does not want to wait "until the testing is completed" but wants to get a job as a night watchman.

Case #14 - Mrs. F.

Age: 45

Church: Lutheran

Sex: Female

Usual Occupation: Housewife & Sewing  
Machine Operator

#### Onset and Severity

Believes that the disease began in Sept., 1952; she became aware of a pain in her left shoulder when she attempted to raise it. Within a month, pain and swelling were apparent in all joints of her body. She has had a number of severe episodes but now has only some limitation of motion in both elbows.

#### Emotional Stability

Seems to be emotionally stable. The home adjustment seemed to be good, but patient tends to be unusually anxious about family's ability to function adequately when she is out of the home.

Case Summary

Mrs. F. is a 45 year old woman who is of German nationality and who had 8 years of schooling. She is married and has two sons, 18 and 15 years of age. The patient has worked for many years as a sewing machine operator. Since the onset of her illness she has only had to take off three months of employment. Mr. F. works as a factory maintenance man.

Mrs. F. feels that her husband and family have been extremely helpful and understanding during her illness. During the acute episodes, she felt that they were able to care for themselves adequately. Her friends have also been helpful to her. However, some relatives at different times have attempted to make her dependent that she felt like "An old and decrepit woman." The patient became annoyed and angered by such actions.

The patient is also concerned about her future in regard to the crippling effects of the disease. This aspect seems to be intensified through Mrs. F.'s working relationship with a severely crippled arthritic woman. She frequently referred to this situation during the interview by saying, "I hope that doesn't happen to me."

Since returning to her job, Mrs. F. finds that her work is becoming too heavy and tiring for her. She wants to ask for a change in duties, but this would represent "a type of defeat" to her. She is also aware of the fact that a change

might not be the solution to the situation. Regarding this she said, "I do have some fear of the unknown. Even if I take a different job, I might find that it also is too difficult for me."

Case #15 - Mr. R.

Age: 58

Church: Methodist

Sex: Male

Usual Occupation: Rural Mail Carrier

#### Onset and Severity

Original onset began in 1934 with swelling and pain in his feet, ankles, knees, hands and elbows, lasting about 10 days. Recurrences were in 1940 and in 1953 of about ten day duration. Another severe attack occurred in March 1954 and patient was admitted to a hospital for the first time. He has moderate limitation of motion and deformity in one hand only.

#### Emotional Stability

Seems to be well adjusted and mature.

Case Summary

Mr. R., who is of French descent, was born in Wisc. and was educated through two years of Normal School. For the last 32 years, he has been a rural mail carrier. He has been married for 30 years, and has a 29 year old married son.

This patient showed an unusual amount of desire to participate in the interview. This might be attributed to the fact that he wanted to talk to someone regarding his hospital experiences. He said that the idea of coming to the hospital was frightening for him because it indicated to him that his condition "is now getting very bad." The doctor felt that he needed rest and that, "he didn't trust me to stay at home and in bed."

Mr. R. is most anxious regarding his illness in its unpredictable nature. Since many of his attacks have occurred while he was working he "lives in constant fear" that one day he may not be able to fulfill all of the responsibilities of his job. He would still be able to deliver the mail in his car, but would not be physically able to stand and do the required amount of mail sorting. However, "if I am forced to retire, we can manage on my pension, but we'll have to live on a smaller scale."

Case #16 - Miss B.

Age: 52

Church: Presb.

Sex: Female

Occupation: Nurse Maid and  
Governess

### Onset and Severity

Onset occurred in December of 1952 and illness has continued except for rather short intervals between acute phases. An injury to her knee in November 1953 has complicated the situation but patient is ambulating. She has some involvement of her hands. She has been on cortisone most of the time since September, 1953.

### Emotional Stability

Patient seems rather dull mentally and has difficulty in interpersonal relationships. She is described by the doctor as "immature" and "flighty". The psychiatrist believes that there may have been some deterioration in mental function.

### Case Summary

This patient is a 52 year old, unmarried, white woman who is attractive in appearance, talks easily but in a rather

"scattered" way. She shows difficulty in focusing her conversation and in remembering.

She is the fourth of six children and describes herself as the "baby" of the family. She was never close to her mother emotionally but says that her father loved and defended her. He died in 1945 and she considers his loss a great one. One brother is mentally retarded and the patient's mother is now quite senile. The patient completed 8th grade and at 18 left school to do housework. She traveled here and there "rising" in her work to the point where she was a rather highly paid governess or children's nurse. By leaving home she broke most of her family ties and has not been able to regain status in her family. She feels that since her illness, her family has been even "colder" to her than before and she believes that they are trying to avoid assuming any responsibility for her care. She says that she had opportunities for marriage but postponed this until it was "too late". She now finds herself very fearful of the future as she sees herself alone and uncared for with the real possibility that she cannot support herself through employment. Even if she can find work it will probably be more unskilled with less pay and social status. She says that she used to "run away" from her problem but cannot do this at present. When she had difficulties with her employer she merely moved to another town or a new job.

Case #17 - Mrs. H.

Age: 61

Church: Prost.

Sex: Female

Usual Occupation: Housewife

#### Onset and Severity

Onset occurred six or 7 years ago when swelling in the right ankle appeared along with considerable pain. It is now most acute in the knees and there is moderate deformity with swelling and limitation of motion in her wrists.

#### Emotional Stability

Apparently a stable well adjusted individual.

#### Case Summary

This 61 year old white housewife lives on a farm with her husband, and a "hired man". Housing is good with all modern conveniences and the husband will help with inside work when she needs him to. She has never done farm work or

very heavy housework.

Since the age of 18, this patient has given piano lessons to the children of her friends. She makes small charges for this instruction but has considered it more of a satisfaction to herself than a source of income. She sees this as a major change in her way of living although she will probably have to give up playing the organ at church which she has done for many years. She belongs to numerous organizations and has many friends. She has carried her share of entertaining but feels it will be more restricted now and regrets this. She sees the cost of medical care as high but considers this a necessary and ongoing expense which the family can probably meet without serious deprivation. She has never had children and hints that this becomes a greater regret as she finds herself more restricted in her activity because of her illness. She will apparently follow medical advice and take any measures including painful exercise in order to avoid further involvement, which aspect of the disease she is most reluctant to think or talk about.

Case #18 - Laverne H.

Age: 6

Church: Congregational

Sex: Female

Usual Occupation: School

### Onset and Severity

Onset at age of three and one-half following an acute illness. She has had 5 or 6 periods of hospitalization, the current one because of a flexion deformity in the hips which has prevented walking.

### Emotional Stability

Patient and entire family appear stable.

### Case Summary

This little 6 year old white girl has had severe rheumatoid arthritis since the age of  $3\frac{1}{2}$ . She has had several hospital admissions for treatment including traction. Her activity has been severely limited and she has used a wheelchair at home and at school. She attends regular school being taken there in the car or by wheelchair. She has sisters 9 and 4 and mother attempts to treat them all "the same" by which she means she forces sharing by patient although she still spansks the other girls she has changed to "yelling at" patient. There is little friction between the siblings although mother notes that the older sister tends to "give in"

to patient. She thinks patient is quite clever in getting people to do things for her but that she is not excessively dependent.

Laverne was always an independent, active youngster and the restriction of activity has been very difficult for her. The parents consider their main problem that of their feelings about inflicting pain on the patient for normal care. They share in managing the child and lean on each other for emotional support during the times that they are very concerned.

Mother wonders whether onset of illness was in any way related to an accident sustained by the father while he was at work and which injured his hands. His return from the hospital was a shock for the children and patient's illness began soon after.

Case #19 - Mr. O.

Age: 51

Church: Lutheran

Sex: Male

Usual Occupation: Farmer

#### Onset and Severity

Onset occurred about 17 years ago and there has been

progressive involvement to the whole body. The symptoms are more severe in shoulders, arms and knees and pain has been severe although it subsides with rest. Patient has had several protracted courses of treatment.

### Emotional Stability

Medical chart reports this man as an emotionally nervous person. His life history would indicate that he is dependent but emotionally rather stable.

### Case Summary

This is a 51 year old white farmer who is married and has 4 children ranging in age from 19 to 7. He has had this disease for 17 years during which time there has been a lessening ability to move about, work and carry on normal social activity. He is now severely handicapped especially from the waist up.

Patient describes himself as having been a frail child and very dependent on his mother who was "good". This dependence has apparently been transferred to his wife and children. His assurance of their love is very important to him and he shows some anxiety lest his handicap alienates them as he may become a greater burden. For example his son has had to take over the farm work and is restless and patient feels that he may want to leave, unless in some way the work can be lightened

for him. Patient has also seemed uneasy about the growing up and independence of his daughters. He feels that his illness has drawn them all closer together and has been a constructive force in bringing up the children to be "thoughtful and generous".

This patient understands that there is an emotional causation in this illness and has wondered whether early sexual difficulties with his wife may have contributed to the onset of his illness. He describes his marriage as a happy one now but admits that this was not always the case. The separation from his family for hospital care has been upsetting. He once tried to spend a winter in a warm climate at the recommendation of his doctor but could not stand the separation and returned to his home in a very short time.

Case #20 - Miss S.

Age: 51

Church: Evangelical

Sex: Female

Usual Occupation: Bank Teller

Onset and Severity

Onset occurred about a year ago and there has been

moderate involvement of the hands, neck, shoulders, and knees and ankles with marked fatigue as a prominent symptom.

### Emotional Stability

Patient is a very controlled person who reveals few feelings. She is apparently stable and has held employment in the same concern for 30 years. She supports herself and sister and denies friction at home or on the job.

### Case Summary

This 51 year old white unmarried woman has been the sole support of herself and her sister since the mid-1930's when the sister lost her employment. Sister now does the housework and patient furnishes the income which she says is an appropriate arrangement. She has worked as a bank teller for 30 years and her salary is being continued through the present illness. She says that her job is being held for her and that if necessary the bank will give her a different position where she will have to use her hands less.

This patient shows partially covered anxiety, about her ability to continue working if the disease progresses much further. She has not faced the future without being able to support herself. She shows hostility towards the doctors who have not been able to help her as much as she wished and in fact plans to change doctors again when she is discharged

from the hospital. She says she will "do anything" to get well or at least to maintain status quo. She was formerly a very active person and is now facing for the first time a limitation in what she is able to do. She resents the time which she has to spend resting and also giving up such occupations as social events and gardening.

Case #21 - Mr. J.

Age: 36

Church: Protestant

Sex: Male

Usual Occupation: Truckdriver

#### Onset and Severity

Began in 1944 with knee pain; several flare-ups, each progressively worse with involvement in joints of knee, ankle, toe, elbows and wrists; pain and swelling and only temporary relief from treatment. Always able to be ambulatory; able to work except for brief periods of a few days at a time.

#### Emotional Stability

Seems to be fairly well integrated person but somewhat

tense; always was independent and probably compulsive worker who put much emphasis on physical stamina and now feels frustrated and humiliated because of limitations. Pleasant person, fairly realistic about the future.

### Case Summary

This tall, well-built man has been married for 17 years and has 4 children; 16, 14, 10 and 14 months. His oldest son is a first string basketball star. The family seems congenial and close-knit. A year ago, after 20 years as a truck driver Mr. J. lost his job because his truck route was discontinued. His illness had been making his job a little difficult for him, but, this was not related to his losing the job. He has, however, been somewhat limited in finding other jobs because his condition limits the types of jobs for which he can apply. In the past year he has had a variety of temporary and part-time jobs and while he feels well enough to work, his stiffness and pain have presented problems on each job. He has gone to a number of doctors and to a chiropractor, has used all his savings on his illness, but has obtained only temporary relief.

This man who has apparently always put a premium on hard work and achievement is quite humiliated about his present limitations and being forced to depend on his wife to help him dress, etc. He feels a great sense of failure toward his family and personal frustration at being forced to

be inactive. "I was never one to ask anyone for help... laying around always got on my nerves." He finds it quite hard to accept living with this handicap, but seems to sustain himself with the hope of recovery (which he claims the doctors have given him). He admittedly gets discouraged and tends to lose motivation, but "the big thing is you can't give up hope."

Case #22 - Mrs. E.

Age: 35

Church: Lutheran

Sex: Female

Usual Occupation: Housewife

### Onset and Severity

Illness began 7 years ago, but patient was "pretty well" until about one year ago. She was bedridden two weeks prior to admission. In 1950 she was hospitalized and made some improvement. She has been on almost continuous treatment for several years. There has been involvement in her hands, knees, hips, shoulders and feet. She was discharged on crutches.

### Emotional Stability

Doctors note "nervous instability" during the acute phase of the illness. There appears to be no history of nervous problems other than those related to the illness and the social difficulties which it has brought about. On the whole this patient appears to be an adequate person caught in an overwhelming social situation.

### Case Summary

This patient is a 35 year old married woman whose illness started about 7 years ago and has brought almost complete incapacitation during the past year. She has four children ranging in age from 14 to 2. For the past two years her husband has been employed 300 miles from home and is with the family only on week-ends. Patient says that one of the worst features about her illness is her inability to be a good "wife".

The patient has carried almost full responsibility for the children during her husband's absence. She finds it difficult in maintaining discipline and has resorted to "family conferences" and delegation of authority to the older children. She has not felt justified in spending funds for a telephone and so has been dependent upon the irregular visits of relatives and friends in order to get her errands done, or assistance with things she cannot manage in the

children's absence.

Family lives in an upstairs apartment and patient had not been able to go out of doors since the previous April. She finds delegating shopping to the children expensive as they do not know how to buy carefully. Income is very marginal and the cost of medication has been a real drain on family resources. Patient has limited the amount of medical attention she has sought because of the expense involved. She would like to move to new housing near her husband's employment but this would involve moving away from her own relatives. She fears loss of their help which she needs. During the current hospitalization they have been caring for four children in separate homes. Patient shows some anxiety for fear she will lose the affection of the children while she is in the hospital and that they will increasingly resent the amount of work and responsibility she must place on them because of her illness.

Case #23 - Mrs. K.

Age: 39

Church: Lutheran

Sex: Female

Usual Occupation: Housewife

### Onset and Severity

Onset of illness occurred 10 years ago but symptoms did not become severe until last September when patient's knee became involved. At present her neck and shoulders have become stiff. Her neck first contracted to one side. This condition persisting for three months. At that time swallowing was difficult which resulted in severe weight loss.

### Emotional Stability

Patient appeared stable though of dull normal intelligence. She spent many years at Northern Colony and was sterilized prior to her discharge. She has always covered up her feelings and tried to be "pleasant".

### Case Summary

This 39 year old woman was placed with her siblings at the Sparta Children's Home at the time of her mother's death when she was 6. She and two older children were transferred to Northern Colony where patient remained until she was 23. At that time she was discharged to her sister's home but only when she agreed to sterilization. She was kept under supervision for several years and worked as a domestic until her marriage in 1945. Her husband is three years her senior and the marriage appears to be a happy one. Patient and her

husband live in his mother's home which is located above some stores on the main street in the town. Patient considers this an ideal location as it permits her to "get in on" the town doings and is convenient for shopping. The mother-in-law has a severe heart condition so that her activity is also restricted. Patient reports that she and her mother-in-law are very congenial, have many friends and recreational activities in common.

Patient worked as a waitress until she suffered severe weight loss and then gave up her job. She went to a doctor under protest and dreaded the separation from home which hospitalization would require. However, she gets along very well with the patients here. At home her recreational activities are described as "mild". She visits with friends, goes to the movies and likes to read. Illness has kept her at home and while her head had to be carried on one side it limited the amount of reading and fancy work which she could do. At that time she also became very fearful of going out alone as she felt she could not observe traffic and might be run over.

This patient has little understanding of her disease and its implications. She has not considered the hereditary factor although her father's rheumatoid arthritis was a large part of the reason for placement of herself and her siblings at Sparta. She does not show much anxiety about possible increase in her illness as she feels that whatever happens she

has a home and her husband will care for her.

Case #24 - Mr. D'L.

Age: 47

Church: Catholic

Sex: Male

Usual Occupation: Iron Molder

#### Onset and Severity

Progressive involvement of all extremities since onset in 1950 with periods of pain, swelling and stiffness. Periodic relief with medication; several hospital admissions; ambulatory and able to do limited work except for short periods.

#### Emotional Stability

Seems a well integrated person with success in personal job, family, and social life. Worried about his condition but seems to have been capable of making necessary adjustments in living to suit limitations of his illness.

#### Case Summary

This patient came to U. S. from Holland at 16. For

26 years he worked as an iron molder until his condition forced him to change to a lighter job at the same foundry. In 1945 his wife died after an 18 year marriage with no children. In 1947, he was married again to a woman 10 years his junior. They have 3 children: 6, 4, and 3. The family seems close-knit and Mr. D. speaks with affection of his wife and children, but is depressed about the effect of his handicap on them: "Seven years ago I was a young man, now I'm an old man." The family is understanding, patient and willing to help. "But when one is sick in a family everybody suffers."

He has been a hard worker all his life and with a recent second marriage and young children he is particularly motivated to have an active and productive life just at the time when his illness keeps him from doing so. He worries about becoming too disabled to work and has already had his salary cut in half and has had to take a job where he does not "feel at home." They get along with savings and the help of friends but have had to forego usual vacations, clothes and comforts. He feels some humiliation at depriving his family in any way. He misses hobbies, social and union activities which his illness has caused him to curtail.

Despite these frustrations and discomforts he seems to remain pleasant and even tempered and states, "I sit in a corner and cry sooner than get made at the kids...sometimes I have to struggle plenty to keep cheerful...I tell you, it's just plain hell to have this." While he fears total disability,

on the whole he remains hopeful about his condition.

Case #25 - Miss N.

Age: 38

Church: Catholic

Sex: Female

Usual Occupation: Paper mill

#### Onset and Severity

Began in 1937, with progressive involvement of the neck, spine, hips and extremities; has been steadily disabling since onset, with weakness, pain and crippling. Four hospitalizations and constant treatment have brought very limited improvement.

#### Emotional Stability

Seems to be a somewhat immature person with limited interests or experiences outside of her immediate family. On the surface is thoroughly placid, pleasant and accepting, but gives the impression of being a person who holds back much of her real feeling.

Case Summary

This patient is one of 12 children the rest of whom are all in good health. After an 8th grade education she did domestic work and then at a paper mill for  $2\frac{1}{2}$  years until her finger stiffness made it necessary for her to quit in 1938, at 22. Since then she has not been employed, but for a time nursed her father who had a similar ailment. He died in 1943 and her mother died in 1947. She then moved to the home of a married sister where she has remained since that time. At first she had some savings, but has mostly been supported by the family.

As an additional complication she fell on her head at 13 and has had petit mal seizures since that time which are fairly well controlled with daily medication. Since her arthritis began she has undergone a wide variety of treatment; extensive medication, baths, massage, exercise, patent medicine, vitamins, herbs, etc. She has been under constant medical attention, but with little success. She is now able to walk only occasionally and has not left the house in months. She has been unable to attend church since 1940. She spends her time mainly watching T.V. and being with her sister, brother-in-law, niece and nephew. She has apparently developed few interests outside the family, sees none of her former job associates and has never had any boyfriends, even before the onset of the arthritis. Religion is important to

her and she has the priest visit at the house regularly.

Her illness undoubtedly causes her much pain and discomfort at being so helpless, but also perhaps a certain amount of pleasure at being in a dependent position. On the surface she displays only calm acceptance of her position. She denies any fear or much frustration because of her condition, but too vehemently protests repeatedly, "I'm no worrier." She apparently fears the consequences of revealing any negative feelings she may have. She always stays "cheery." She states, "If you treat people kind they treat you kind; that's the way to be."

## CHAPTER V

### FINDINGS -- FACTORS AND THEIR CONSEQUENCES

Prior to selecting the sample for the study, a review was undertaken to determine the number, age, and sex of patients with rheumatoid arthritis admitted to the hospital during the first 11 months of 1953. A total of 161 admissions occurred, 96 females and 65 males. This ratio of 3 to 2 was consistent with the findings of Comroe who noted that "Females are more commonly affected than males in a ratio of 2 or 3 to 1." <sup>1</sup> The review shows that the females ranged in age from 2 to 84 years, while the males ranged from 17 to 81 years. A substantial number of persons admitted were over 60 years of age, 24 females and 13 males. This was consistent with the age range for the overall study of stressful factors in 4 disease entities in which age limits were set as 3 to 65 years.

Table I, page 73 gives a picture of the general characteristics of the total group of 25 cases interviewed for this study of rheumatoid arthritis. Fourteen of these patients were females and eleven were males; this ratio is fairly consistent with the ratio in the survey of hospital admissions. The age range for the females was 6 to 64 and for the males

Table I.--General Characteristics of the 25 Patients Interviewed.

<u>Case Number</u>	<u>Sex</u>	<u>Age</u>	<u>Marital Status</u>	<u>Church Affiliation</u>	<u>Usual Occupation</u>
1	F	47	Married	Catholic	Housewife
2	F	31	Married	Methodist	Housewife
3	M	18	Single	Lutheran	Student
4	M	55	Married	Protestant	Lithographer
5	M	54	Married	Lutheran	Factory Laborer
6	M	50	Married	Lutheran	Farmer
7	M	22	Single	Methodist	Student
8	F	59	Married	Presbyterian	Housewife
9	F	29	Married	Lutheran	Housewife
10	M	38	Married	Protestant	Student
11	F	64	Married	Protestant	Janitress and Housewife
12	F	31	Married	Lutheran	Housewife
13	M	44	Married	Lutheran	Brewery worker
14	F	45	Married	Lutheran	Sewing machine operator & housewife
15	M	58	Married	Methodist	Rural mail carrier
16	F	52	Single	Protestant	Governess
17	F	61	Married	Protestant	Housewife
18	F	6	Single	Congregational	Student
19	M	51	Married	Lutheran	Farmer
20	F	51	Single	Evangelical	Bank Teller
21	M	36	Married	Protestant	Truck Driver
22	F	35	Married	Lutheran	Housewife
23	F	39	Married	Lutheran	Housewife
24	M	47	Married	Catholic	Iron molder
25	F	38	Single	Catholic	Paper Mill Worker

it was 18 to 58 years. All but 6 of the total number were married at the time of the interviews. Regarding church affiliations, three patients were Catholic. Twenty-two patients were Protestant and of this number, 10 were Lutherans.

In looking at the usual occupations for the total group, the table indicates that of the 14 females, 8 gave their occupations as housewives only, while 2 others listed occupational jobs in addition to their household duties. Four persons in the study were students; 2 were attending the university, 1 was in high school, and the fourth, a 6 year old girl, was in the first grade. Only 2 persons were farmers. Six patients were employed in various types of factory jobs. The remaining 5 patients, (2 females and 3 males) listed their occupations as governess, bank teller, lithographer, truck driver, and rural mail carrier.

Table II.--The Degree of Disability

<u>Length of illness</u>	<u>Minimal</u>	<u>Moderate</u>	<u>Severe</u>	<u>Very Severe</u>	
3 months to 2 years	XX	XXX			7
2 years to 8 years		XXX	XXXX		7
8 years to 15 years		XXX	X		4
15 years and over				XXXX XXX	7
Totals	4	9	5	7	

Table II, page 74 shows in a general way the amount or degree of disability resulting from the disease process from the onset to the present time. When this interval was from 3 months to 2 years, 4 of the persons were considered as having minimal involvement, and 3 persons as having moderate joint and body involvement. Of the persons whose onset began between 2 and 8 years ago, 3 had moderate and 4 had severe degrees of disability. In the group with 8 to 15 year duration, 3 persons had moderate involvement and one had severe disability. All 7 persons who had had rheumatoid arthritis for over 15 years were considered to be very severely handicapped.

From this table it can be seen that a total of 4 persons had minimal involvement which affected only 1 or 2 joints of the body. Nine persons in the total group had moderate involvements which influenced their appearance and use of extremities. Five persons had severe involvement and found it difficult to get about without the aid of appliances. The 7 others were considered as being very severely disabled or handicapped were non-ambulatory. The pattern here appears to be consistent in that the degree of disability increased with the length of time since the onset.

The degree of emotional stability for each patient was evaluated, and of the 25 cases it was felt that 17 patients

could be considered as being stable individuals. Four persons (cases #2, 6, 13, 25) seemed to have been immature, 2 were unstable (case #10 and #4 also neurotic), and one patient (case #9) was described as being controlling. The length of illness for the 4 immature persons varied from 4-1/2 to 17 years. One unstable person had been ill for 3 months and the other one for 8 years. The "controlling" patient's onset of illness occurred when she was 10, and she was 29 years old when interviewed. There did not seem to be any relationship between the degree of emotional stability and the degree of physical severity or the length of illness.

#### Public Attitudes

The first aspect that was to be studied in the overall project was that of public attitudes towards persons having the four diseases. The factors of "anxiety creation" and "social repulsion" were considered. It was felt that the former factor (anxiety) might precipitate or create fear in the patients or cause social withdrawal with perhaps ostracism. Social repulsion might precipitate the anticipated consequences of ostracism, wishing oneself dead, social withdrawal, an employer's refusal to hire, threats of institutionalization, and tendency to deny the illness because of stigma.

The data obtained in the study of rheumatoid arthritis revealed that the factors and the consequences as above were

not present, but that a pattern did exist in public attitudes towards the arthritic patients. The attitudes were represented by curiosity, sympathy, lack of interest in the disease, and too high expectations for recovery or accomplishment by individuals suffering from the illness. Table III (see appendix) shows that in 17 of the 25 cases, opinions regarding public attitudes were present. Three of these patients felt that there was an undue amount of curiosity on the part of the public in respect to persons having rheumatoid arthritis. One patient said, "They always have to say something about it to you. They're only curious and anxious to tell other people about your difficulties."

In contrast to this feeling, a larger number of patients, 9 in all, felt that generally, the public was sympathetic towards them. They spoke of the fact that relatives, friends, and even strangers felt sorry for them, offered to help them, and were generally nice to them. One patient (#14) had negative feelings about this because of the extensive amount of help offered when it was not always needed. It made her angry to have to accept the unwanted attention.

Three of the patients commented that there is a general lack of public interest in the disease. One female patient thought this might be true since in some instances one's illness "does not always show." Another patient (#9) who is

embittered because of her illness feels that more money should be spent to discover ways of controlling the disease. She decided that, "We (patient and her husband) are not going to give another dime for the other things as long as they don't do anything about rheumatoid arthritis."

Four patients had opinions regarding the fact that public expectations were too high with respect to the degree of recovery from the disease. (Two of these four had also expressed other feelings; one towards sympathy and the other regarding curiosity.) One male patient (#6) felt that it was difficult to explain continuously why he had not recovered while other persons in the community with "similar ailments" had recovered enough to return to their jobs or usual occupations. Another patient feels that her friends are expecting her to recover although they seem to be aware of the fact that such is not realistic for her at this time. Mr. D. L. (#24) commented on how he must force himself to "remain cheerful" in order to avoid social rejection since he has not recovered.

One notes from the above that the patients did not tend to withdraw socially as it had been expected when the decision was made to study public attitudes regarding social ostracism of persons who are chronically ill or crippled as a result of this illness.

### Etiology

The second phase of factorial components considered in the study was in regard to the etiology of rheumatoid arthritis. Since the actual cause of the disease is unknown, it was decided that the factors of "hereditary tendency," "neglect in care," and "unknown" causal elements, could appropriately be analyzed. Of the 3 factors studied here, the hereditary factor receives most attention in the literature regarding causal components of the disease. It is felt that, "It (rheumatoid arthritis) has a slight tendency to be familial."<sup>2</sup> This seemed to have been a good factor for study for knowledge regarding a disease which may have been inherited or may be passed on, tends to lead to feelings of hostility, guilt, and various fears.

Neglect in care was chosen since emotional responses and reactions can become intensified when a patient believes his condition became more degenerative because of a delay in diagnosing or if for various reasons he did not care for himself properly, thus, causing further physical breakdown. These patients, therefore, might have hostility or guilt feelings toward persons in charge of their medical care or towards

themselves. The factor of unknown causation of the disease certainly might lead to frustration, confusion, guilt, and perhaps a search for the impossible regarding a cure.

A discussion of the 3 factors will follow in sequence as they affected or produced consequences for all the 25 patients studied. The results of the data gathered have been systematically tabulated for each factor on separate charts. The headings for these charts were set up to include (factor) "not present," (factor) "presence inferred," (factor) "presence accepted," "consequences denied," "consequences present," and "others." The distinction between "presence inferred" and "presence accepted" was made because in some instances it was found that results were evident through implication only. In the column marked "others," the unanticipated consequences are presented and will be discussed. Similar charts or tables will appear for all of the factors being considered in the study, and are to be found in the appendix.

#### Hereditary Tendency (Table IV-a, see appendix)

The factor of hereditary tendency was found to be present directly in 4 of the 25 cases. In 11 cases it was present by inference, and in 10 of the cases it was not present at all. In 7 of the 25 cases, consequences were denied. It was felt

that the low incidence of the factor being present directly occurred because most of the patients were not aware of the familial tendency of the disease of rheumatoid arthritis. Many did comment that various members of their families "had some form of arthritis." However, they did not believe that the fact that these persons had "swollen joints, painful knees, or were severely crippled" was in any way related to their own physical condition. This attitude might also be attributed to the fact that there are many different forms of arthritis or rheumatism and the patients did not know specifically which form of the disease the relative "suffered from."

When the factor was not present, the patients would make comments similar to the one expressed by the high school student (case #3), "No one on either side of my family had ever had anything like this." If a patient felt that the element was present and had consequences, he or she might say as Mrs. E. (#22) said, "It seems to be a family pattern, my mother, and brother have it, and now my daughter is starting to have some pains."

As previously stated, 11 patients felt that the factor was present by inference. Seven of them denied the existence of consequences. The types of comments that these 7 patients made were as follows: (#6) "There was a little rheumatism on

my father's side." (#12) "My grandfather and two of his sisters had some form of arthritis and were severely crippled." (#13) "Now that I think of it, my mother had some form of arthritis in her hands."

Consequences resulting from the factor of hereditary tendency was found in 4 cases. The consequence of blame of parents appear in 2 cases by inference. Mrs. L. (#1) said, "I've lived a good life. Why didn't this happen to someone else in the family?" A similar feeling was implied by another patient, (#25) as she commented, "My father had a similar ailment. I wonder why, out of 12 children, I was the only one to get it."

The elements of guilt of parents with overprotection, fear of marriage, and fear of having children did not appear to be consequential. However, fear for children as a consequence was present in 4 cases. Mrs. E., who was referred to previously, worries about her 2 children, girl 10 and boy 14, and she watches them closely in anticipation of arthritic symptoms. She has had medical consultation regarding their conditions. Two patients said that their children were beginning to have symptoms similar to theirs. Although the fourth patient's children have not had any known symptoms so far, the patient (#5) felt and was fearful that, "This could happen to my children just like it happened to me."

Regarding the others or unanticipated consequences, one 45 year old female patient (#14) who had had rheumatoid arthritis for about 1-1/2 years felt that the factor of hereditary tendency was, generally, anxiety producing. She expressed this feeling when she said, "My mother developed arthritis when she was 65; I wonder if I could have had a tendency toward it." Another unexpected consequence occurred for Mrs. K. (#23) who was not aware of the familial tendency. When her mother died, her father had to place the children in an institution mainly because of the severity of his condition due to rheumatoid arthritis.

Neglect in Care (Table VI-b, see appendix)

In 12 of the 25 cases studied, the factor of neglect in care was not present. It was inferred in 5 cases, and directly expressed in 8 cases. One or more consequences resulted in the total group of 13 cases where the factor was present.

Six persons blamed others or themselves with resulting guilt for the neglect in their care. Some patients felt they might have gotten rheumatoid arthritis because they did not protect themselves properly. (Cases #17, 23, 24.) This feeling was especially related to working conditions wherein the type of clothing the patient wore was not appropriate to "radical temperature changes." Mr. L., a student, (#10) felt that he had definitely neglected his own care between the time

of onset and hospitalization. He said, "I kept hoping it would go away. This delay may have aggravated the condition."

The consequence of intensification of symptoms with consequent anxiety was present in 7 cases. The patients in cases #13 and #22 felt that their conditions became worse when they neglected their care because of the expense of medical treatment. Mrs. F.'s (#14) care was neglected when she took an extensive trip, returned home 2 months later and had to be hospitalized.

Five of these same patients also expressed as a consequence, feelings of hostility towards their doctors. Most of these patients based these feelings on the lack of prompt medical attention due to delayed or incorrect diagnosis. One patient felt that she did not get any treatment for rheumatoid arthritis until her condition became very bad and her husband "went out and found another doctor who sent me to the hospital."

#### Unknown Causation (Table VI-c, see appendix)

This factor was accepted in 14 of the 25 cases, was inferred in 6 cases, and was not present in 5 of the cases. In three of the 6 inferred cases, the existence of consequences was denied. Mrs. S. (#12) indicated that she was not concerned about this factor because, "The doctors don't know, so why should I worry about it."

Seven anticipated consequences were considered in connection with this factor. The first element of looking for reasons with consequent guilt appeared in 15 of the cases. In classifying the various reasons given, 3 patients felt that their work conditions or the physical labor exerted while working might have caused the condition to develop. Three other patients considered poor diets and the lack of nutritional food as having caused the disease. In some instances, the patients gave two reasons for their condition. Five patients felt that their conditions developed as the results of infections starting mainly with their teeth. An additional five patients explained how they considered worry, nervous strain, and emotional shock or stress as being the causal element. In one of these cases, (#2) the matter of nervous strain was discussed with the patient by the doctor. Three persons who had infections also discussed this with their doctors.

The consequence of self-blame or condemnation was present in 5 cases. Two patients (#8 and 13) felt that their laxity in taking care of infected teeth and tonsils contributed directly to the onset of the disease. Another patient (#25) blames the development of her condition on the extensive use of a drug to control another disease. She feels that "it's better to have arthritis than (petit mal) seizures."

Confusion was the consequence in another 4 cases. In these cases, the patients admitted that the unknown causational factor worried them. This consequence was present for 2 of the students, one of whom having only recently been informed of his diagnosis. The high school student (#3) said, "I guess its just something I picked up somewhere. I don't know why." An elderly patient (#5) implied that he was anxious because he could not give or be given a reason why he developed rheumatoid arthritis.

In the case of the 6 year old girl (#18), it might be considered that the consequence of parental blame was present. The mother wonders if the emotional shock of seeing the father's severely burned hands when he returned from the hospital influenced the onset for the child and felt that she should have given the child better preparation.

It was felt that in 9 cases, the attempts which had been made to explain the condition or the anxiety of not knowing the cause of the illness had lead to feelings of guilt in the patients.

In 3 of the cases there seemed to have been definite attitudes of mistrust of doctors. In case #2, Mrs. K. went to 4 doctors before her condition was correctly diagnosed. Mr. L. (#4) felt that he had to spend at least a thousand dollars before, "they could discover what was wrong with me."

Two of these same patients, plus 4 more or a total of 6 persons looked for or sought miracle cures as a result of not knowing the cause of rheumatoid arthritis. Two of these patients (#8 and 9) attempted to find cures with herbs, home remedies, and "Indian medicines." The 2 males in cases #6 and #13, sought cures through mud and steam baths, massages, and "electric treatments." Mr. J. (#21) has bizarre theories about cures; one such theory is that "carrying half a potato in your pocket" will cure aches and pains.

### Symptomatology

The third aspect of the disease with which we are concerned is symptomatology. As indicated in the literature, there appear to be 7 factors which increase or influence social stress as a direct result of the disease symptoms. Each of these is considered for all 25 patients and recorded in systematic charts. They will be discussed by factors in sequence as they were listed at the end of Chapter II.

### Chronicity (Table V-a see appendix)

This factor was found to be present in all 25 cases. It seemed accepted only inferentially by 4 patients while the others accepted it directly as an element in the disease. All but 4 persons discussed consequences which resulted from this factor. One patient (#20) felt that she was going to get better

or stay the same in which case she could "get along." Mrs. S. (#12) is consciously trying to forget the chronic aspects since she appears to have almost completely recovered from the affects of the disease. She had to wear low heel shoes during the acute period of exacerbation. She says, "Now I wear the highest ones that I can find -- sort of in defiance."

The consequence of overprotection by family was present in 2 cases. Examples of this was found in cases #2 and 3. Mrs. K's (#2) family allows her to do only a small amount of work in the home. In case #3, many decisions regarding the degree of physical exertion and limitations are made for the patient by his family. In this particular case, a contributing element may be the patient's age since he is an adolescent. The low incidence of this consequence might be attributed to the fact that most of the patients "struggled" to maintain their independency and would not allow overprotection.

Economic Stress appeared to be a prominent consequence, as 15 patients discussed problems in this area. For the most part these were related first to the loss of employment, second to the on-going expense of medical care, and third to the need for the wife and/or children to go to work. Mr. L. (#6) gave up farming and sold his farm 5 years ago. Most of the money was spent for medical care. His wife and daughter went to work in a local shoe factory. The high school student (#3) had to spend his part-time employment savings for medical

expense and to purchase a car to provide transportation to and from school. Mr. D. L. (#24) feels some discouragement regarding the extensive medical costs and the prospects that "I may never be cured."

It was felt that the consequence, lack of motivation, was represented in 5 of the cases. These patients seemingly were "resigned" to their illness and the physical limitations it placed upon them. Miss N. (#25) ably described this feeling when she said, "You get so tired of it after 18 years."

Security and meeting dependency needs appeared in 5 cases. These patients have actually benefitted through being reassured of the affection and attitudes of helpfulness from the family and friends. One patient (#4), who was described as neurotic, has many of the symptoms of his mother and wife, and feels the similarity of his problem identifies him more closely with them. Another man (#19) said he felt his illness had drawn the family close together and has taught his children to be thoughtful and considerate. Mrs. K. (#2) reflected on how her family and friends act kindly towards her and said, "If people are willing to do for me, then I just let them."

Shopping for a cure, as a consequence, occurred in 10 cases. Some patients tried a variety of types of treatment including osteopaths, chiropractors, chiropodists, indian

remedies, and a series of medical physicians and facilities. Five of these patients (#7, 17, 18, 19, 22) went out of the state looking for a cure. Two persons (#17 and 18) went to the Mayo Clinic and Mr. W., the university student, went to Arizona for 3 months because he had heard that "the warm climate would help." When this did not improve his condition he returned to his home in Wisconsin.

The consequence of <sup>D. management</sup> mis-management and depression appeared in 14 of the cases. For some it occurred largely at the time when the symptoms were acute. Mrs. L. (#1) and Mrs. R. (#8) had similar feelings which were related to their husbands having to assume responsibility of household duties. Mrs. L. felt badly about this at first, but now has made up her mind "that it had to be that way." Mrs. R. commented that "It's terrible when a man has to do all your work for you." The parents of the 6 year old girl (#18) have been able to accept the chronicity, but are quite depressed regarding the child's future. These parents continuously try to "cheer each other up" and express feelings only after the children are in bed at night. As she discussed long time planning for her condition, Mrs. E. (#22) who has had rheumatoid arthritis for 7 years, mentioned trying to secure downstairs living quarters since she has not been able to get out of her apartment for many months.

In 2 of the 25 cases, another consequence appeared which had a religious connotation. This was related to the thinking of the 6 year old girl and a man whose onset of the disease occurred 17 years ago. LaVerne (#18) believes that God will cure her and wonders if the delay is because "He is busy curing someone else." The man (#19) has prayed for recovery and is disappointed in the results. He says, "The Lord does what is best for you, doesn't do what you want," patient feels this is God's way of keeping one "humble."

Unpredictability of Increase in Symptoms (Table V-b, see appendix)

This factor seemed to have been one of the most disturbing of those considered in the study. It tended to make the patients anxious for as they frequently commented, "One day you feel fine and the next day you don't." This situation was also embarrassing at times since "the pain comes on at any time or anyplace."

This factor was present in 20 of the 25 cases; of this number it was inferred by 2 patients, and acknowledged as causing consequences by all but one person. It was felt to be non-consequential in the case of Mrs. K. (#23) who implied that, "If you have more symptoms, you wait until you feel better to do things."

Four consequences were considered in relation to this factor. The first consequence limitation in social

participation appeared in 9 cases. Most of these patients feel that the element of unpredictability has caused them to stop making specific and definite plans for future social activities. Mrs. R. (#8) participates now only in such things as card playing with her close friends. She said, "Sometimes while playing, the joints of my fingers act up, but I won't stop. I just act as if nothing has happened. Sometimes it's very painful though." Another female patient (#19) was frequently embarrassed for "It (unpredictable element) always seems to happen when we have company. I get stiff from sitting and have to ask my husband to help me up. He doesn't mind, but I felt so bad about this." Mr. L. (#4) had a number of similar experiences while attending the theater. He had to ask the person next to him to pull him up out of the seat. He said, "You feel like a fool, but I did have to get up." Another male patient (#19) had to leave the "planning" up to the family when he felt worse, therefore, he was left out since he had lost control of the situation.

The consequence of interference with job activities was also found in 9 of the cases. In most instances this occurred either in the job situation, as in the case of the man (#4) whose fingers would become stiff while he was engraving metal plates for printing, or in relation to the job adjustments the

patients made. The high school student's original job at a grocery store had been to unload trucks. After he became ill, he was assigned the duty of keeping the shelves stocked. Regarding this he says, "Sometimes, I can't even do that because I can't bend over. On those days, I grind the coffee and put out the cheese." This element has caused great anxiety for Miss B. (#16) as she attempts to maintain job as a governess. She believes she will be safer if she "lays her cards on the table," with her employers so that they will be aware of "the ups and downs" in capacity to work.

Constant fear of attack as a consequence appeared in 3 of the cases. A female patient (#25) whose "attacks" were frequently so sudden that she couldn't even finish a letter, felt that the "inevitability of another attack tends to spoil periods of feeling well." The other 2 patients who were experiencing this feeling were males (#24 and #15), and it appeared in relation to their work. Mr. D. L. said, "You never know if you can work the next day -- it gives you an uneasy feeling." Mr. R. is fearful of losing his employment since most of the recurrences of exacerbation have occurred on his job. He states, "This makes me very nervous and tense because I never know when something will happen."

It was felt that mutual anxiety with relatives or parents was present as a consequence in 5 cases. This appeared in the

parent-child relationship of the high school boy and the 6 year old girl. Also, Mr. J. (#21) finds that he must frequently interrupt his wife's activities when he suddenly finds himself unable to get up from a chair or to put on his shoes. Over a period of time, he feels that this will become frustrating to his wife. Mrs. E. (#22) who has 4 children ranging in age from 14 to 2 years, feels anxious and guilty about having to give additional responsibilities to the children when she is feeling badly. When she is better, she tries to "make this up to them."

Two other or unanticipated consequences appeared in relation to the factor of unpredictability. They were both in regard to the use or need of medical care. Miss S. (#20) blames the presence of this factor on the doctor, who, she feels, provided inadequate care. A student (#10) said, the unpredictability frightened him, thus, he sought hospital care. In reflecting on this element, he said, "I awakened one morning and couldn't move. I took a couple of aspirins which were next to my bed. About one-half hour later, I got up, dressed, and went to the hospital."

#### Progressive Severity (Table V-c, see appendix)

As one might anticipate, the factor of progressive severity was found to be directly present in each of the 25 cases. In

all of the cases it was felt that at least one consequence resulted from this factor even though in some instances, the problem occurred largely during the time when the condition was acute.

The consequence of increased maladjustment also appeared in all 25 cases. However, the amount of maladjustment ranged in degree from complete delegation of duties and responsibilities to other persons by some patients to a minimal amount of change for some. Only minor effects were evident in cases #7, #14, and #17; these patients were not too concerned because they felt they were "getting better" or because there were few physical changes in their conditions, following the acute stage. These 3 patients feelings might be exemplified by Mrs. F.'s (#14) comment, "I thought I was stuck with it, but now I am getting better and it's not so bad." Many of the other 22 patients are experiencing progressively increased dependency on relatives and friends. They, therefore, find it impossible to manage or maintain control over various life situations.

Many of the 25 patients found that the above mentioned consequences lead to discouragement. Seventeen patients commented on the existence of this element. Mr. L. (#6) who has been ill for about 15 years, had adjusted his way of life to being "the housewife" in the home while his wife and

children worked. He said, "I looked forward to doing the various jobs in and out (garden) of the home. Now the family is having to do more and more of this work also. It's so discouraging." Mr. O. (#19) said, "It is hard to see yourself less and less able to work and provide the family with what they need to keep up with others." Mr. D. L. (#24) felt that the recurrent episodes became worse and worse. This is discouraging and frightens him because he fears becoming unemployable.

Four patients felt that the factor of progressive severity made them irritable. Two of these 3 patients were the university students. One said (#7), "Small things are beginning to irritate me now." Another student (#10) who has "just a small handicap," has been advised to reduce the amount of walking that he does for pleasure. The thought of having to cut down on this activity "annoys" him. Mrs. K. (#21) feels that her children, who are understanding and helpful, tend to irritate her more and more as the degree of severity increases.

Loss of motivation as a consequence occurred in three cases. One female patient (#2) who is not severely disabled, felt that she can't get better, but could get worse. She is resigned to the situation and shares in only a minimum amount of household and social activities. Mr. L. (#6) would like to pursue his hobby of rug making further to see if it would

have commercial benefits, but feels that by the time he got things set up, his condition would be too bad to continue.

Four persons desperately sought medical attention as a result of this factor as they attempted to get better medical care. As the disease process continued, however, these patients saw themselves losing great degrees of their independence and becoming burdens on their families. Mrs. R.'s (#8) comment is typical of this group. She said, "It was hard to face the fact that I was becoming more and more dependent. I guess that's why I kept going to so many different doctors." The consequence of futility appeared in three of these cases and in 5 more or in a total of 8 cases. These patients felt as Mr. P. (#13) did regarding the progressive severity. They didn't want to ask for more help (sometimes financial as in case #5) but it was necessary, for, "when you're so helpless, you don't have much choice."

The element of fear of death appeared in only one case. Mrs. K. (#23) has been fearful of going out alone as she could not turn her head to see traffic, thus might be "run over."

Four patients felt that consequences other than those listed above resulted from the factor of progressive severity. Three of these consequences related to the creation of anxiety and the fourth was in regard to guilt feelings. Mr. S. (#5) was anxious and frightened by the rapid progression of the

disease entity. He said, "I became ill on one day, and the next day, I couldn't move." Mrs. G., (#11) who has been ill for 8 years now, has anxious moments because of the loss of her ability to socialize which has occurred only during the last 12 months. Mr. O. (#19) becomes anxious when he relates how he didn't seek medical attention during the early stage of the disease, thus believes he may be worse now because of this. Mrs. R. (#8) felt guilty when she had to ask her children to do more and more work in the household as her physical condition became more severe.

Deformity (Table V-d, see appendix)

When the factor of deformity was considered, 13 of the patients accepted its presence, and six inferred that it existed. A total of 9 patients denied that there were consequences resulting from this factor. Six patients, felt that deformity was not present in their cases.

Regarding the 9 people who denied consequences (6 from the "accepted" group and 3 from the "inferred" group), most of them felt as Mrs. E. (#22) did in that she used to be "self-conscious about her hands but doesn't mind it any more." Another patient's (#8) response might also be considered as typical of this group. This patient feels that most of her friends and family "take my appearance for granted now" mainly because they have known her for so long and because the changes have been so gradual.

Social rejection as a consequence seemed to have been present only in case #9. This patient, who is severely deformed in her hands, legs, and feet, casually implied that her appearance made her withdraw socially.

Six of the 25 patients felt that being the object of pity resulted from this factor. However, they did not feel threatened or anxious about it because it was not noticed "too much." The high school boy has not actually experienced this since the degree of his deformity is minimal, but he does think that people will pity him if he does become severely crippled. The university student (#7) is trying to stop hiding his hands, "since people don't seem to notice it much anyway." The mother of the 6 year old said, "People do notice her, and are kind and sympathetic." Miss S. (#20) feels that her hands are conspicuous in her work as a bank teller; however, it doesn't seem to disturb the customers.

Avoidance of other people might be considered as being a consequence in the case (#18) of 6 year old La Verne. Although she seems to enjoy the overall attention she receives from other people, her mother has noticed that she does avoid looking directly at people when they associate with her.

Two male patients felt that their appearance would limit job opportunities. In one case, the man is fearful that this might eventually cause him to lose his job. Mr. J. (#21) said,

"Why should they hire me when there are plenty of able-bodied men around." He felt this would be the case if he had to "hobble into an office."

The need for specialized clothes was present as a consequence in 3 cases. The male patient (#21), who was concerned with this, found it impossible to wear his regular shoes on certain days because of swollen feet. The bank teller (#20) finds it is necessary to wear extra size gloves because of his swollen finger joints. Mrs. G. (#11) who has been married for about 40 years, hasn't been able to wear her wedding rings for the last 5 years. Regarding this she said, "This makes me feel bad. I feel as if part of me is absent or missing."

Anxiety regarding being loved was consequential in one instance. This occurred in the case of the high school senior who is fearful of not being able to "find a girl if I am a cripple." No un-anticipated consequences appeared as a result of the factor of deformity.

#### Persistent Pain (Table V-e, see appendix)

This factor was found to be present in 23 of the 25 cases. It was inferred in 8 cases and the pain for these patients tended to occur only periodically during the time of acute exacerbation. When considering the overall discomforts during such periods, persistent pain appeared to be a prominent

feature. Most of the patients were able to engage in few activities then and felt, as did Mrs. F. (#14), who said, "It was very painful. So much so, until you don't know what to do with yourself." These patients denied the existence of consequential results.

Fifteen patients accepted the presence of the factor since persistent pain tended to be constant with them. Three of these denied consequences, for they had made conscious attempts to forget it. One student (#10) said, "I just take a few aspirins, and refuse to think of the pain." A total of 11 patients felt that consequences did not exist as a result of this factor.

Irritability as a consequence occurred in 7 of the cases. One patient (#4) described the pain as being "like a bee sting, and it makes me angry." Mr. W. (#7) felt that this factor made him feel very irritable and causes small things to annoy him. He feels that this is contributing to the present difficulties he is having with his girl friend who is really an "understanding person."

The consequence of limited job performance leading to feelings of unworthiness was present in 5 cases. One male patient (#6) felt that he could do very little with his arms and that "a kid could do most jobs better than I because I do have so much pain." Mr. J. (#21) can only work about 2

days a week, which constitutes an economic threat and makes for feelings of unworthiness in this man who has a wife and four children. Miss N. (#25) is especially anxious about the "sharp, deep pain" because it limits her ability to help with the work in her sister's home. Thus she is not able "to do her share to make up for what they have done for me."

Two patients felt that the persistent pain limited socialization. This was found in cases #19 and 25. Both of these patients felt it was easier to get along with their families when they "withdrew" or "isolated" themselves in their rooms.

Several un-anticipated consequences appeared in relation to the factor of persistent pain. One patient (#8) who has been ill for 24 years is now almost insensible to pain but is very nervous. She said, "I don't pay any attention to the pain, it's my nerves that bother me now." Expense as a consequence resulted from Mrs. D.'s (#9) attempts to reduce the amount of pain. The parents of 6 year old LaVerne commented that, "This (the fact that the child is in pain) is the hardest thing for us to take." It disturbed them very much and they felt they could cope with the burden of caring for her if the pain was not an element. Mr. J. (#21) thought this factor was a threat to his masculinity as he is not able to keep up physically with his wife because of the pain which walking causes. Two patients appeared to benefit from the

attention received at times when the pain was rather severe. One male patient (#19) said he felt loved and protected during such periods. Two patients (#19 and 22) implied that the factor of persistent pain had caused problems related to their sexual activities. Mrs. E. (#22) denied that this causes a hardship for herself or her husband. However, it is notable that 2 years ago he took a job in a distant town. This patient also says, "The worst thing about this illness is that I can't be a good wife."

Lack of Mobility (Table V-f, see appendix)

The presence of this factor was found in all 25 cases. However, in 4 of them, its acceptance was only inferred, and each of these 4 patients denied the existence of any consequences. One (#15) of these patients said this factor did not concern him except during acute periods since he reported, "I'm very active for my age." Mrs. K. (#23) has merely "done less" around the house and has not worried.

Over dependence did not appear to be consequential because of lack of mobility. Social isolation resulted as a consequence in 10 cases. In most instances, this was evident through a general form of restriction in recreation. Mrs. S. (#12) felt that she didn't want to go out and have people feel sorry for her. Therefore, she only entertained a few relatives in her home. Occasionally the relatives would "prepare

the meal as a part of the entertainment." Miss N. (#25) has not been able to leave the house in months, not even to go to church. She sees no one but her family.

Nine patients felt that lack of mobility was a vocational handicap, and would either influence their ability to obtain gainful employment or threatened their ability to keep their present positions. Mr. W. (#7) feels that it is necessary to inform his employer of his condition because "there are some things that I just can't do." The patient (#16) who was a governess, feels that she may have to change occupations since it would be difficult for her to "keep up" with the children. This factor has seriously affected Mr. O.'s (#19) ability to operate his farm. At times he has had to employ help; thus, cutting the income below a subsistence level for his family. He has occasionally had to "sell a cow to make ends meet." Mr. O., the truck driver (#21) feels that if his job should be discontinued, he cannot be flexible in seeking other jobs. Even while working at this job for the past few years, he has been in constant fear and under tension because if there was ever a blowout or truck trouble he would be unable to walk for help or to do the repairs himself.

Problems regarding keeping up with others was another prominent consequence, appearing in 9 cases. Mr. B., the high school student, first motorized his bicycle and then bought a car to help himself in keeping up with the other

students. The university student (#7) related how he sometimes forgets the fact that he can't do things. He said, "I was at a 4-H picnic once and got into a peanut race. I forgot that I couldn't run like the others on my knees." Sometimes his "knees snap" at dances and he has to stop dancing. In order to keep up with her siblings, 6 year old LaVerne controls them with demanding behavior or flattery to get them to limit their play to things that she can do, or to get them to do errands which she can't manage. Mr. O. (#19) feels that he was not able to keep up socially since he could not provide for his family as well as neighbors and friends have provided for theirs.

Problems related to home management and child supervision resulted as a consequence in 8 cases. While Mrs. S. (#12) was acutely ill, her husband took over the management of the house and both disciplining and entertaining their boys. Punishment for the 6 year old child (#18) is no longer by means of spanking as it is for the siblings but is done by "yelling at her." Discipline of the children in case #22 must be maintained by "family conferences." The more difficult problems are handled by the father on week-ends when he returns home from his job. Mrs. H. (#17) is disturbed at times when the lack of mobility keeps her from doing some of her housework. Another patient has to ask her sister to do the heavier housework or hire someone to do this.

Lack of recreational interests was consequential in 8 cases. This seemed to have been affective in 2 areas; one concerning the patient's own recreational outlets, principally dancing, and the other the degree to which the patient could participate in play with their children. Mrs. K. (#2) whose main form of recreation before her illness was dancing, has given this up and now has a weekly "movie and dinner date" with her husband. Mr. S. (#5) said of himself, this element, and his wife, who was recently treated for a heart condition, "Between my condition and my wife's bad heart, I don't guess we'll be able to dance much any more at all." Mr. J. (#21) feels that his role as husband and father is being threatened since he's "not a buddy to the family any more." He is especially unhappy at not being able to be a hunting and fishing companion to his 16 year old son.

In addition to the above consequences, 2 patients were irritable and frustrated because of lack of mobility. Regarding this, Mrs. R. (#8) said, "I want to do things and I can't. It makes me so irritable and agry." Not being able to move when she wants to causes frustration and impatience for Miss N. (#25). She tends to hide this; as she said, "I don't get angry; I just lay down."

Low Activity Tolerance (Table V-g, see appendix)

The presence of this factor was accepted in 13 of the 25 cases in this study on rheumatoid arthritis. The presence was inferentially accepted in 4 additional cases. It was not present in 8 cases. Five patients implied that consequences resulting from this factor did not exist. Most of these patients realized the necessity of resting; did this, and did not tend to worry about it.

The consequence of limited accomplishment leading to feelings of unworthiness appeared in 3 cases. Mr. J. (#21) said he tires easily and can only work on a part-time basis. This made him feel unworthy and causes an economic threat. Another man (#24) felt that this factor has affected his ability to work at his carpentry hobby. This leads to a feeling of unworthiness because he wanted to teach carpentry to his children and make things for the house.

Dependency, as a consequence, existed in the case (#8) of Mrs. R. This patient's activity tolerance had been relatively high until 4 weeks ago when she had to use a cane and finally "had to take to the wheelchair." This is very disturbing to her because it has made her so dependent. She feels that the only thing she can do now is sit around and she said, "I don't know what to do with myself anymore."

Frustration and irritability appeared as a consequence in 5 cases. Mr. B. (#3) was irritated by fatigue and stated,

"I can't go out in the evenings and do the things like the other kids do." The fact that another patient (#19) can do things for only short periods of time and therefore, frequently can't finish what he starts has become upsetting to him. Mr. J. (#21) can no longer engage in hunting, fishing, or gardening. Formerly, he was always active and strong; "never laid around." This makes him restless and unhappy.

Nine patients felt that low activity tolerance caused the consequence of restricted social and work activities. Mr. L. (#6) finds that after being up and as active as possible during the day (patient is alone), he must rest during the evening when the family returns. He is not able to participate in social activities, therefore, he and his wife tend to "sit around and read or listen to the radio." Mr. P. (#13) indicated that previously he and his wife had gone out together frequently. Now they seldom do; sometimes he "Just walks out to see the boys." Miss S. (#20) now becomes tired and for the first time in her life, finds she must rest. This is a problem as it keeps her from doing things she would like to do. Miss B., (#16), the governess, feels that she must take jobs offering "light work" which would not involve the lifting and running after small children as she has done in the past.

There were no other or un-anticipated consequences resulting from the factor of low activity tolerance.

## Treatment

The fourth and final aspect of the disease entity of rheumatoid arthritis to be considered in this study is that of treatment and management. The results of six factors which seem to increase <sup>social</sup> stress and problems for patients under treatment, have been systematically recorded on separate tables. (see appendix) The factors and the consequences will also be discussed here in sequence as previously listed.

### Consistant Medical Supervision (Table VI-a - see appendix)

The presence of this factor was accepted in all 25 cases, and in each, consequences were present also. Most of the patients accepted the necessity of medical supervision because they thought it was important if one wanted to maintain the best possible health.

Expense appeared as a prominent consequence; it was present in 18 of the cases. These patients commented on how the expense of extensive care and treatment affected their net incomes, caused them to need public financial assistance, used the bulk of their savings, or how they were still able to manage in spite of the expense. Mrs. K. (#2) feels that the expense has been "a drain" on her husband's income, but they try not to worry about it. Mr. S.'s (#5) family had to apply for and received partial public assistance. Since her savings have been used on doctors and medication, Miss B.

(#16) believes she will need public funds for the continued care of this illness. If this is necessary, it might impose a restriction on the patient because of "residence regulations." She would have to give up her desire to work as a governess "in warm dry climates." Mr. D.L. (#24) frequently needs a doctor as often as 2 to 3 times a week. This has been expensive. Friends have helped him to pay these bills and he says, "This makes me feel ashamed of myself." Mrs. L. (#1), who has been ill for 16 years said, "It was a strain, but we were able to purchase and maintain a home. The children have offered to help, but I won't accept this because I want to maintain my financial independence as long as possible." Mrs. H. (#17) acknowledges the rising cost of medical care, but feels the family can probably meet this expense without serious deprivation.

The consequence of dependence on the doctor seemed to have been present in 7 cases. Mr. L. (#4) seems to enjoy his experiences with new doctors as he tended to "challenge" them to cure him. Mrs. G. (#11) doesn't hesitate to go to the doctor. She wants medical advice and, generally, tries to follow it. This patient had the same doctor for 28 years. She had to change recently when this doctor became ill. Another female patient (#16) said she has seen so many doctors until she can't remember them. She said, "I used to go to the doctor for any slight symptom." The parents of LaVerne (#18) feel that they are very dependent on doctors and that

the doctors are doing the best they can for the child.

Discouragement regarding varied opinions and inconsistencies in treatment resulted in 11 cases. Three of these patients (#7, 17, 19) felt that they might have been being used experimentally or as a "guinea pig," however, the 2 latter patients did not mind this. Mrs. D. (#19) feels that consistent medical supervision has not been too beneficial. This feeling might be based on the fact that she has been receiving various forms of treatment since she was 10 years old and is still "not cured." Another female patient (#20) has similar feelings and is dissatisfied with doctors who "lack interest" and the ability to work out a plan for a cure.

LaVerne, the 6 year old girl, seems to have worked out her system of expressing feeling regarding the various types of treatment she has, thus far, received. According to her mother, the child does a lot of playing of doctor and nurse. In reality, she seems to have an increasingly good relationship to doctors, but when she "plays" she "yells and gets angry" both at the "doctor" and at the "patient."

Limitations in where a person could live was found to be a consequence for one patient, Mr. W. (#7), the university student who wants to be an agricultural engineer feels that this factor might restrict job opportunities since he would have to stay in a country or area wherein medical treatment would be available.

Communication and transportation needs as a consequence

of consistent medical supervision did not appear.

It was felt that one patient (#10) experienced an un-anticipated consequence. This patient objects to the regu-  
lative aspects of medical supervision and care. He said, "I know that it's valuable, but I still don't like it. It's too regulating. You're forced to do many things you don't want to do."

Regular Medication (Table VI-b - see appendix)

This factor was accepted as being present in 20 cases. It was not present in 5 cases. Three patients denied resulting consequences. Mr. L. (#4) didn't mind taking from 10 to 12 aspirins per day; and Miss B. (#16) did not feel the cost of her medication was excessive.

Eleven patients felt that this factor was an expensive consequence for them. Because of the actual expense of the medications, the patients in cases #5 and #13, implied that they might not be able to comply with the recommendations regarding drugs. Mrs. E., (#22) feels that if the cost of medications could be cut, it would be a great help in the family's financial situation.

Responsibility for one's own health regarding medica-  
tions seems to have been a consequence in one case. During a visit to the out-patient clinic, Mrs. S. (#14) was advised to continue taking aspirins, and was assured that they would help her. Regarding this, she said, "I don't want to become

dependent on them, but I guess I'll take them if they will keep my fingers from getting worse."

Side effects from drugs appeared as a consequence in 4 of the cases. Two of these patients (#2 and #11) were fearful of what they thought might happen to them if they took certain drugs over a long period of time. The former patient was afraid because, "they didn't know what it would do to me." Mrs. G. said, "I know some people who have had bad affects from it (cortisone). It might give you something else. I would rather suffer only with arthritis."

The two other patients said they had actually experienced side affects from their medications. Mrs. F. (#14) said, "Some minor changes did occur; I seemed to be moody, but I would take it again if my condition became bad again." The other patient Miss N. (#25) implied that she would hesitate to take the medication again because of the side effects of burning in the stomach, nausea, and vomiting.

Anxiety regarding the availability appeared as a consequence in one case. Miss S.'s (#20) doctor was out of town when she needed a prescription, so she changed doctors.

The elements of addiction to drugs, fear regarding dosage, solicitousness of relatives did not appear as consequences resulting from the factor of regular medication.

It was felt that regular medication as a constant reminder of the disease did appear in 2 cases in what one might consider a form of projection. In this, the high school

student (#3) said, "People would think you were dead if they saw you taking something every day for over a month." A university student (#10) felt that the prescribed medication was not too expensive. He said, "It's only aspirin. But I hate the idea of taking it every day."

Painful Treatment (Table VI-c - see appendix)

The presence of this factor occurred in 8 cases. It was not present in 17 cases. For some of these patients, painful types of treatment had not been prescribed. Others felt the physical therapy treatments they had received "were pleasant." Four patients who had accepted the presence of the factor, denied the existence of consequences. Comments regarding this were as follows: Case #1, "It was painful, but it's better to do than not to do the exercises. I don't want to get stuck in any one position and then not be able to move." Case #9, "It hurts, but it's important in order to keep going." Case #14, "Originally, it was painful, but it did help. I still do some of the exercises." Case #22, Mrs. E., accepted the painful physical therapy treatments as for her "own good."

Reluctance to take treatment was a consequence in 4 cases. This was present in the case of Mrs. R. (#8) because each doctor she saw, offered different treatment plans. However, she has continued with some of the exercises even though they are painful. Six year old LaVerne (#18), seems

to realize that they will help her, but it also seems to be difficult for her to take them. Mrs. K. (#23) shows reluctance by seemingly wanting others to give the treatment to her. She does exercise alone, however, when it's necessary.

Questioning the worth of treatment was not a consequence. One patient (#25) was fearful of treatment. She explained that one series of heat treatments had been very painful; she feared the treatments would cripple her worse than the arthritis. Anxiety of others giving the treatment was a consequence in one case. This was present in case #18, wherein, LaVerne's parents gave the treatments to the child. The parents considered this as being one of the hardest things for them to take because the treatments were painful for their daughter.

The consequences of reluctance of others and of anxiety communicated by others to the patient were not present. Neither were other consequences evident.

#### Hospitalization (Table VI-d -- see appendix)

The factor of hospitalization was accepted as being present in 24 of the 25 cases. One case was recorded on the chart under the heading of "presence inferred." This patient (#7) had never been actually admitted as a hospital in-patient, but he was receiving physical therapy on an out-patient basis. Three patients (including the "out-patient") denied consequences resulting from this factor.

Eight patients considered expense as being a consequence resulting from this factor. Along with the actual expense of hospital care, Mrs. K. (#2) had the additional expense of hiring a girl to help with the children at their home. Mr. S.'s (#5) comment regarding the expense was, "I knew that this (hospitalization) would probably help me, but I didn't want to come because of the added expense. Financially, we just couldn't afford another hospital bill." Hospital expenses for LaVerne's (#18) parents, "has been a real financial burden."

Separations with possible disruption of normal pattern and possible loss of status with the family was a consequence in 12 of the cases. Three of these patients, (#8, 12, and 25), two of whom were severely crippled, felt that their periods of hospitalization helped by reducing the family burden of their care. Mrs. R. (#8) said this gave her husband a chance to "rest for a while also." She thought him deserving of this period of "freedom" from having to take care of her.

Four of these 12 patients felt that they lost some status with the family while they were hospitalized. Mrs. F. (#14) was surprised to discover how well her husband the 2 sons managed without her in the home. Mrs. E.'s (#22) children were placed with relatives when she came to the hospital. She seemed to be a little fearful that they would prefer to stay where they were rather than return home to more work and responsibility and less "fun." Mr. J. (#21) and Mrs. D.L.

(#24) are afraid that their young children "may not recognize" them when they return home. Another patient, Mr. P. (#13) who was sent to the hospital for an evaluation as part of the State Vocational Rehabilitation program, did not want to come into the hospital at this time because his wife "was not feeling too well."

Hospital adjustment had consequences for 6 patients. Mr. L. (#4) "hates hospitals" because he finds it difficult "to stay still and in bed." Mrs. R.'s (#8) difficulty was concerned with the doctors. She said, "You can't talk to them and if you do, they won't tell you anything." One of the university students (#10) implied that it was difficult for him to be dependent on others (hospital personnel). Whether brief or lengthy, separations for Mr. O. (#19) are difficult for him to accept because he "gets very lonesome."

Two patients had preconceived ideas regarding their hospital experiences. Mr. B., (#3) the high school student, was convinced that he would have surgery. Mr. R. (#15) had similar feelings. He said, "You never know what they're going to do next. They might just cut off your leg." It was felt that these same 2 patients and one additional one, also had feelings of anxiety as a consequence of the factor of hospitalization. The student admitted to being frightened about the prospects of coming to the hospital. The fact that fellow employees had "teased" him about possible types of treatment, such as spinal taps and blood tests, did not help in this

situation. Mr. R. said he was fearful of "the unknown" aspects of hospital care and treatment. The third patient who might be considered as being anxious regarding hospital care is the 6 year old child (#18) who is becoming increasingly reluctant to come to the hospital.

One patient felt that his period of hospitalization was concrete evidence that his illness invoked pity. This patient was Mr. L. (#10) who said his friends were very attentive while he was hospitalized. However, he was glad when he was up again, for "no matter how nice people are, I don't like them waiting on me."

The element of protectiveness appeared as a consequence in 9 of the cases. Many of these patients spoke of the hospital as being "a good place, and the last resort" for treatment. Mrs. K. (#2) felt that she wanted "to come and stay and get well." Although he felt his first hospital experience was not beneficial, Mr. L. (#6) explained that "the hospital is the best place to go because there they really study your case" and help you if they can. Mrs. B. (#16) commented on how she "loves it here" and it is a refuge from her family; and by being a state patient, she "won out" over the family in her demands for medical care.

Required Activity (Table VI-e -- see appendix)

The presence of this factor was accepted in 13 of the 25 cases. The presence was inferred in 3 of the total number

of cases, and was not present in 9 cases. Nine patients denied the existence of consequences. The patients who denied the consequences here, tended to remain active, even though in some instances, the movement was painful. Mrs. D.'s (#9) comment regarding this might be considered as typical for the group. She said, "I feel if I ever stopped going, I'd stop for good. Therefore, I must keep on moving and being active."

Two consequences were considered in relation to the factor of required activity. That this factor may induce pain with consequent irritability and fretfulness, resulted as a consequence for 5 patients. Mrs. G. (#11) feels that it's sometimes painful to be active, but believes that recent inactivity might have contributed to the severity of her present condition. Mrs. S. (#12) said, "The doctor told me to keep moving and I did even though it's painful. Sometimes it's a terrific effort to make yourself get up and go especially when you feel your body is such a burden." In order to "take the pain" Mr. J. (#21) said, "You've got to grit your teeth and make up your mind to keep going." Sometimes he feels like stopping but can't; this makes him irritable. Mr. D. L. explained how when he comes home from work tired, he would like to fall asleep in a chair, but knows "it would be hell to get up." Therefore, he has mixed feelings and must struggle within himself to keep active when he doesn't feel like it.

The consequence of hostility towards persons recommending or reminding the patient of treatment was present in the cases of two of the students. Mr. B. (#3) generally does not do his exercises until his mother forces him to do so. Sometimes he feels hostile towards both the mother and the doctor. Mr. W. (#7) has similar feelings when his mother, who is a nurse, "encourages me to keep active and moving."

Use of Appliance (Table VI-f -- see appendix)

The factor of use of appliances was accepted in 7 cases out of 25. It was present inferentially in 3 cases; it was not present in 15 cases. Five patients felt that this factor did not have adverse consequences for them. Mrs. L. (#1) who uses a "homemade wheelchair" feels that "aids of some type" are frequently necessary and useful. One of the male patients, (#13) has a cane, but doesn't use it because he feels it's not necessary. Mr. R. (#15) has been using crutches since his "last attack." These had not been medically recommended for him at the time of the interview, but he had gotten them because he thought they would be helpful. He said, "I don't mind people seeing me on them." Mrs. E. (#22) was pleased that she was learning to use crutches for she sees this as a help in being able to get around at home.

Expense as a consequence, did not appear in relation to the factor of use of appliances. One patient (#6) felt that an appliance he had previously used had been pain producing.

The first appliance he was advised to use was an arch support. "They were painful and useless." He used them for about one month, now regrets having spent the money for them.

One patient felt that using appliances pointed up the disability. For Mrs. R. (#8), it was a matter of the degree of disability which disturbed her. She felt that when she had to use a cane and then a wheelchair, it meant that she had really lost all of her independence. Regarding the similar consequence of inviting pity, Mrs. G. (#11) said, "I didn't want people to see me using the cane because then they feel sorry for you. But I had to get over that idea and get one."

Self-consciousness and humiliation appeared as a consequence in 2 of the cases. Mr. B. said, at the time of the interview, "I won't mind a brace for no one could see it, but I don't think I would like to use crutches." The patient was discharged from the hospital with crutches, but returned to the out-patient clinic about one month later without them. An interested friend, brought Mrs. S. (#12) a cane to use. She did not use it, but put it in "plain sight" and saw it each day. The patient said, "It became a challenge to me to keep going without it." Later when the patient came to the hospital, she was forced to use a wheelchair as she was taken to various departments in the hospital. Regarding this, she said, "This was necessary because I walked too slowly. It hurt my feelings to be made to use the wheelchair. My family

was more considerate and waited for me when I was at home."

#### Diet Limitations - An Un-anticipated Factor

The element of diet, appeared during the interviews with 4 of the 25 patients seen for this study. Miss B. (#16) has been advised to keep her weight down. She seems to understand the reason for this recommendation, but tends not to pay much attention to the diet. A salt free diet has been recommended for Miss S. (#20). She does not like the taste of this type of foods, but says cooking for herself and her sister, with whom she lives, is not difficult because of her diet. Mrs. K. (#23) has been worrying about a recent loss of weight. However, she thinks she will be able to eat more when she goes home since she does like to cook and to eat.

Mr. D. L. (#24) seemed to have been the only one of this group of patients who really felt that adverse consequences resulted from this factor. This patient is on a salt-free diet because of medication and also on a reducing diet because lessened activity had caused weight gain, therefore, observation of 2 diet regimes is "hard" for his wife. He feels guilty for giving his wife extra work in food preparation and marketing. It also annoys him to have to watch his diet.

## Footnotes to Chapter V

1. Bernard I. Comroe, Arthritis and Allied Conditions, Ed. by Joseph Lee Hollander, M.D., (Fifth Edition, Lea & Febiger, Philadelphia, 1953), 123.
2. American Rheumatic Association, Primer on the Rheumatic Diseases (prepared by a Committee of the American Rheumatic Association, 1953), 27.

## CHAPTER VI

### CONCLUSIONS AND RECOMMENDATIONS

Since this study of factors which appear to increase or precipitate social stress for persons who are chronically ill due to rheumatoid arthritis is one segment of a larger research project, wherein 4 disease entities are being analyzed, extensive conclusions will not be formulated.

However, as proposed in the Introduction, an attempt has been made to evaluate the validity of suggested "factors" for this disease, through determining if the anticipated stress factors actually appeared, and obtaining an impression of the general types of problems (consequences) that were precipitated or aggravated. The conclusions regarding these will be given below.

#### Conclusions:

In general, it was felt that of the 4 "factor" areas, public attitudes, etiology, symptomatology, and treatment, which were suggested for study, the area of public attitudes is least valid for this particular study in its present form. Public attitudes regarding persons having rheumatoid arthritis did exist, but seldom in such a way as to precipitate

social stress. However, the substantial number of consequences which were evident in the data gathered, seemingly, would give validity to the other "factor" areas.

Table VII (see appendix) is a master chart of findings regarding the presence (this includes both "presence accepted" and "presence inferred") of the anticipated stressful factors which were considered in the study.

It can be noted from this table that most of the factors related to the other three aspects of the disease appeared in a majority of the cases. Only 2 such factors, "painful treatment" and "use of appliances" appeared in less than one half of the cases. These two factors occurred in only 8 and 10 instances. There was also a low incidence in the factor of "neglect in care" which was evident in 13 cases.

Nine of the factors were present in at least 20 or more of the 25 cases. Three factors, "progressive severity," "lack of mobility," and "consistent medical supervision" occurred in all 25 cases. "Hospitalization" appeared in 24 of the 25 cases, one patient never having been admitted to the hospital on an in-patient basis. The remaining factors appeared 15, 16, 17 and 19 times in the case sample. This overall high incidence would indicate that the designated factors actually appeared in the disease under study.

When considering etiology, it is evident that a majority of the patients (20 in all) were greatly concerned with respect to the "unknown causation" of this disease. Fifteen

of these patients looked for their own reasons for the development of their illness. This tended to lead to feelings of guilt and self-condemnation. It is interesting to note that only a few of the patients were aware of the familial tendency of rheumatoid arthritis, therefore, the consequences precipitated in this regard were minimal.

In the area of symptomatology, the consequences precipitated or aggravated most frequently, were concerned with loss of control and management of personal affairs and situations, limitations in social participation, and restrictions in employment opportunities. Problems regarding "deformity" and "persistent pain" were minimal for many patients, and prominent mainly with the more severely disabled ones.

In treatment and management of patients with this disease, the expense of "consistent medical care" was the prominent consequence. Closely associated with this was discouragement regarding inconsistencies in medical opinions regarding medical care. The element of "hospitalization" created problems of anxiety with respect to separation and loss of status in the family.

The un-anticipated consequences were generally concerned with fear and feelings of anxiety regarding the disease process and course. In some instances, this was attributed to the rapidly disabling element which is possible in rheumatoid arthritis. Some of the other un-anticipated consequences were: guilt because responsibilities had to be delegated to

others, especially to the children; threats to masculinity; interferences with sex life, and objections to the regulatory nature of medical care and treatment.

The results of the data gathered, indicate that many and varied problems (consequences) are precipitated by the stressful factors in rheumatoid arthritis. However, the group of 25 patients interviewed appeared, in the main, to be "struggling" to maintain as much independence as possible in view of the continuous disabling process of the disease.

#### Recommendations:

Findings from this limited study might justify a few recommendations for those participating in the medical and social care of persons with this illness.

A notable number of patients were concerned regarding the etiology of this disease. It is, therefore, felt that some discussion of this element with them might be helpful in relieving feelings of anxiety.

Since this is a chronic disease affecting a large number of persons during their productive years, and since a number of the patients were concerned about their vocational futures, it is felt that a more extensive use of vocational rehabilitation services would be beneficial for the patients, especially the younger ones.

The data gathered indicated that the expenses of long-term medical care influenced the amount of treatment many of

the patients sought to receive. Recognition with them of the expense element and encouragement to obtain financial assistance when it is necessary, through local resources, might help to relieve the financial burden of the illness and increase opportunities for continued care and treatment.

In regard to the larger research project, it might be recommended that public attitudes as a "factor" area for study of this disease be re-evaluated. It would also seem that prepared charts would be helpful in tabulating the factors and their consequences as each case study is completed and recorded. These might also be used as interview guides.

APPENDIX

TABLE III. PUBLIC ATTITUDES

Case Number	Present	Not Present	Present	Curiosity	Sympathy	Lack of interest in rheu. arthritis	Expectation to high	Consequences or Patients' Reactions
1			x			x		Dis-interest because "it doesn't show".
2	x				x			People look at you and feel sorry if you are "a cripple".
3	x							
4	x							
5	x							
6	x		x				x	Dislikes having to answer questions and explaining limitations.
7	x							
8	x							
9			x					Will discontinue support of other health programs.
10			x			x		Believes there is more interest in native Denmark.
11	x							
12		x		x				People tactless and curious; discuss patient in front of others.
13	x							Offers of help make patient angry.
14		x						
15	x							People are pessimistic, but patient enjoys help from strangers.
16								Friends are concerned and are sympathetic. Even strangers feel sorry for you.
17	x							Resentment
18	x							Friends anxious and concerned but expect recovery.
19	x		x					Worries that dependence on wife will be misunderstood.
20	x			x				People feel sorry and want to help.
21			x					People feel sorry and send mail to hospital.
22	x							People expect you to be cheerful.
23	x							People are sorry and therefore nice to her.
24	x							
25	x							
	8		3	3	9	3	4	

TABLE IV-a HEREDITARY TENDENCY

Case Number	Consequences			Consequences			Anxiety	Placement of children
	Not Present	Present	Inferred	Blame Parents	Guilt of Parent with overprotection	Fear of Marriage Having Children		
1								
2			X		X			
3			X					
4	X							
5				X				
6			X					
7			X					
8				X				
9								
10	X							
11					X			
12	X							
13	X							
14								
15			X					
16	X							
17	X							
18	X							
19	X							
20	X							
21	X							
22								
23			X					
24	X							
25			X					
10		4						
11								
11								
7								
2								
4								
2								

TABLE IV-b NEGLIGENCE IN CARE

Case Number	Consequences			Blame & self-blame with guilt			Intensification of symptoms with consequent anxiety			Hostility toward M.D.		Others
	Not Present	Presence Inferred	Presence Accepted	Consequences Denied	Presence	Accepted	Blame & self-blame with guilt	Intensification of symptoms with consequent anxiety	Hostility toward M.D.	Others		
1	X											
2		X						X		X		
3		X						X		X		
4	X											
5	X											
6	X											
7	X											
8	X											
9	X											
10		X					X					
11	X							X				
12		X						X		X		
13			X					X		X		
14		X					X			X		
15												
16	X											
17		X					X					
18		X										
19		X										
20			X					X				
21	X											
22		X					X			X		
23							X					
24		X					X					
25	X											
12			8				6			7		5

TABLE IV-C UNKNOWN

Case Number	Presence		Consequences		Looks for		Consequences		Miracle Cures
	Not Present	Inferred	quences Denied	quences Accepted	self-blame reason, consequent blame	or condemnation	Parents' fusion or relatives take blame	all leads to Doc-tors	
1									
2				X	X			X	X
3				X	X				
4				X	X		X		
5				X	X		X	X	
6				X	X				
7				X	X		X	X	X
8				X	X		X	X	X
9				X	X		X	X	X
10	X					X			
11		X							
12		X			X				
13		X			X				
14		X				X		X	X
15		X					X		
16		X				X			
17		X				X			
18	X								
19		X				X		X	X
20		X				X		X	X
21		X							
22	X								X
23	X								
24				X				X	
25				X		X			

5 6 14 3 15 5 4 1 9 3 6

TABLE V-3 CHRONICITY

Case Number	Not Present	Presence Inferred	Presence Accepted	Consequences Denied	Consequences		Others			
					Overprotection by family	Lack of economic motivation				
					Security needs	Shop-ping for cures	Mis-management and depression			
1			X				X			
2			X			X	X			
3			X							
4			X		X	X				
5		X			X					
6			X		X	X	X			
7			X		X	X				
8			X		X	X				
9			X	X						
10			X				X	X		
11			X		X					
12		X		X						
13			X		X		X	X		
14			X		X		X	X		
15			X		X					
16			X		X					
17			X		X		X	X		
18			X		X		X	X		
19			X		X		X	X		
20		X								
21	X			X						
22	X				X	X	X			
23			X	X				X		
24			X		X			X		
25			X		X	X		X		
4			21	4	2	15	5	10	14	2

TABLE V-b UNPREDICTABILITY OF INCREASE IN SYMPTOMS

Case Number	Consequences			Limits in social participation			Interference with job			Consequences		
	Not Present	Present	Inferred	Presence	Accepted	Denied	Presence	Interference	Constant	of anxiety	Mutual	Others
1	X											
2		X						X				
3		X					X	X				
4		X					X	X				
5	X											
6		X					X					
7		X					X	X				
8		X					X	X				
9	X											
10		X					X					
11		X					X					
12	X						X					
13		X					X					
14		X					X					
15		X					X					
16		X					X					
17	X											
18		X										
19		X					X					
20			X									
21		X										
22		X										
23		X										
24		X										
25		X					X					

Frightened into seeking medical care.

Blame of doctor

5 2 18 1 9 9 3 5 2

TABLE V-c PROGRESSIVE SEVERITY

Case Number	Consequences		Consequences		Consequences		Consequences		Consequences	
	Presence	Not Present	Increased maladjustment	Discouragement	Irritability	Loss of motivation	Fear of death	Desperation	Futility	Others
1	X		X		X		X		X	
2	X		X		X		X		X	
3	X		X		X		X		X	
4	X		X		X		X		X	
5	X		X		X		X		X	
6	X		X		X		X		X	
7	X		X		X		X		X	
8	X		X		X		X		X	
9	X		X		X		X		X	
10	X		X		X		X		X	
11	X		X		X		X		X	
12	X		X		X		X		X	
13	X		X		X		X		X	
14	X		X		X		X		X	
15	X		X		X		X		X	
16	X		X		X		X		X	
17	X		X		X		X		X	
18	X		X		X		X		X	
19	X		X		X		X		X	
20	X		X		X		X		X	
21	X		X		X		X		X	
22	X		X		X		X		X	
23	X		X		X		X		X	
24	X		X		X		X		X	
25	X		X		X		X		X	
26										
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28										
29										
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31										
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TABLE V-d DEFORMITY

Case Number	Consequences			Consequences			Others	
	Not Present	Present Inferred	Present Accepted	Consequences Denied	Consequences Accepted	Consequences Appeared		Consequences Appeared
				Social Rejection	Object of Pity	Avoidance of other people	Specialized clothes needed	Anxiety of being loved
1			X					
2			X					
3			X					
4		X			X			X
5								
6	X							
7			X					
8			X					
9		X						
10		X		X				
11								
12	X						X	
13			X					
14	X							
15	X	X						
16								
17		X						
18					X			
19			X					
20			X					
21			X					
22			X				X	X
23			X					
24	X							
25	X							
								1
								2
								3
								6
								9
								13
								19
								24
								25

TABLE V-e PERSISTENT PAIN

Case Number	Consequences			Irritability	Limited job performance leads to feeling unworthy	Consequences	Others
	Not Present	Present Inferred	Present Accepted				
1		X	X				
2			X				
3		X	X				
4				X			
5	X						
6		X	X	X	X		
7		X	X	X	X		
8		X	X	X	X		
9		X	X	X	X		
10		X	X				
11		X	X				
12				X			
13		X	X	X			
14		X	X	X			
15		X	X	X			
16		X	X	X			
17		X	X	X			
18			X				
19		X	X				
20						X	
21	X						
22		X	X	X	X		
23		X	X	X	X		
24		X	X	X	X		
25		X	X	X	X		
	2	8	15	11	7	5	2
							7

insensitive to pain, nerves bother expense

disturbs parents interferes with sex life; meets dependence needs  
 threat to masculinity interferes with sex life meets dependence needs

TABLE V-f LACK OF MOBILITY

Case Number	Consequences		Consequences		Recreation	Others
	Presence	Not Present	Over dependence	Problems in "keep up"		
	Accepted	Denied	Social Isolation	Problems in "keep up"	tion	
1	X		X	X		
2	X		X		X	
3	X		X		X	
4		X				
5	X		X		X	
6	X		X			
7	X		X			
8	X		X			irritable
9		X				
10	X				X	
11	X				X	
12	X		X		X	
13	X		X			
14	X		X			
15	X		X			
16		X				
17	X				X	
18	X				X	
19	X		X		X	
20	X		X		X	
21	X		X		X	
22	X				X	
23		X				
24	X		X		X	
25	X		X			frustration
	4	4	10	9	8	2

TABLE V-9 LOW ACTIVITY TOLERANCE

Case Number	Consequences			Consequences					
	Not Present	Presence Inferred	Presence Accepted	Denial	Limited accomplishment	Dependence	Frustration & irritability	Restricts social & work activities	Others
1	X								
2	X						X		
3			X						
4	X								X
5	X								
6			X						
7		X			X				X
8			X						
9		X			X		X		
10	X								
11			X		X				
12			X		X				
13			X		X				
14	X								X X
15		X							
16					X				X
17	X								
18	X								
19									
20			X						X X X X
21			X						
22			X						
23			X						
24		X			X				
25			X						X X
8		4	13	5	3	1	5	9	



TABLE VI-b REGULAR MEDICATION

Case Number	Consequences		Expense		Consequences		Sollicitousness of relative	Need for constant remembering dis	Others										
	Presence	Not Present	Accepted	Denied	Response	Side effects				Addic	Fear re:	Anxiety							
1	X																		
2			X																
3			X																
4			X																
5			X																
6			X																
7			X																
8			X																
9			X																
10			X																
11			X																
12			X																
13			X																
14			X																
15			X																
16			X																
17																			
18																			
19																			
20																			
21																			
22																			
23																			
24																			
25																			

5 20 3 11 1 4 1 2

TABLE VI-c PAINFUL TREATMENT

Case Number	Consequences		Consequences		Anxiety of others	Reluctance of others	Fear of treatment	Question of worth	Reluctance to treatment	Anxiety of others	Reluctance of others	Anxiety Communicated to Patient	Others
	Presence	Not Present	Denied	Accepted									
1													
2			X										
3	X												
4	X												
5	X												
6	X												
7	X												
8									X				
9										X			
10	X												
11	X												
12	X												
13	X												
14									X				
15	X												
16	X												
17	X												
18													X
19	X												
20	X												
21	X												
22													
23													
24	X												
25													
17	8	4	4	4					X				1

TABLE VI-d HOSPITALIZATION

Case Number	Consequences		Consequences					Others		
	Presence	Not Present	Expense	Separation anxiety & loss of status in family	Hospital Pre- adjustment received ideas	Anxiety evidence invoking pity	Concrete evidence		Protectiveness	
1	X							X		
2	X		X					X		
3	X				X		X	X		
4	X									
5	X		X					X		
6	X			X				X		
7		X		X				X		
8										
9										
10	X			X			X			
11	X									
12	X			X				X		
13	X			X				X		
14	X			X						
15	X									
16	X					X		X		
17	X		X							
18	X		X							
19	X									
20	X		X							
21	X		X							
22	X		X							
23	X		X							
24	X		X					X		
25	X		X							
	1	24	3	8	12	6	2	3	1	9

TABLE VI-e REQUIRED ACTIVITY

Case Number	Consequences			Consequences		Others
	Not Present	Present	Inferred	Presence Accepted	May induce pain, irritability & fretfulness	
1		X		X		
2	X					
3		X				X
4	X					
5	X					
6	X					
7				X		X
8			X	X		
9			X	X		
10	X					
11				X	X	
12				X	X	
13			X			
14				X	X	
15	X					
16	X					
17	X					
18				X		
19				X		
20				X		
21				X		X
22				X		
23	X					X
24				X		X
25				X		
	9	3	13	9	5	2

TABLE VI-f USE OF APPLIANCE

Case Number	Consequences			Consequences					Others		
	Not Present	Presence Inferred	Presence Accepted	Ex- penses Denied	Pain producing	Pro- ducing ability	Points up Dis- ability	Invites pity & humiliation		Self-con- sciousness & humiliation	Over- indul- gence by others
1											
2	x		x								
3		x							x		
4	x										
5	x										
6			x		x						
7	x										
8			x				x				
9	x										
10	x										
11			x					x			
12			x								challenge
13			x								
14	x										
15			x								
16	x										
17	x										
18			x								
19	x										
20	x										
21	x										
22											
23	x		x								
24	x										
25	x										

15 3 7 5 1 1 1 2 1

TABLE VII - MASTER TABLE OF FINDINGS

Case Number	PUBLIC ATTITUDES				ETIOLOGY			SYMPTOMATOLOGY						
	Curiosity	Sympathy	Lack of Interest in Disease	Expectations too High	Hereditary Tendency	Neglect in Care	Unknown	Chronicity	Unpredictability	Progressive Severity	Deformity	Persistent Pain	Lack of Mobility	Low Activity
1	X		X		X		X	X		X	X	X	X	
2					X	X	X	X	X	X	X	X	X	
3	X	X				X	X	X	X	X	X	X	X	X
4					X		X	X	X	X	X	X	X	X
5					X		X	X	X	X	X	X	X	
6	X	X		X	X		X	X	X	X	X	X	X	X
7					X		X	X	X	X	X	X	X	X
8					X		X	X	X	X	X	X	X	X
9	X		X				X	X	X	X	X	X	X	X
10	X		X		X	X		X	X	X	X	X	X	
11							X	X	X	X	X	X	X	X
12	X	X			X	X	X	X	X	X	X	X	X	X
13					X	X	X	X	X	X	X	X	X	X
14	X				X	X	X	X	X	X	X	X	X	
15					X		X	X	X	X	X	X	X	X
16	X					X	X	X	X	X	X	X	X	X
17	X					X		X	X	X	X	X	X	
18	X					X		X	X	X	X	X	X	
19	X	X				X	X	X	X	X	X	X	X	X
20	X			X		X			X	X		X	X	X
21	X			X			X		X	X	X	X	X	X
22	X				X	X	X	X	X	X	X	X	X	X
23	X				X	X		X	X	X	X	X	X	X
24	X			X		X	X	X	X	X	X	X	X	X
25	X	X			X		X	X	X	X	X	X	X	X
17	3	9	3	4	15	13	20	21	20	25	19	23	25	17



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