McGILL UNIVERSITY

ADAPTIVE PROCESSES IN FAMILIES OF RHEUMATOID ARTHRITIS PATIENTS

A Study of Eighty Families of Rheumatoid Arthritis

Patients from three Montreal Hospitals, 1952

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PREFACE

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CHAPTER I

INTRODUCTION

This is a study of the adaptive processes in the families of eighty rheumatoid arthritis patients. It will deal with adaptations in the structure, function and emotional patterns of the families in response to the impact of the illness of one of the members. This is one section of a pilot study, undertaken to secure experience prior to larger studies and to gain information as to the ways in which the possible multiple stresses bring about rheumatoid arthritis, and of how these tensions affect the social field prior to and following this illness.

The entire project was undertaken by four social work students under the direction of two psychiatrists. The other three sections of the pilot study will deal with the parent families from which the patients came, some aspects of the personality structure of the patients, and various aspects of the patients' illness. Each of the four social workers taking part in the study interviewed twenty patients with diagnoses of rheumatoid arthritis, according to a plan structured in co-operation with the psychiatrists. The material from all eighty interviews was shared among the four participants, with each

participant dealing with a separate aspect of the material.

Background For Study

Study of Rheumatoid Arthritis.-

The suggestion has been put forward that various stresses in the medical, psychological and social fields may bring about a predisposition to certain diseases, and may also precipitate them. Rheumatoid arthritis is said to be one of these diseases. The formulation is inherent in the whole concept of psychosomatic medicine, which has been described in essence as being, "the systematized knowledge of how to study bodily processes which are fused and amalgamated with emotional processes of the past and present".[1] The present day interpretation of illness, according to Margolis, emerges as a result of exploration of both physical and environmental factors, and as a realization that the symptoms presented are in reality an expression of the interaction of both functional and organic factors, with the somatic component predominating in one case and the psychic in another. He sums this up in the statement, "....either organic drives or conflicting drives may initiate stress, not as isolated phenomena, but as closely and inseparably linked factors".[2]

Several studies have been made in order to explore the psychodynamic background of rheumatoid arthritis. The most detailed

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[1] Felix Deutsch, "The Use of the Psychosomatic Concept in Medicine", reprinted from the Bulletin of the Johns Hopkins Hospital, Vol. LXXX, No. 1 (Jan., 1947), p. 71.

[2] H. M. Margolis, "The Psychosomatic Approach to Medical Diagnosis and Treatment", Journal of Social Casework, Vol. 28, No. 8 (Dec., 1946), p. 292.

work was done by Johnson, Shapiro and Alexander.[1] This presented psychodynamic findings in the cases of thirty-three rheumatoid arthritis patients, twenty-nine of whom were female. The theoretical conclusions of the study indicated that the general psychodynamic background of these patients was a chronic, inhibited, hostile aggressive state as a reaction to the earliest masochistic dependency on the mother that is carried over to the father and to all human relationships, including the sexual. They concluded that when the discharge of hostility through the characteristic masculine competition, physical activities and serving and dominating the family, was interrupted, increased muscle tonus in some way precipitated the illness. They felt, however, that since these factors were also commonly found in patients not suffering from arthritis, additional etiological factors would have to be postulated. They considered that the nature of these factors was probably somatic; inherited, traumatic or infectious. Their main conclusion was that recrudescence of the psychological conflict situation was largely responsible for relapses, and improvement of the psychological situation for remissions.

Cobb, Bauer and Whiting made a study of fifty rheumatoid arthritis patients by means of evolving life charts to show the chronological relationships between various events in the lives of the patients and their illness. Their conclusions were that "Environmental stress, especially poverty, grief and family worry, seem to bear more than a chance relationship to the onset and exacerbation

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[1] Adelaide Johnson et al, "Preliminary Report on a Psychosomatic Study of Rheumatoid Arthritis", Psychosomatic Medicine, Vol. 9, No. 5 (Sept. - Oct., 1947), p. 295.

of rheumatoid arthritis. The relative importance of these factors can be estimated only by a much more detailed psychiatric study on a large number of patients".[1]

Several others have made valuable contributions to the understanding of the psychic component in this disease. McGregor[2] concluded that in certain cases of rheumatism with structural changes, psychological factors were found with great frequency and appeared to be closely related to the onset and exacerbations of the disease. Ripley and others[3] felt that the significance of emotional stress in its method of action in regard to rheumatoid arthritis remained unsettled but that the field was worthy of further investigation. Thomas[4] found that the rheumatoid arthritis patients he had investigated had, as a general rule, been neurotic for years, and that they tended to develop the disease in the midst of severe conflict. He also found that their sexual adjustment was usually inadequate. Booth[5] considered that these patients derived their libidinous satisfactions on a physical level, and that the illness began in predisposed people

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1 Stanley Cobb et al, "Environmental Factors in Rheumatoid Arthritis - A Study of the Relationships Between Onset and Exacerbation of Arthritis and the Emotional or Environmental Factors", Journal of the American Medical Association, Vol. 113, No. 8 (1939), p. 670.

2 H. A. McGregor, "The Psychological Factors in Rheumatic Diseases", The Practitioner, Vol. 143, No. 858, p. 627.

3 Ripley et al, "Personality Factors in Patients with Muscular Disability", American Journal of Psychiatry, Vol. 99, No. 3 (May, 1943), p. 781.

4 Giles W. Thomas, "Psychic Factors in Rheumatoid Arthritis", American Journal of Psychiatry, Vol. 93, No. 1 (Nov., 1936), p. 693.

5 Gotthard C. Booth, "Psychological Factors in Rheumatism", Journal of Nervous and Mental Diseases, Vol. 85, No. 6 (June, 1937), p. 637.

when they could no longer preserve an equilibrium between their vitality and the demand of their environment. Nissen and Spencer[1] pointed out that rheumatoid arthritis patients escape from emotional conflicts through physical or somatic function rather than through fantasy, as schizophrenic patients do. They found the absence of rheumatoid arthritis among psychotic patients significant in this regard. Smith[2] demonstrated that physical and emotional trauma occurred in great frequency in one hundred and two cases of rheumatoid arthritis studied. Halliday[3] found that rheumatoid arthritis patients tended to show marked restriction of emotional expression and that they were apt to show strong elements of self-sacrifice to the point of accepting and undertaking tasks beyond all reason. He found compulsive feelings in regard to duty, and obsessional trends. These characteristics were considered to have antedated the actual onset of the disease.

Weiss and English have summed up the most widely accepted viewpoint when they say,

> We believe that there are within the individual, certain emotional factors that may express themselves through tensions and spasms of the voluntary muscular system and thus influence the working of the joints. In other words: if there are numerous interacting factors such as predisposition,

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1 A. Nissen and K. A. Spencer, "The Psychogenic Problems in Chronic Rheumatoid Arthritis", New England Journal of Medicine, Vol. 214, No. 12 (March 19,1936), p. 576.

2 Millard Smith, "A Study of 102 Cases of Atrophic Arthritis", New England Journal of Medicine, Vol. 206, No. 5 (Feb. 4, 1932), p. 211.

3 James M. Halliday, "Psychological Aspects of Rheumatoid Arthritis", Proceedings of the Royal Society of Medicine, Vol. 35, (Feb. 1, 1942), p. 455.

> fatigue (which may also be psychologically determined), specific infection, and perhaps even other factors, then arthritis may develop.[1]

This latter represents the viewpoint from which this study was undertaken, in the emphasis on a multi-factorial approach.

Most rheumatologists at the present time agree on a few fundamental principles of treatment. An adequate, basic program of management is considered to be of importance. This includes a careful balance of rest and activity, diet and normal management, correction of anaemia, cautious removal of foci of infection, exercises to improve muscle tone, and prevention and correction of joint deformities. Many of the later medical works are beginning to mention "psychological adjustment" as part of the basic program. Among specific treatments, cortisone, ACTH, and, recently, Compound F appear to be the most powerful anti-rheumatic treatments used at the present time, and most medical authorities feel that these hormones offer hope for a specific remedy in the future. However, at the present time, they have the obvious disadvantage of being very expensive; in addition, they cannot restore destroyed joints and must be given continuously or intermittently to be effective.[2]

Comroe,[3] one of the foremost writers on rheumatology,

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[1] Edward Weiss and O. S. English, Psychosomatic Medicine, (Philadelphia and London, 1949), p. 740.

[2] W. P. Holbrook and D. F. Hill, Manual of Rheumatic Disease, (Chicago, 1950),pp. 37 - 44.

[3] Bernard Comroe, Arthritis and Allied Conditions, (Chicago, 1944), p. 35.

considers that arthritis should be put at the head of all other chronic diseases as of pre-eminent medical, economic and social importance. Of the various types of arthritis, rheumatoid arthritis is considered to be the greatest crippler, and has special significance as its greatest incidence is in the most productive years of life. It is a constitutional disease, with such symptoms as fatigue, loss of appetite, low grade fever and anaemia. It manifests itself in a chronic, progressive crippling of the joints which may progress to the stage of chronic invalidism. These patients tend to have cycles of being better and worse. Complete, spontaneous remissions are considered extremely rare. There is no known single cause and no specific cure.[1] In their anxiety to find a cure, patients are often victimized by medical "quacks" and besieged by conflicting advice as to "go to bed and rest" or "keep going for fear of their joints becoming permanently stiffened". Modern medical treatment provides a mixture of both rest and exercise with other specific therapeutic measures.

Study of Adaptive Processes.-

This specific section had as background, the concept of a family, as well as an individual, having an equilibrium or balance. Following Richardson,[2] the family is considered as being in a state of dynamic equilibrium, like that of the human body, which by the homeostasus of body temperature, strives to maintain a normal temperature through flushing and perspiring to get rid of excess heat, and by

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[1] Holbrook and Hill, op. cit., pp. 15-16.

[2] Henry B. Richardson, Patients Have Families, (New York, 1945), p. 76.

blanching and shivering to retain heat or increase the supply. These outward signs are symptomatic of the body's attempt to regain equilibrium. In the same way, the family as a unit is considered to be constantly reacting to stimuli in various ways, desirable or undesirable, to maintain a state of balance. The state of balance that is reached may be more or less efficient and more or less permanent. Whatever the nature of the equilibrium, it is the only possible one for this unit under the existing circumstances. What happens to any one member of the unit may exert an influence over the other members, so that an adaptation is made and the balance is changed. The equilibrium that is reached may be on a less effective level, as in the case of one of the members developing a psychoneurotic condition. As the psychiatrist exerts care not to upset the existing adjustment within the individual, however ineffective it appears, without making sure that a better one can be achieved under the existing circumstances, so the social agencies dealing with family units have learned to exert the same care in the field of social relations.

In this section, the illness of the patient is considered to be the stress factor, to which the individuals in the family group, and the group as a unit, are reacting. The family acts as a stimulus to the patient; the patient responds partly through his illness, and the patient and his illness in turn again act as a stimulus on the family, in a kind of chain reaction. Some of these reactive processes in the families are examined in this section of the study.

CHAPTER II

THE STUDY

This chapter contains a discussion of the purpose, scope and methods of that part of the pilot study to which the student social workers contributed. Evaluative comments concerning methodology, as it applies to the pilot study, and to this specific section, will be made in a separate chapter.

Purpose

The statement of the psychiatrist-director of the comprehensive project was as follows,

> With the aim of determining adverse environmental factors responsible for mental ill-health and of eliminating them at the source, it is suggested that a team of workers should correlate the incidence of mental ill-health with socio-psychological factors in two contrasting small communities, one agricultural and one industrial.

This comprehensive study was to be preceded by a series of pilot studies. The present study is a small section of the first of these. The pilot studies of the first part of the comprehensive study were to investigate specific disease entities considered to be

of psychosomatic significance, and were to be capable of later integration, in order to give as complete a picture as possible of the way in which sick individuals and the community reacted with each other.

Rheumatoid arthritis was chosen for the topic of the first pilot study by the psychiatrist in charge of the project, as it is a fairly common disease, and is one which is recognized as being psychosomatic. This was formulated with two main purposes in view. (1) Because little has been written concerning the methodology of other studies,and because it was felt that a consideration and examination of the efficiency of actual methods and techniques employed would be of benefit to future research, this was advanced as one of the main functions of this study. (2) The second major function was formulated by the psychiatrist as a study of the medical, psychological and social factors which may predispose the patient to rheumatoid arthritis, of how multiple stresses bring about rheumatoid arthritis and of how tensions affect the social field prior to and following the illness. The pilot study was to be undertaken by a team, including a physician, a psychiatrist, a psychologist, and four student social workers. The student social workers were to attempt to study the dynamics of interpersonal relationships of the patients and compare these with the siblings acting as controls, and to study how the illness affected the patients and those around them, with special reference to the way in which the community adapted itself to illness.

This specific section of the study, as part of the pilot study, aimed to study and examine the efficiency of the method as applied to the section, and secondly to attempt to examine the adaptations of the patients'immediate families to the illness, with the

concept of the illness acting on the dynamic equilibrium of the families.

Scope And Limitations

The discussion in this section will be confined to the pilot study, the part played in it by the student social workers and the scope and limitations of this specific section.

For the purposes of the investigation, a purely arbitrary unit of the total field was chosen for the initial study. This social unit comprised the family formed by the parents of the patient and was to include all the secondary families subsequently formed by the patient and his siblings. The study was to be carried out by a physician, a psychiatrist, a psychologist and four student social workers. The physician was to be responsible for studying the personality of the patient from the standpoint of internal medicine; the psychiatrist was to study the patient from the standpoint of ego structure, emotional equilibrium and character formation; the psychologist from the standpoint of intellectual performance and fixed character traits as revealed by various test procedures; while the social workers were to study the dynamics of the interpersonal relationships of the patient, both with regard to his immediate family, occupation, recreation and community activities and to compare these relationships with those of the siblings as controls. An attempt was to be made to assess the effect of his illness on these relationships. At the same time, the reaction of community was to be studied and an assessment made as to whether this helped or hindered the patient's recovery.

The final division of the student social workers' part of the study results from an arbitary division of material in order for

each of the social workers to be able to complete a separate and individual study. The data were dividied into four sections, one for each of the four student social workers. One section deals with the parent families from which the patients came; one section deals with the character formation of the patients; one section deals with the patients and their illness; and the present section deals with the reactions and adaptations of the families of the patients to the illness.

In this particular section, the adaptive processes in the families are dealt with from three aspects; the structure of the families, including dwelling and human structure; the function of the families, including financial adaptations and changes in division of labor; and adaptations in emotional patterns.

An attempt was to be made to investigate one hundred cases of rheumatoid arthritis chosen as random samples from the patients being treated for this disease from the Out-Patients' Department of the Royal Victoria Hospital. It was necessary for the patients to be able to speak English, as none of the interviewers spoke French. In the absence of evidence that most rheumatoid arthritis patients come from the lower economic strata, the origin of the sample represented a definite limitation. Further limitations were enforced because of the difficulty of finding patients. The number had to be reduced to eighty, and it was not possible to restrict these to current patients. Some of the patients had not been attending clinic for as long as three years. Some cases could not be used because of lack of transportation and because of time limits in relation to the geographical sections in which the patients lived. Additional cases had to be obtained from St. Mary's Hospital and Montreal General Hospital.

The sample of eighty, then, represented a cross-section of English-speaking patients who had been diagnosed by the rheumatologists as having rheumatoid arthritis, had attended Out Patients' Clinics at some time, and who lived in accessible sections of the city.

The original formulation of the scope of the study had to be modified as the study progressed, first in the size and sources of the sample, and second in the data to be collected. Because of the time limitations and the difficulty in obtaining this material in many cases, the study of the secondary families formed by the siblings and the use of siblings as controls could not be carried out. Because the individual studies are segmental, severe limitations have resulted both in regard to purpose and scope. Because of this segmentation, it is not possible to present joint conclusions as a means of validating the basic hypothesis of the whole study. The individual sections had to be arranged in this way so that each participant would be dealing with a topic that could be handled as a unity. In splitting the material in this way, there has been inevitable over-lapping and inevitable gaps in the total picture. Each separate study of the eighty cases studied by the student social workers forms a complete unit within itself. An integration of the social workers' data with the material from the psychiatrists' reports has not been possible. These separate studies have been completed from the material gathered by the student social workers themselves, using their own professional skills in interviewing but with orientation and direction from the psychiatrists. A fifth integrating study would have to be made in order to make overall conclusions.

There have been further limitations in that it has not been

possible to use psychological or psychiatric findings. Because of the administrative difficulties in regard to case finding interviewing time was limited, and it was not possible for more than a few relatives of patients to be seen. This meant that the material was more superficial in nature and less complete than was intended in the original formulation. It was not possible to obtain more than broad generalizations in many cases. This has meant a severe limitation in scope.

Because the material was all collected through interviews and was the testimony of the patients as interpreted and recorded by the interviewers, personal bias and subjectivity must be considered as a possible limitation. This type of limitation, however, is felt to be inescapable in a dynamically oriented study of people. In this project this tendency has been minimized to some extent by the fact that materials used in each section were collected by four separate interviewers.

The scope of the present section is limited, then, to an observation and description of some of the various adaptive processes observed in the families of the eighty patients studied. As this material was not specifically sought in the interviews, the findings are not conclusive, but merely tentative. The conclusions will be limited to this particular segment of the study.

Types of Research Involved

Library Resources.-

The use of library resources was one of the methods used to enable the social worker students to become orientated to the illness. It was important for the participants to obtain a fairly thorough general background concerning the psychosomatic approach to an illness,

upon which concept the study was constructed. It was necessary to acquire a more specific background concerning rheumatoid arthritis, as one of those illnesses in which the psychogenic element was recognized as being important. In order for the study to have meaning for the participants, it was of value to them to have an understanding and knowledge of the physical effects of the disease, what medical treatment facilities were available, and what the general course of the illness was like. It was necessary to be conversant with the formulations from the field of medicine regarding the etiology, and the social and emotional and environmental components of what is considered the usual personality structure of those individuals who have this illness. In order to obtain this kind of background, it was helpful for the participants to familiarize themselves with other studies which had been done in this field, as well as more general writings which summed up theories from these studies, together with material concerning the physical effects, treatment possibilities, etc.

In this specific section, an orientation to theories regarding the family as a unit, with special reference to the effects of chronic illness upon it, was necessary. In this connection, it was of interest and value to look into a more sociological approach, as well as the more familiar medical and family casework viewpoint.

Conferences.-

Conferences with the two psychiatrists, the advisor, and the four social workers, were arranged as frequently as possible. These conferences were to provide instruction, interpretation and further orientation to the topic. Common problems of management and planning were discussed, and a few sample cases were presented for joint

consideration. These conferences also provided a measure of integration.

Original Investigation.-

Original investigation was undertaken by the following methods:

Medical charts were scanned in each case, in order to obtain identifying information, and in order to check to see that diagnoses had been made of rheumatoid arthritis or rheumatoid spondylitis, which is considered as a variant of rheumatoid arthritis.

In a few cases, social service files were consulted after the patient had been interviewed. This was done in cases where the hospital Social Service department or an outside agency had had a close contact with the patient and his family over a period of years. This was of value in these cases, in providing additional information concerning the relationship of the patient to the agency. Whenever additional information was obtained in this way, the source of the information was indicated. Interviews were undertaken with the patients in their homes, in the clinic and with relatives whenever possible. Those interviews were structured under the direction of the psychiatrist. This plan is included in the Appendix.[1] The interviews generally required about two and a half hours. In some cases the patients were seen in two interviews. In others, a relative was seen in addition to the patient.

Steps

Orientation.-

Orientation to the illness and to the research patterns was

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[1] Appendix B, p. 139.

the first step, but it was also a continuing process throughout the project. Considerable preliminary reading was done before the interviewing began, and some orientation was given through conferences with psychiatrists. These conferences and reading continued throughout the project.

Development of Interviewing Schedule.-

The next step was the development of a schedule for interviews. The preliminary plan was for the interviews to be structured with a delineation of the main areas to be covered but without the use of a definite schedule, in order that each interviewer would be free to use his own interviewing techniques. The material was to be full enough so that specific questions could be answered from it. The main areas to be covered were seen by the psychiatrists as the patterns of the parent family, with special reference to disruptive and cohesive tendencies, and the patterns in the family in which the patient was living at the time of the study, in regard to structure of the families, income and emotional patterns. It was felt that detailed studies of the inter-personal, inter-familial and extra-familial activities of these families would be important. At this point there was no delineation or structuring of how this material might be handled in relation to the whole project. The psychiatrist saw the plan for the material as being arranged from these viewpoints:- What actually did take place? What did the members concerned feel about this? What did an outside observer (the interviewer) feel about it? How did the interviewer sum up the relationships between the reality situation and the informer's attitude to it? Two or three test interviews were to be arranged, at which time the material from the interviews was to be evaluated, and

modification could be made in the plans for further interviews on the basis of this material.

As it was felt that there was danger of too much subjectivity in this method, an attempt was then made to construct a specific questionnaire, by which each informant would receive a similar stimulus, and the answers would be specific and statistically comparable one to the other. Because this method appeared to be too limiting, and since it did not seem possible to draw out the necessary material by using it alone, the final schedule was evolved in co-operation with the psychiatrist as an attempt to combine both methods.

There were still problems after this plan was evolved, as it was found that because of the complicated structure of some of the families, some of the material, which seemed significant, could not be fitted into this plan. It was decided then that all significant material should be included under separate headings, even when it did not fit into the schedule as structured.

Management Phases.-

The next step was the management phases. According to the projected plan, one hundred patients were to be available from the Royal Victoria Hospital Out-Patients' Arthritis Clinic. These patients were to be English-speaking, and were to be current cases, which had been diagnosed by the rheumatologist as having rheumatoid arthritis. The patients were to be prepared by the rheumatologist or the nurse, so that they were made aware of the research, and of the purpose of the interviews in relation to it. It was anticipated that with this kind of careful preparation the majority of the patients would be willing to participate and the sample would retain as much of a random

quality as the other limitations would allow. These arrangements had been made with the rheumatologist by the psychiatrist in charge of the project.

The interviewers were to obtain from the nurse in charge the names of the patients who fitted the qualifications, and who had indicated their willingness to participate. The next step was to consult the medical charts for such identifying information as addresses and telephone numbers. The interviewers were then to make their own arrangements with the patients for time and place of interviews. The interviewers were to make arrangements also for appointments for the patients with the psychiatrist. The content of the interviews was to be discussed in frequent conferences with the psychiatrists in charge.

As the project got under way, there were many problems in management that had not been anticipated. As most of the patients attended the clinic on an irregular basis, it was not possible for them to be prepared before the student social workers' interviews, except in a very few cases. It became necessary for the interviewers to take on this function. There was no way in which the interviewers could ascertain whether or not this preparation had been done except through direct contact with the patients. Because of the administrative arrangement at the clinic, it also became necessary for the interviewers to screen the cases through the medical charts or through direct contact as the clinic office itself had no information concerning the patients except for the names and diagnoses. It also became necessary for the interviewers to check with each other, as several duplications were made. Because of the seemingly limited supply of English-speaking patients, it was decided that it was not possible to

limit the sample to current cases. This meant delays because many former patients had died, or had changed their addresses. This also meant that in the cases of the patients who had not been attending the clinic for several years, the medical charts were often difficult to obtain, because of the nature of the filing system. There was no indication on the medical charts of whether or not the patients could speak English. This could be determined only by means of attempting to get in contact with them.

As the study progressed, the problem of case-finding became very acute. This constituted a serious problem, as the time of the interviewers was limited. Cases could not be obtained in large enough numbers so that they could be checked for duplications and screened for suitability and availability, in order to make appointments in advance, so that the project could be kept going without delays. It was often difficult to arrange interviews at times other than afternoons when the families of the patients were most likely to be away. This made for difficulties as the interviewers had only one or two free afternoons in each week. Much time was spent in making visits to arrange appointments in the cases of patients who had no telephones. There was also some difficulty in arranging for interviewing space for those patients who could not be seen in their own homes. As the delays increased and the time pressure became more acute, it became necessary to discard some cases where residences were too far away. It also became necessary to dispense with second interviews, which would have been desirable in many cases; likewise interviews with relatives were omitted from the study. None of these administrative and management difficulties had been anticipated at the outset, and each one had to be

handled in the best way possible, as it came up.

In regard to the supply of cases, when it was definitely established that no more cases were available from the Royal Victoria Hospital, arrangements were made with the Arthritis Clinics at St. Mary's Hospital and the Montreal General Hospital for cases to be supplied. There was a further time-lag while these arrangements were being made. It was finally necessary to reduce the sample to eighty rather than a hundred cases.

In the cases of patients who had no telephones, arrangements were made with the secretary of the psychiatrist in charge to write letters informing the patients of the study and arranging appointments. This was only partially successful as patients frequently neglected to answer the letters if the time suggested was not convenient. In addition to this, many letters were not returned when the patients had moved. This meant that some fruitless visits were still made. Every effort was made to arrange as many interviews as possible on evenings and week-ends, in order to leave afternoons free for those patients who could not be seen at other times.

Towards the end of the last target date set for completion of the interviews, invaluable assistance was given by the psychiatrist's secretary who screened cases and arranged appointments on the basis of a detailed time schedule prepared by the social work students.

Interviewing.-

The most important and most time-consuming step was the actual gathering of material by means of interviewing. In the experience of this writer, the patients were very co-operative on the whole in supplying information about themselves and their families. None of them

refused to participate, and a large proportion said that because they had been helped themselves they were willing to participate in a research project. The response during the interview seemed at least partly dependent on the amount and quality of the preparation they had received. The response was better from the small number of patients who had been prepared from the clinic in advance. It seemed an important part of the interpretation to set the limits of the interviews very definitely, so that a casework relationship was not being built up, which might have conflicted or interfered with their relationships with hospital Social Service departments or outside Social Agencies.

These patients discussed the details of their illness very freely. It was much more difficult to obtain valid or useful material concerning parent family groups, and emotional relationships within the families. This was partly due to the fact that some of the patients were older people who had come from large families, and had difficulty in recalling some of the material. Some of the patients also tended to present what appeared to them as a socially acceptable picture in this area. It was not possible, frequently, to obtain a rounded picture of the relationships within the family group in which the patients were living at the time of the study. This was sometimes more difficult when it was not possible to see the patients without a relative being present. It was also more difficult for the patients to see how this could be of assistance in the research, and in addition they lacked the incentive they would have had in a casework interview where they were seeing these relationships as part of their problem. In the case where it was possible to see a relative in addition to the patient, more information could be obtained in this

area. It would appear, however, that much more intensive interviews would be necessary in order to obtain really useful and valid information in these areas.

Because of the observation that it was more difficult to obtain information in some areas than in others, the interviews were arranged so that the material on the illness was obtained first. The interviews seemed more effective when handled in this way. In most cases, the interviewers then went on to a discussion of the patterns of the family in which the patient was living at the time of the study, and concluded with the more difficult material on the parent family.

Interviewers attempted to ask leading, rather than direct, questions whenever possible, in order that the patients might feel free to express themselves with spontaneity. As much of the material as possible was recorded verbatim.

As it was not clear in what manner the recorded matter resulting from the interviews was to be used, there was some difficulty in deciding upon the form in which the material should be recorded in order that it should have maximum meaning and usefulness to all the participants. It was finally decided that in order to preserve clarity, it should be presented under headings and numbered according to the form suggested by the psychiatrist, but preserving the verbatim nature as far as possible, and including summaries and comments by the interviewers. When one case was presented in a form which seemed acceptable, mimeographed outlines were prepared for use during the interviews in order to facilitate the recording. This outline was prepared to follow what had appeared to be the most effective order of

interviewing.

Analysis.-

When the interviewing was completed, the participants began detailed analyses of the material obtained. The eighty recorded cases were shared among the four participants, so that every individual had a copy of each case. Since the analyses were to be sectional, the first plan had been to divide the material on each family into the four sections, so that each participant would have his own section from all of the cases. This proved to be impracticable, however, as it was felt that it was necessary for each individual to be able to see his section in relation to the whole case, so that the present plan was decided upon. This meant that each participant provided four copies of each of his twenty cases, one for his own use, and one for each of the other participants.

The original plan had been for the analyses to be done in terms of the whole project. This would have meant a common introduction, four separate chapters on individual aspects of all the cases, and joint conclusions. Because it was necessary for each participant to prepare a separate study, the analyses have been done on an individual basis, with little integration possible.

In this section, the material was analyzed through the use of key cards for each of the three major sections. This analysis was made more difficult because these three quarters of the material was unfamiliar, the interviews had not been structured to bring this material out specifically, and when material was lacking it was often not possible to distinguish whether it was unknown to the patient or the interviewer. In addition to this, the recording was not always done in

a uniform way, so that additional time had to be spent in searching for material in some cases.

Presentation.-

In this specific study, introductory material has been presented in the first two chapters. The first chapter contained general background material as an orientation to the topic. The present chapter has dealt with the purpose, scope and limitations and methods of the study.

The body of this study contains three chapters of findings from the analysis of the material. As the interviews were not specifically structured to bring out this material, no conclusive findings have been possible. All conclusions, for this reason, must be regarded as tentative.

Chapter III deals with adaptive processes within the structure of the families, and has been presented from two aspects, that of the family dwellings and of the human structure of the families. Chapter IV discusses the reactive processes as shown in financial adaptations and changes in division of labor due to the illness. Chapter V deals with adaptations within the dominance patterns of the families insofar as this was possible.

The general conclusions from this study are presented in Chapter VI. Chapter VII makes some evaluative comments on the methodology of the study. This is designed to be of assistance to future group research.

The Appendix contains a sample case, a study of some characteristics of the sample, the activities of the interviewer, and

the interviewing schedule, together with the charts and key cards used in abstracting information from the cases.

CHAPTER III

ADAPTIVE PROCESSES IN THE STRUCTURE OF THE FAMILIES

This chapter deals with adaptive and reactive processes within the structure of the families of the eighty rheumatoid arthritis patients studied, as direct results of the impact of the illness on them. The structure of the families has been considered first from the aspect of the dwellings in which they were living, and second from the aspect of the actual human structure of the families.

Adaptations In Dwelling

Since the sex incidence of rheumatoid arthritis is considered as being 3 women to 1 man, and since 80 per cent of the cases occur between the ages of 25 and 50, with the peak at 35 to 40,[1] it can be assumed that the greatest proportion of patients are housewives. The sex and age incidence of patients considered in this study follows this general trend. For this reason, the dwelling in which the

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[1] Primer on the Rheumatic Diseases, prepared by a Committee of the American Rheumatism Society, (Chicago, 1949), p. 24.

[2] Appendix A, p. 135.

patient is living and working would appear to have particular importance and significance in the management of the illness, especially in regard to the avoidance of strain on the affected joints.

At the time of the study, 4 patients of the 80 were in hospitals. Of the 70 remaining, 38 patients, exactly half of the group, expressed dissatisfaction with the dwellings in which they were living. A large proportion of these patients mentioned specific difficulties in their homes in relation to their various disabilities. Table I lists specific complaints mentioned.

TABLE I

Complaints Regarding Dwellings In Relation To Illness of 80 English-speaking Rheumatoid Arthritis Patients Who Had Attended Royal Victoria Hospital, Montreal General Hospital, or St. Mary's Hospital Out-Patients' Arthritis Clinics At Some Time During the Course Of Their Illness(a)

Complaint	Number
Total Complaints	46
Dwelling cold, damp or both	21
Difficulties in structure(b)	18
Shopping centre too far away	2
No hot water	3
Other difficulties	2

(a) All Tables hereafter refer to this sample.
(b) Complaints of stairways being difficult to manage and of dwellings being too large to manage without undue strain were the most frequent in this group.

A large proportion of these patients mentioned difficulties in regard to their disabilities as secondary to other considerations. The other complaints appeared to represent a cross-section of the common dissatisfactions of city dwellers in low income groups, ranging from a desire to live outside the city, through complaints of being too crowded and finding their flats dark and gloomy, to wanting other types of accommodation which could not be found or financed.

Dwelling, cold, damp or both.-

Coldness, dampness and chilling have long been regarded among both patients and physicians as aggravating rheumatic diseases. More than one quarter of the patients studied were living in residences which they considered cold or damp or both, at the time of study. Table II includes the group of patients living in residences considered by them to be adequately heated with those living in residences considered cold or damp in terms of their ability to function at the time of study.

TABLE II

Comparison of Degree of Disability of Patients Living in Adequately Heated Residences with Those Living in Cold or Damp Residences

Patients' degree of disability(a)	Total	Residences	
		Cold, damp, or both	Adequately heated
Total number of patients	76(b)	21	55
Severely disabled	15	10	5
Moderately disabled	32	8	24
Minimal disability	29	3	26

(a) These classifications are arbitrary, and are based upon ability to function.

(b) The 4 patients in hospital at time of study were not included.

While the sample is small, and the subjective judgment of the patients was accepted as the only means of determining this factor in the homes, this comparison is of interest. It seems noteworthy that nearly one half of the patients living in residences that were cold or damp were severely disabled at the time of study, while only a fifth of the patients who were living in adequately heated dwellings were disabled to this extent. In the same way, only one seventh of the patients living in cold or damp residences had slight disabilities, while half of the other group were in this category.

Sixteen of the patients of the total group studied reported that they had lived in residences that were cold, damp or both at the time their illness began. A comparison of the degrees of disability of these patients yields the same type of proportion, with a preponderance of patients in the more seriously disabled group.[1] In this connection, it is of interest to note that Selyé found in his experiments with hormonal production of arthritis in rats that exposure to cold appeared to facilitate production of the disease.[2]

There is not one case among the twenty-one in which a family was reported to have moved because of this factor in regard to a patient's illness. In one case a heater was installed.[3] This is the only mention of any attempt at adaptation.

Some of the patients whose illness was advanced felt that

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[1] Of the 16, 9 are now confined to house, 4 able to work part-time, and 3 able to work full time.

[2] Hans Selyé, "Hormonal Production of Arthritis", Journal of American Medical Association, Vol. 124, No. 4 (Jan. 22, 1944), p. 201.

[3] Case No. 67.

coldness and dampness was a factor in this illness, but showed an attitude of stoical resignation to it. The following cases illustrate this.

> One 65-year-old man[1] was completely incapacitated and had not been able to work for 12 years. He had been living in the same residence for 18 years. He said, "We moved in here because it was cheap. During the first winter there was no heat at all - it was unfinished. The snow came in the cracks in the walls. It's been fixed up now, but it's never been warm enough - it's very damp - the cellar's full of water when it rains. That's why I'm sick like this now. What can you do when you're poor? It's too late for me now anyway".

> Another 64-year-old man[2] was completely incapacitated and had not worked for 6 years. The family had lived in the same flat for 12 years. He said, "Everyone says we should move. This house is bad for me - we've never been able to heat it very well in winter, and it's so damp that everything gets mouldy if it's shut up for a few days even in the summer. But what can we do? We'd never find another place on the ground floor that we could pay for - there's nothing to do but stick it out and suffer".

Many of the patients who were not so seriously disabled showed little evidence of concern about this aspect of their dwellings in regard to their illness.

> One 56-year-old woman[3] had had fairly severe pain and swelling in both her arms for a year. She described her home as a "barracks"

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1 Case No. 74.

2 Case No. 71.

3 Case No. 6.

> because it was so cold, but wanted to move not because of this factor but because, she said, "People in this district aren't worth saying 'hello' to".

Difficulties in Structure of Dwellings.-

Rheumatologists consider that strain on affected joints may cause "risk of progressive and complete destruction".[1] Some dwellings, because of structural aspects, make for considerable strain on affected joints, in such aspects as having long stairways, or being too large for a housewife to manage without strain.

Eight of the patients studied complained of stairs being long or difficult to manage. In four additional cases, this was noted as a difficulty by the interviewer. Three of these patients at some period during the time they had been living in the same residence had been so disabled as not to be able to leave the house without assistance. One woman[2] had so much difficulty in getting down the stairs in order to be able to get to the Arthritis Clinic once a week that her son had to support her, at the same time placing her feet on each step. Another elderly woman[3] could not get up or down her long outside stairway without the aid of the taxi-driver. The third woman[4] resolutely refused all offers of assistance, in spite of the fact that it took her as long as fifteen minutes to get up the stairs herself.

Four residences had steep inside flights of stairs. Three

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1 Holbrook and Hill, op. cit., p. 39.

2 Case No. 72.

3 Case No. 64.

4 Case No. 61.

of the patients living in these residences were housewives. Each of the three found that the stairs made it much more difficult for them to perform their household tasks without undue fatigue and strain. A typical comment was, "The stairs kill me - I'm exhausted at the end of the day, but I manage". One man,[1] living in a hostel, had considerable generalized pain and stiffness. That he had to climb two flights of stairs to get to the dormitories was mentioned as one of the lesser complaints.

Four housewives complained that because of their disabilities their dwellings were too large for them to look after.

> One woman[2] was so disabled during an acute phase of her illness that she was unable to do any ofher work for a period of months. As soon as she began to regain some movement, and the pain began to lessen, she began to attempt to do all the work in a large 5-room flat with long hallways. She drove herself from morning to night to accomplish this, and said that she often cried with the pain as she worked, and was completely exhausted at the end of each day.

> Another woman[3] had been badly crippled for seven years. She walked only with the greatest difficulty and her hands and wrists were very swollen. In spite of this, she was attempting to do all the work in a 5-room flat herself. In order to do this, she had to lie down about ten minutes out of every half hour.

Some of the dwellings had other particular structural

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[1] Case No. 56.

[2] Case No. 72.

[3] Case No. 61.

difficulties for these patients. One woman,[1] whose feet were painful, found that the uneveness and slope of her floor made it very hard for her to walk. Another woman,[2] who had continued to do most of her own work, was able to get around only by means of a chair, to which castors were affixed. She was not able to get out on her gallery on sunny days because the threshold was too high to allow the chair to run over it. In addition to this, the position and construction of her sink placed much strain on her arms when she was trying to work from her chair, as it was too high and the underside was closed in so that she had to reach up and forward.

None of these families has been reported to have made any serious attempts to find other accommodation or to have made modifications within the residences which were causing these difficulties to the patients.

Shopping Centres too far Away.-

Two housewives found difficulty in managing shopping because their dwellings were too far away from shopping centres. One woman,[3] whose feet were swollen and painful had to walk five blocks to the nearest store. Many of the patients had solved this difficulty by telephoning orders to the stores and having deliveries made.

No families had moved because of this difficulty.

No Hot Water.-

Three housewives had no hot water in their flats, and had to

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1 Case No. 70.

2 Case No. 46.

3 Case No. 20.

heat all water for washing, bathing, etc. In each case, this meant heavy lifting, and strain on affected joints of hands, wrists, elbows and shoulders. One woman,[1] whose wrists had been swollen and painful in varying degrees for the past five years, had four children to bathe.

None of the families had moved or planned to move because of this.

Other Difficulties.-

Some other difficulties were mentioned by patients. One woman[2] at one time had to hang all her washing outside, even in winter, for lack of facilities within the house. This appeared to cause further swelling and pain in her hands.

Another woman[3] had to spend most of the day, when her husband was at work, on the bed, as she could not raise herself from a chair without help. No one had made any attempt to provide any sort of simple device to give her leverage, such as a ring or rope to grasp.

Summary.-

Only the most minimal adaptations have been noted within the dwellings of these patients. In one case,[4] an additional heater was installed; in two cases,[5] inside clothes-lines were put up; in one case,[6] a hospital bed was purchased; and in one case, sleeping arrangements

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1 Case No. 77.

2 Case No. 63.

3 Case No. 66.

4 Case No. 67.

5 Cases Nos. 63 and 77.

6 Case No. 78.

were changed, so that the patient[1] was able to sleep on the second floor, which was considered warmer and drier. It is possible that other slight adaptations have been made, but it seems unlikely that there were any great number.

There is no instance recorded of any of these families moving to another dwelling because of the needs of the patient, or of any family considering such a move at this time. It seems significant that the patients themselves often mentioned their needs in relation to their illness as secondary considerations in their dissatisfactions with these dwellings.

Since these patients have all been attending Out-Patients Clinics, it may be assumed that as a general rule they fall into the lower economic brackets. For this reason, major adaptations in dwellings would be more difficult to manage than for those families who were not so economically limited. Because the local housing situation is particularly difficult and housing costs are high, this would appear to add to the difficulties in the situation. In addition to this, the fact that patients do not die of rheumatic arthritis as they do of some of the other chronic diseases, such as tuberculosis, and the fact that it is often considered as a kind of rheumatism that is too familiar to be frightening, may mean that there is less feeling of urgency about the need for adaptation because of it.

It would appear, however, that the personality structure and attitudes of the patients themselves, accounts for at least a proportion of the lack of adaptation in dwellings because of the illness. Many

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[1] Case No. 49.

of these patients appeared to have a strong desire towards independence, which included a determination to keep their troubles to themselves, and to keep going as long as possible. In some cases, there appeared to be an element of masochism, as in two of the cases previously cited. In one case,[1] the patient wept as she forced herself to do her housework in spite of considerable pain; in the other case,[2] the patient continued resolutely with her work, lying down frequently in order to be able to do it. The following case seems illustrative of such attitudes.

> Mrs. G.,[3] aged 43, lived in an over-crowded, poorly heated house, with an inside stairway. There were no shopping centres within a reasonable distance, and it took an hour or more for her to get into the clinic for treatment. Mrs. G. had been ill for nineteen years. The course of illness had been fluctuating, with some very acute phases. Her husband was working steadily, and in spite of fairly heavy medical expenses in the past there were no debts. Mrs. G.'s sisters were very anxious for this family to find other accommodation, as they felt the dwelling was having adverse effects on her, both physical and psychological. Mrs. G. however was adamant in her refusal to consider a move, and was strongly resentful of the suggestions of her sisters, saying, "Why can't they leave me alone? I'm perfectly satisfied, I get along all right. Everyone has always tried to run my life". One of the sisters said, "I can't understand her attitude, she fights to get better, but it's as if she wants to suffer, too".

Adaptations In Human Structure

Because there is no known specific cure for rheumatoid

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1 Supra, p. 33.

2 Supra, p. 33.

3 Case No. 63.

arthritis, it frequently becomes chronic and crippling. The patient's need for physical care or financial assistance may necessitate adaptations within the human structure of the family. The patient's need for care may necessitate his moving to another group or institution, or other members may move into the group to assist him. Housewives may no longer be able to look after their children, which may mean placement of the children away from home on a temporary or permanent basis. As in the case of all chronic and long term illnesses, there are severe emotional stresses for the patient and his family. This may be the cause of further adaptations in the human structure. The adaptations in themselves may cause a different type of stress, as the patient may feel his dependence more keenly and the displaced member who is helping may feel like a martyr.

Major Adaptations.-

Table III gives an indication of the major effects of the illness observed in the human structure of the eighty families studied. This picture may not be complete, as the capricious and episodic nature of the disease makes it difficult for some of the older patients to recall many of the adaptations made at different stages. The various effects and adaptations are discussed in the same order as given in the Table, as this makes for greater clarity. These effects are arranged in order of frequency rather than of their importance to the family group.

One of the common adaptations was for married children to live with the patients. Among the eight patients who had married children living with them, two were elderly men. In both cases, this

TABLE III

Major Effects of Illness on Human Structure in Relation to Sex of Patient and Degree of Disability at the Time of the Effect

Effects of illness on human structure of families	Total male and female patients	Male Patients				Female Patients			
		Total	Degree of disability at time of effect(a)			Total	Degree of disability at time of effect		
			Advanced	Moderately advanced	Minimal or arrested		Advanced	Moderately advanced	Minimal or arrested
Total number of families affected	22	4	4			18	7	11	
Adult children living with patients(b)	8	2	2			6	2	4	
Single unit families breaking up(c)	4					4		4	
Placement of children	4					4	3	1	
Breaking up of marriages	2	1	1			1		1	
Patients returning to parent family	1					1	1		
Patients living with married grandchildren	1					1	1		
Patients living with friends	1					1		1	
Patients living with other relatives	1	1	1						

(a) These divisions are arbitrary, and have been made in terms of the patients' ability to function.
(b) These children are all married with one exception.
(c) These patients all entered nursing homes, convalescent homes or institutions.

arrangement was made because the patients were no longer able to support themselves and their spouses. Both of these men had been severely disabled over a period of years and there seemed little hope in either case, particularly in the light of their ages, of their ever being self-supporting again.

> Mr. Y.[1] aged 64, was not completely bedridden at the time of study, but was unable to move about without the most severe pain. His arms and hands were almost useless. He had stopped work six years previously, and had never improved enough to be able to work again. Arrangements were made for a married daughter and her husband to move into the house at the time he stopped work. Mr. Y.'s wife looked after him, the house and a six-year-old grandchild. Both the daughter and son-in-law worked. The patient and his wife were completely dependent upon them for financial support. This arrangement had caused tension in the whole family group. The younger couple would have liked to be on their own, and found the financial burden trying. The patient felt tremendously guilty about being "a burden", and found the presence of the lively six-year-old grandson distracting at times. This appeared to have been the only adaptation possible for this particular group.

> Mr. Q. was 65.[2] Like Mr. Y., he had been disabled for many years, and had considerable pain. An unmarried 35-year-old daughter was living with Mr. Y. and his wife, and appeared to be devoting her whole life to her parents. She supported them on her small salary as a store clerk, with irregular help from the other children. Because Mrs. Q. complained a great deal about her own health and the extra work she had in connection with looking after Mr. Q., the daughter

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[1] Case No. 71.

[2] Case No. 74.

> helped her mother around the house when she was not working. She appeared to have neither the energy, the time, nor the money to have a life of her own. Mr. Q., like Mr. Y., appeared to have a tremendous load of guilt feelings concerning his financial dependency on his daughter. This, too, seems to have been the natural equilibrium for the individuals in this family to have found.

In the cases of the 6 female patients, where this type of family adjustment has been made, 2 were disabled enough to need physical care, and 4 were moderately disabled but could look after themselves to some extent. Their ages ranged from 56 to 72.

In 2 cases, because the husbands were also ill, the patients and their spouses were dependent on their children for financial support. In 4 cases, the patients had some income of their own, but needed help in looking after themselves and their homes.

> Mrs. T.[1] was 58. She had considerable generalized pain and stiffness, and was not physically capable of doing her own housework, and sometimes needed help in dressing herself, doing her hair, etc. Since her husband was ill too, they were also financially dependent on the daughter and son-in-law who lived with them. Mrs. T. found little satisfaction in her own home. She felt her financial dependence keenly, and felt as if everything was out of her hands, as if she were an intruder in her own home. She drove herself to do as much work as possible to offset these feelings, in spite of considerable pain. The daughter and her husband felt as if they were carrying a burden that was too much for them.

> Mrs. A.[2] was 56. Both her arms and hands were swollen and painful. She was not able

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[1] Case No. 49.

[2] Case No. 6.

> to use her right hand at all. Her married daughter had to do all the heavier housework and looked after some of Mrs. A.'s personal needs, such as doing her hair. Her husband was working and there was no financial dependence. The daughter had to give up her work in order to look after Mrs. A. Her attitude was unknown, but Mrs. A. frequently went to her room to cry.

For each of the families who responded to the impact of the illness of a parent by having adult children to live with him, this kind of equilibrium seemed to have caused considerable tension. For the patients, the tension seemed to be in direct ratio to the degree of their dependency. They appeared to feel their dependency most keenly in the financial field. The children, who with one exception were all married, appeared to obtain some degree of satisfaction from the situation, but also seemed to feel the burden.

In four cases, single family units broke up. These four patients were all women. In every case the illness was at least moderately advanced, but they had all been able to look after themselves to some extent in the past in spite of varying degrees of disability. Two of these patients were single and two were divorced. Three of them had been self-supporting until the illness became too severe, and one had been supported by her children.

> Mrs. N.,[1] divorced, aged 77, supported herself as a masseuse as long as she was able, then lived in a room, supported by a social agency. When she was no longer able to look after herself, she was moved to a Nursing Home.

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[1] Case No. 3.

> Miss M.[1] aged 53, single, worked as a domestic as long as she was able. She then looked after herself in a room and was supported by a social agency. As she had reached the stage of needing care, she was moved to a welfare institution.
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> Mrs. E.[2] aged 62, separated for many years from her husband, was supported first by her parents and later by her children. She lived alone for a period of years, with this support. When she needed further care, she was in a Convalescent Home for a year. She showed some improvement and was again living in a room, with Social Service financial support at the time of study. Because of her age and her increasing disability, it appeared that she would need this type of care again before long.
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> Miss L.[3] aged 65, single, worked as long as she could as a domestic, then lived in a room, supported by a social agency. At the time of the study, she had been moved to a home for elderly people where she could obtain the care she needed.

With the exception of one case, these patients appeared to cling to their independence and "single family" status as long as they could. When Mrs. N.[4] was moved to a Nursing Home, she made as much difficulty about it as she could, in spite of the fact that she knew she was unable to look after herself properly.

In four cases, children were placed away from home because a parent had rheumatoid arthritis. In two of four cases in which

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1 Case No. 58.

2 Case No. 64.

3 Case No. 40.

4 Supra, p. 42

children had to be placed away from home, this adaptation appeared to be a permanent change in the family structures.

> Mrs. J.,[1] aged 32, had 10 children. During the time her husband was overseas, her illness, which had been minimal, reached an acute phase when she was in urgent need of hospital care. In order for her to be able to get treatment, plans had to be made for the children. A married daughter took 2 of the children, her sister took 2, 3 went to foster homes, and the 3 oldest were left on their own. By the time she was discharged from the hospital, after 2 years, her husband was also home. Because she was still badly disabled, the children were not returned to her, on medical advice, although she was very willing to have them. This was 10 years prior to the study. Mrs. J.'s family had never been re-united, and she had never recovered to the extent where she could take on this responsibility. Some of the ten children were still in foster homes at the time of study. In the light of Mrs. J.'s advanced and apparently chronic condition, there seemed little possibility of the children ever being returned to her.

> Mrs. A.,[2] aged 34, had 2 children by her first marriage. Because of her illness and because she was separated from her husband, the children were placed with relatives, where they still were at the time of study. Two years later, she remarried. Her second husband was a widower with 3 children, all placed in orphanages. Mr. A. then brought his 3 children home. Mrs. A. in the meantime, had had another child by Mr. A. She then had 4 children to look after, 3 of whom she did not want and found very difficult to manage. When her illness became acute, after 2 years of stress, the children were placed away from home. At the time of study, it seemed extremely

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[1] Case No. 46.

[2] Case No. 76.

> unlikely that Mrs. A. would ever again be able to do any more than look after the one child of her present marriage.

In two other cases, temporary placements were made to meet an emergency situation.

> Mrs. Q.,[1] aged 41, had 6 children. During an acute phase of her illness when she was sometimes unable to feed herself, placement for the children was arranged so that she could go to the hospital. During the 17 months of her hospitalization, the children were in a welfare home. Mrs. Q. made a good enough recovery in the 17 months to have the children home again.

> Mrs. Y.,[2] aged 28, had 3 children. During the acute stage of her illness, she had hospital care for a few months and the children were placed in foster homes. They remained there for a few months after Mrs. Y. returned to her home until she was considered well enough to look after them. The family was finally reunited, and Mrs. Y. had been looking after them for the 4 years prior to the study.

Two marriages were broken up because one of the spouses had rheumatoid arthritis. In one case, the patient was a man; in the other, a woman.

> Mr. H.,[3] aged 55, had been disabled to some extent, for 13 years. According to his story, when he could no longer work, his wife had told him to get out. His two sons stayed with the mother. Mr. H. said, "When a man is sick, he's not much good to anyone. My wife told me to

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[1] Case No. 10.

[2] Case No. 77.

[3] Case No. 26.

> get out and even my sons are mad at me - they blame me for the separation". In this case, Mr. H.'s illness appeared to act as the precipitating factor in a marriage that had been unhappy for years.

> Mrs. C.,[1] aged 38, had been separated from her husband for 8 years. Her own comments on the situation were as follows, "When I was beginning to get really sick, my husband and I agreed to disagree. He had no patience with sick people, and it was all I could do to look after myself, without having to look after him, too. He went back to live with his mother and I stayed on by myself. We both thought it would be better for me that way. We never had got along together very well". Mr. C. continued to support Mrs. C. until 2 years ago, and visited her occasionally. In the 2 years since she had been bedridden, both the support and the visits had stopped. As in the case of Mr. H., the illness seemed to act as a precipitating factor in this final breaking up of an unhappy marriage.

There was only one case reported where a patient returned to a family group because of illness.

> Mrs. D.[2] had had rheumatoid arthritis in fluctuating stages since she was 20. While her husband was alive, she got on fairly well, with her husband doing most of the heavier housework. When he died, she could not manage by herself and moved back with the parent family group. She had remained with them for the 16 years immediately prior to the study. She was financially dependent on the family until she succeeded in arranging for a pension as a widow of a veteran. She was using this money at the time of study for treatment, and the family seemed to be satisfied with this arrangement.

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[1] Case No. 62.

[2] Case No. 44.

> There was no indication that her return to the family had caused any particular stress, except for the added financial burden which the family had been able to carry with no real difficulty.

There was only one case reported where a patient had moved into the home of a child (in this case, a grandchild) because of the illness. In the light of what appears to be a strong drive towards independence as a general trend in these patients, the fact that the patients studied tended to have children move in with them rather than the reverse would appear to have some significance.

> Mrs. P.,[1] aged 73, a widow for many years, had kept house for her son. She had also brought up the child of her daughter, who had died shortly after the birth. By the time both the son and grand-daughter were married, Mrs. P.'s illness had progressed to the point where she could no longer look after herself. At the time of the study, she was bedridden and the grand-daughter was looking after her. Mrs. P. was able to contribute that portion of her Old Age Pension that was not used for medical expenses, to the household. (She had used up all her savings and money from the sale of her house on medical expenses.) In spite of the contribution she was able to make, she still felt that she was not paying her way, and at one point when the grand-daughter's husband was out of work, refused to eat. As Mrs. P. was completely helpless at the time of study, the grand-daughter had to donate a large portion of her time to Mrs. P.'s physical care, giving her bed-baths, bringing her bed-pans, etc., so that she had little time to herself.

In only one case, a patient was living with friends as a direct result of rheumatoid arthritis.

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[1] Case No. 78.

> Miss S.,[1] aged 30, had had rheumatoid arthritis in fluctuating stages for 12 years prior to the study. After her parents had both died, she kept house for a brother in the family home in a farming district. When her illness reached an acute stage, she came to the city for treatment, and had been living with friends for the past year before the study. She was not able to work but paid board to her friends from an allowance supplied to her by her brothers. The family with whom she was living was described by the interviewer as being "full of tension". It would appear that Miss S.'s presence in the home may have been contributing to that tension. Miss S. reacted to the general tension by going out as much as possible.

One man was living with a brother-in-law. No other cases were reported in which patients were living with relatives, other than children or grandchildren, as a direct result of this illness.

> Mr. E.,[2] aged 55, had been becoming progressively more disabled since 1939. He had not been able to work for the 2 years prior to the study and was almost entirely confined to house. After he was no longer able to work, he spent several months at the home of a married son, in the country. He had been living, for a few months prior to the study, with a brother-in-law in the city in order to be able to obtain treatment. Because of his change of residence, he no longer received financial assistance from the community. His only income was five dollars a week from his sons. The brother-in-law was feeling the financial burden and Mr. H. was uncomfortably aware of this. He was not well enough to be able to relieve his own guilt feelings by helping around the house.

Minor or Temporary Adaptations.-

In almost every case of prolonged illness, some minor or

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1 Case No. 54.

2 Case No. 26.

temporary adaptations in human structure have to be made by the families at some time. This has been true of the sampleof rheumatoid arthritis patients studied. It has not been possible to estimate the numbers and frequencies of these lesser adaptations, particularly as this disease often has a prolonged and fluctuating course, which means that the patients have difficulty in recalling the whole picture at the various stages. It does seem clear, however, that in the majority of cases, some changes, however minor, have been made in the human structure of the families to meet the impact of the illness. In many cases, the member who is ill has had a temporary period in the hospital. In other cases a relative or friend has come into the home to help out on a temporary basis. Some of the patients have spent short periods of time at the home of relatives. All these temporary adaptations are most likely to occur in acute stages of the illness. The patients themselves have appeared to be anxious to restore the former family equilibrium as quickly as possible.

Indirect Adaptations.-

In a few cases, patients felt that the illness had interfered with the natural development of their family structures, such as having children or getting married. The specific cases where this was mentioned to the interviewer were as follows :

One woman and two men stated that they would have married but for the illness.

Miss S.,[1] aged 49, had had rheumatoid

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[1] Case No. 39.

arthritis since she was 21. When she knew she had "rheumatism", she thought of her mother who had been bedridden with arthritis for the last 9 years of her life. Miss S. immediately gave up her plans to be married because she did not want to be a "burden".

Mr. M.,[1] aged 31, was living with his parent family at the time of study. His illness had had a fluctuating course for the previous 8 years. He had had to give up his last job 3 years before, as it was too heavy for him. He had little education, no specific training, and experience only in laboring jobs which he was no longer able to manage because of his physical condition. Although both Mr. M. and the hospital Social Service department had made many efforts to find work for him of a type he could do, nothing seemed suitable, and he was financially dependent on his family. At the time of the study, he was very anxious to be married to a girl he had been seeing for 2 years, but was completely blocked in this because of his financial situation which was a direct result of his incapacity.

Mr. Y.,[2] aged 49, had been in a convalescent hospital for several months at the time of the study, and had been unable to work for the previous 10 years. Mr. Y. said, "Arthritis stopped me from getting married. The girl friend didn't marry either. I knew her for a couple of years before I got sick. Even if I do get better, I'm too old to think of marriage now".

Mr. P.,[3] aged 43, was a widower with children. He had been disabled in varying degrees since 1931. At the time of study, he was able to work but his earnings were reduced as he was not able to work at his own more highly paid trade. He would have liked to have remarried,

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1 Case No. 73.

2 Case No. 21.

3 Case No. 59.

> particularly because of the needs of his children, but was fearful to take on more responsibility in case his illness should once more reach an acute stage.

In one case, the interviewer thought that a male patient would not have married at all, if he had not had arthritis.

> Mr. D,[1] aged 49, had had rheumatoid arthritis to some degree for the previous 22 years. He had made a lot of money and had enjoyed a hard-drinking, casual life, before his disability had become acute. He had got married at a time when he needed care. His wife was a quiet, maternal, home-loving woman, who seemed happy to wait on Mr. D.

Three families were reported not to have had children because of the illness.

> Mr. X,[2] aged 47, had had arthritis for 20 years. He had not been able to work for the previous 5 years, and was dependent on his wife for financial support. He had never wanted children because of the added responsibility and because he felt that they might inherit a tendency to have rheumatoid arthritis. (His father "died of rheumatism")

> Mrs. L.[3], aged 46, had had rheumatoid arthritis for 18 years. She had had 2 miscarriages. She said, "I always wanted a big family. After I had the miscarriages, I was going to adopt a child, but I got ill and couldn't".

> Mrs. K.,[4] aged 36, had had some disability for

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[1] Case No. 55.

[2] Case No. 36.

[3] Case No. 47.

[4] Case No. 32.

> 8 years. At the time of study, she was disabled to the extent where she could do very little for herself. She said, "Before I got so bad, we often used to plan to adopt a little boy. We never did it, because I kept getting worse".

It could be surmised that among the sample, there might be other indirect adaptations to illness in family structure. The above comments were spontaneous remarks of the patients and, in one case, a comment of the interviewer. The interviews were not specifically planned to bring this out.

Summary.-

One quarter of the families studied were reported as having made major adaptations within their human structures as reactions to the illness of one of the members. In the great proportion of the cases, these appeared likely to be permanent changes. The sample was not large enough to show really significant trends in regard to comparisons between families of male and female patients. In this study approximately one seventh of the families of the male patients showed reactive changes in structure, while approximately one third of the families of female patients showed these changes. It would seem likely, however, that this might represent a trend, as adaptations seem more likely to be forced when housewives are disabled. In a family group, the major function of the man is generally that of breadwinner. If he is disabled, this does not necessarily demand an adaptation in the family in terms of structure. The same family structure may be able to make adaptation in terms of function. Most of the female rheumatoid arthritis patients are housewives. Because their

function includes care of children and because others are dependent on them, it seems more likely that adaptations would have to be made in terms of changing the human structure to meet this need. This was accomplished most frequently by the family group adding another member who could take over some of the functions of the housewife.

In the whole group, a small number of families were broken up because of the illness of one of the members, by broken marriages and by what appeared to be permanent placement of children. It seems clear that all these families tended to carry on with little change until the situation became very acute. This tendency appeared to be related to the patients' drive towards independence. It is of interest that only four of the women patients gave up caring for their children. in three cases, this was not done until the patients became so acutely ill that they were physically unable to go on. In the third case[1] (No. 76) the woman was looking after step-children, whom she had never wanted. She did not appear to make such a strong effort as the other women made to carry on with the care of their children. This tendency seemed more related to a determination to keep on, than to unusually strong feelings for the children. In this connection, it would seem significant that patients generally tended to have a helping person come to live with them if assistance were needed, rather than to make a change themselves.

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[1] Supra, p. 44.

CHAPTER IV

ADAPTIVE PROCESSES IN THE FUNCTION OF THE FAMILIES

This chapter will deal with adaptive processes in the function of the families, which have been observed in the study as reactions to the illness of the patients. As in other sections, the picture may not be complete and may not show adaptations which have occurred in previous stages of the illness. This chapter will deal more specifically with the present situation. Such material on past adaptations as has been found in the recording of the interviews will also be included.

For the sake of clarity the material has been divided into two main sections. The first section deals with financial adaptations and the second with adaptations observed in changes of division of labor within the family groups.

Financial Adaptations

The following Table indicates the major effects of the illness on the incomes of the patients studied and the number of patients out of the total sample of eighty whose incomes were affected by illness.

TABLE IV

Major Effects of Rheumatoid Arthritis on Income of Patients and Number of Patients Affected

Effects of illness on income	Total male and female patients affected	Male	Female
Total	48(a)	24(b)	24(c)
Income stopped for 6 months or more through illness	29	15	14
Income markedly reduced through illness	15	7	8
Income affected indirectly by illness	2	1	1
Income increased through illness	2	1	1

(a) This total represents more than half of the total sample of 80.

(b) Total number of male patients in sample was 27.

(c) Total number of female patients in sample was 53.

From the material in this Table, it seems clear that the illness has had financial effects on a much higher proportion of male than female patients, as would be expected. Out of the total of 27 male patients studied, incomes have been affected at some time during the course of the illness in 24 cases, while among the female patients, in 24 cases out of 53 incomes have been affected in some way. It would be expected that because of the present economic pattern, the effects on the income of the male patients would have more serious consequences

for families than in the case of the female patients, who are not expected to be breadwinners of families.

In 48 cases out of the total 80 (or more than half of the sample), financial effects were noted because of the illness.

Table V shows 32 cases of the sample of 80 where incomes were not affected by illness to any appreciable extent. In 3 cases out of the 27 male patients studied, no effects on income were noted except for minor medical expenses. In each of these cases, the disability was minimal. Two of the men had been able to continue to work; one was off work for a short period, but continued to be paid during this time. All of the men were married, but none had children.

In 29 cases of the total sample of 53 women patients, there were no appreciable effects on income. The majority of the women patients were married. In these cases, there had been varying degrees of medical expense, but these expenses had not been financially crippling to any of the families concerned. None of these women had been contributing financially to their families before they became ill. In the cases of the 5 women who were widowed, all had been financially dependent on their families, or were supported by the community before they became ill. There were some medical expenses in all these cases, but expenses had not been heavy. One woman,[1] who was separated from her husband had supported herself and her family for twenty-six years. She had been able to continue to work after she became ill. The other woman,[2] who was separated, had never worked. She had been given a

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[1] Case No. 69.

[2] Case No. 62.

TABLE V

Degree of Disability and Marital Status of Patients where Illness has no Appreciable Effect on Family Income

Marital status at time of study	Total male and female patients showing no financial effect	Male Patients				Female Patients			
		Total	Degree of disability at time of study			Total	Degree of disability at time of study		
			Advanced	Moderately advanced	Minimal or arrested		Advanced	Moderately advanced	Minimal or arrested
Total patients	32	3			3	29	3	13	3
Married	25	3			3	22	1	10	1
Widowed	5					5	1	3	11
Separated	2					2	1		1

separation allowance by her husband for several years and then kept house for her uncle. Her illness had had no effect on her income.

In Families of Male Patients.-

The effects of the illness on the income of the male patients and adaptations in families will be examined first. Out of the 27 male patients studied, there were 15 (more than half of the total number) where income had been completely stopped for six months or longer because of the illness. At the time of this cessation of income, 9 of these 15 men were breadwinners of families. The following adaptations were observed in the families of the 9.

In four cases of the 9 support was divided in the family. The following cases illustrate this type of adaptation.

> At the time of study, a 64-year-old man[1] had not been able to work for 12 years. An adult unmarried daughter lived with the parents and paid the major part of the expenses, with irregular contributions from the other married children.

> Another man[2] had not worked for 6 years at the time of study. He was being supported by a brother-in-law, with some help from two of his unmarried sons.

In one case of the 9, a child took over full support of the family, rather than support being divided as in the previous cases.

> This man[3] was married with 3 children. When

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[1] Case No. 74.

[2] Case No. 26.

[3] Case No. 31.

> his illness began, his son left school to work. This son, aged 16, was the sole support of the family. This was noted as being a cause for considerable concern to the patient.

In one case of the 9, the wife became the sole support of the family.

> This married man[1] had not been able to work for 5 years. There were no children. The wife earned a living for both as a store clerk and the patient was well enough to do some of the housework. The patient appeared to accept this passive role fairly easily, but the wife's earnings barely covered expenses. The patient stated that he sometimes asked his friends for extra food.

In one of the 9 cases, the patient was kept on as an employee with his company and was in receipt of insurance while he was off work.

> This man,[2] whose children were self-supporting had had several prolonged periods off work because of his illness. He and his wife were able to get along fairly well on his company insurance and their savings. A son who was away from home had also been contributing $20.00 a month.

In one case of the 9, a family was supported by a social agency for 3 years because the breadwinner was unable to work.

> This man,[3] with a wife and 2 dependent children was not able to work for 3 years during an acute phase of his illness. The family was supported by a social agency during this

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[1] Case No. 36.

[2] Case No. 29.

[3] Case No. 25.

> period. This man had since recovered to the point where he was able to run his own business and the family were getting along well.

In one of the 9 cases, a family was partially supported by a social agency and partially by the children.

> This man[1] had not been able to work for a few months prior to the study. A social agency had been contributing to the family for 9 months. The two wage-earning children who were living in the house were both contributing heavily. A 16-year-old boy was earning $80.00 a month and was giving $60.00 of this to the family.

Four of the 15 men whose incomes ceased for a period of months because of rheumatoid arthritis were single. All four had been paying board in the family groups in which they were living. In all these cases, the families appeared to manage very much as they had before. No particular adaptations were noted as a result of the lack of contribution from the disabled member. At the time of study, three of the 4 men were in hospitals, where they were being supported by the community. One was living at home with his parents. The following case is an illustration.

> This 31-year-old single man[2] had not been able to find work which he could do for 3 years - prior to the study. He was well enough to do light work, but had no training or experience in anything other than laboring, which he was no longer able to do. He had been living

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[1] Case No. 16.

[2] Case No. 73.

> with his parents and siblings during this time and was completely without income. He felt his dependency very strongly, and disliked having to ask for money. Numerous requests had been made for assistance from the community, but this had never been granted.

Two of the 15 who were unable to work were separated. In both cases the separations antedated the onset of the illness. Their financial responsibilities to their estranged wives were unknown. Neither had been able to work for a period of years. Both were supported by social agencies, one living in a men's hostel and one in a single room.

> This 58-year-old man[1] had been unable to work from 1928 to 1938 because of his illness. At the time of the study he had again been unable to work for 4 years. During this time he had been living in a single room, supported by a social agency.

> This 51-year-old man[2] had not worked for an unknown number of years. At the time of study, he was living in a men's hostel and was supported by a social agency.

The attitudes of these male patients towards their financial dependency because of their illness, seemed to vary considerably. Case No. 36[3] seemed to derive some satisfaction from his opportunity for dependency, while others appeared to fight against economic dependency. The following case illustrates the latter attitude.

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[1] Case No. 19.

[2] Case No. 56.

[3] Supra, p. 59

> This man at 36[1] had an acute onset of illness and required 21 months' hospital care. He had a wife and 6-year-old son. He had been working steadily but had no savings. During his hospitalizations, his father-in-law supported his wife and son but the hospital bills mounted. The wife was unable to find work. On discharge, the patient immediately returned to a different type of work which he had taught himself while he was in the hospital, and his wife was also able to find work. He insisted that she stop work in 2 years' time although the debts were not paid off. Since that time there had been heavy additional medical expenses, and the family was again in debt. The patient had continued to work, missing very little time in spite of severe pain and disability. He had continued to refuse to allow his wife to return to work. During the interview, he said, "No one will ever know how humiliating it is not to be able to support your family. I'd never let my wife go back to work. As long as I can stand up, I'll be the head of my own house".

In the cases of 7 male patients of the total 24 who showed financial effects, incomes had been reduced markedly at some time during the illness. The exact amount of the reduction is not known in any of these cases. In 4 of the 7 cases, income reduction had come about through changes in jobs made necessary by the patient's disabilities. Three of the 4 patients were married, the fourth was single. The following cases illustrate this financial effect.

> This 49-year-old man[2] was married but had no children. Before his illness, he had been a personnel manager in a hotel. Since his illness, he had been doing accounting and auditing, which he found less demanding and from

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[1] Case No. 79.

[2] Case No. 55.

> which he felt more able to take time off when he was not feeling well. Although this had meant a sharp reduction in income this family was still in fairly comfortable circumstances.

> This 43-year-old man[1] was a widower with 3 children. He had left his trade of plumber in 1940 as he found it too tiring, and considered that he was working in cold damp atmospheres too frequently. Since this time he had been working in an aircraft factory where his earnings were considerably less.

In two cases of the 7, income was reduced through male patients being unable to work full-time. Both were contributing to families.

> This 43-year-old man[2] was divorced and had been living with his parent family since 1948. While he was able to work full-time, he was contributing as much as $50.00 per week to the family. Since the onset of his illness in 1949, he had only been able to work part-time at a garage. He was still contributing the major part of his earnings, about $10.00 a week, to the family and was keeping only spending money for himself, at the time of study. The only other family income was the father's Veteran's Allowance of $80.00 per month. In speaking of the reduction of income, he said, "At first it was really tough. After a while you get used to it". A social agency assisted at one time with the expense of treatment.

> This 28-year-old man[3] was married with no children. Since his illness he had not been able to work as long hours at his trade of barber so that his earnings were reduced. His wife, who had worked all through the marriage, became the major financial contributor.

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[1] Case No. 59.

[2] Case No. 51.

[3] Case No. 30.

In one case of the 7, although the patient had been able to work except for brief periods during his illness, expensive treatment and hospitalization had reduced the family income.

> This 50-year-old man[1] was married with 2 children. His illness had had an acute onset about a year prior to the study. During that year, he had had an 8-week period in the hospital, and most expensive medication, including cortisone. The family's savings had to be used for this purpose, and at the time of study they had managed without incurring heavy debts. The family income had not been supplemented in any way.

In one case of the 24 in which income was affected, the effect appeared to be an indirect one.

> This 38-year-old man[2] was married and had 4 children. He had worked as a mechanic but at the time of study was working as a clerk. He had not taken this job as a direct result of his illness, but had drifted into it during a period of unemployment. At the time of study, however, although he knew he could earn a better living as a mechanic he was afraid to try changing jobs for fear of the effect it might have on his illness.

In one case of the 24, the family income had actually increased through a patient's change in job due to illness.

> This 35-year-old man[3] was married with 2 children. Before the onset of his illness, he had worked in mines, as a laborer and in

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[1] Case No. 23.

[2] Case No. 42.

[3] Case No. 60.

> factories. Because he was no longer able to do this type of work owing to his illness, he bought a taxi. At the time of study, he was earning more than he ever had before.

In Families of Female Patients.-

Twenty-four cases, almost half of the women patients studied, showed some effects on income through illness. The effects on the families were less noticeable, and fewer adaptations were necessary among the families to meet this situation.

Of the 14 women patients of the total 24, whose income was noted as having been stopped because of illness, none had dependents. Six of the 14 women were single, with no dependents. After the income ceased, 4 of the single women were supported by a social agency, 1 by the parent family and 1 by her brothers. Only 1 was known to have been contributing to a family. The following cases are illustrative.

> When this woman[1] was about 20 years old, she was working as a domestic, having been brought up in a foster home. With the acute onset of her illness, she required hospital care. She was never able to return to work, and was supported by a social agency until her marriage.
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> When this woman[2] was 20, she had to stop work for about 6 months, at which time her legs were in casts. During this period, she was supported by her parent family with whom she was living, and to whom she had been contributing.

Two of the 14 women patients were widows at the time their income

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[1] Case No. 76.

[2] Case No. 44.

ceased. Neither had dependents, but both were self-supporting. Both were being supported by social service at the time of study.

> This 67-year-old woman[1] supported herself by working in a factory until 2 years ago, at which time her illness became more severe. She was living alone in a room and was being supported by a social agency at the time of study.

> This 61-year-old woman[2] had supported herself as a cook after she was widowed. Since she had become too disabled to work, a social agency had been supporting her.

Four women patients of the 14 were divorced or separated, and had no dependents. At the time of study, three of the 4 were being supported by social agencies, and one by a daughter.

> This 72-year-old separated woman[3] had supported herself by having roomers until she could no longer carry on. At the time of study, she was being supported by a social agency with some additional help from a daughter.

> This 39-year-old separated woman[4] worked as a laundress and supported herself in this way until about 6 months prior to the study. At the time of study, she was being supported by a social agency.

Two of the 14 women were married and had been actively contributing to

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[1] Case No. 15.

[2] Case No. 43.

[3] Case No. 7.

[4] Case No. 28.

the families in which they were living.

> This woman[1] worked in a candy factory until she became too disabled to be able to continue. Her husband assumed the sole support of the family when she stopped work.

> This woman[2] had been working full-time in a hotel, and contributing equally with her husband until the acute phase of her illness, about 6 months prior to the study. The husband had been able to support them both during this period but the savings had been used up.

In eight of the cases of the total 24 where income was affected, there had been some reductions in income. In two cases of the 8, this reduction had been due to change of job because the patients were no longer able to do their former work because of the illness. In both cases children supplemented the income.

> This separated woman[3] had supported herself and her children by working as a waitress. When she could no longer continue with this, she did light housework and baby-sitting. Her elder son assumed more financial responsibility to meet this situation.

Two single women of the 8 were unable to work full-time because of the illness. One of these women had a dependent sister, the other had no dependents. In one case, a social agency helped with her support;

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[1] Case No. 5.

[2] Case No. 66.

[3] Case No. 2.

in the other case, brothers assisted financially.

> This single woman,[1] aged 37, had been able to work only spasmodically and part-time. She had been supported on and off for the 5 years prior to the study by a social agency.

> This 68-year-old woman,[2] supported herself and her sister by working as a Nurses' Aid as long as she was able. When her illness became more severe, she was able to work only part-time. Her brothers assisted financially during this period.

Three women of the 8 were particularly noted as having had long term, expensive treatment. Two of the 3 were married and the husbands were able to assume the expense. One of the 3 was separated and required temporary assistance by a social agency. The following case is an illustration.

> This woman[3] spent a total of 9 months in hospital and had various expensive treatments. Her husband assumed this expense.

One woman of the total 8 whose incomes showed reductionshad to give up part-time work when she became too disabled to be able to carry on.

> This 43-year-old woman[4] was adding to the family income by selling cosmetics in her spare time. When she became increasingly disabled, she had to give this work up. At the time of study, she was searching for some other way of earning money, within her

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1 Case No. 37.

2 Case No. 70.

3 Case No. 10.

4 Case No. 67.

> physical capacity, and was resolutely refusing to have medical treatment for herself because of the expense.

In one case of the 24 which showed financial effects, there appeared to be an indirect effect on income.

> Prior to the study, this family[1] had been supported by a social agency at intervals for 3 years because the husband was ill. But for her disability, which was moderately advanced, the patient would have been working.

In one case out of the total 24, the family income increased as a result of the patient's illness.

> This woman[2] had had arthritis for 15 years. Until she became severely disabled she ran a grocery store with her husband. When she was no longer able to work, the husband found outside work, and had been earning more since then than when the couple were working in the grocery store.

In the case of the women patients, they seemed, on the whole, very anxious to keep on working as long as they were physically able to do so, and very reluctant to give up any of their independence. As illustrations of this attitude, Case No. 44[3] kept on working in a candy factory with her wrists bound in spite of considerable pain. She did not give up until her locomotion was severely affected. Case No. 5[4] had continued to work in a factory in spite of considerable

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1 Case No. 77.

2 Case No. 41.

3 Supra, p. 65.

4 Supra, p. 67.

difficulty with her feet. She said, "When my feet began to hurt, I kept it to myself. For 15 years I stayed home Sundays and rested my feet".

Summary.-

Of the adaptations among the families of male patients studied, the families themselves managed the support in the majority of cases. In some cases, however, social agencies' assistance was required. In some cases, the patients seemed able to accept their dependence fairly easily; in others, they appeared to fight against it.

Among the families of female patients, the effects of cessation or reduction of income were less severe. None of the women whose income was completely cut off had been breadwinners of families. In eight cases of the 24, the patients themselves had received financial assistance from social agencies at some time. In all other cases, the families had been able to make adaptations themselves to meet the situation. The majority of these women appeared to make strong efforts to continue working as long as they could.

From the incomplete results of this study, it would appear that rheumatoid arthritis has had fairly serious economic effects on the families of the patients and on the community. Because of the frequently chronic nature of this disease, it seems likely that this economic loss would continue in these cases. The economic loss was apparently minimized to some extent by what appeared to be a strong drive to keep going as long as possible, which seemed characteristic of many of the patients. This may be counteracted, however, by

damage done to affected joints by the strain, so that these patients, too, may eventually become financially dependent upon their families or the community.

It would appear that this drive to keep going may have fairly serious implications in regard to treatment from the medical aspect. This would seem to be one of the problems of treatment in which a multi-disciplinary approach could be very effective. It would seem probable that in order for these patients to be able to make full use of medical treatment and advice, they must be treated as individuals, and there must be full understanding on the part of the medical staff of what their illness means to them in terms of their drives and emotional reactions. An adequately staffed Social Service department, working in close co-operation with the medical staff, would seem to be one way of achieving this.

Although the interviewing in this study was not intensive enough for the total picture to have been demonstrated, it seems clear that the impairment of the patients' earning capacities through the disease has had serious social consequences for the families, as they struggled with their anxieties and adjustments to it. In many cases, children have been forced to take on responsibilities for family support, which should never have been expected of them. In some cases, it seems likely that this type of adaptation has carried considerable stress, both for the patient and the other family members, with each one reacting on the other. From this it seems clear that any therapeutic work from the social standpoint, needs to be focussed on the family as well as the patient. Unless this can be done, it seems likely that groundwork is being laid for future difficulties.

Adaptations Through Changes In Division Of Labor

In this study, divisions of labor within the families is considered from two broad aspects, that of breadwinner and household management - the one function ordinary expected to be that of the male, the other of the female. In our present culture, there are many variations in this pattern, with husband and wife sometimes sharing both the function of breadwinner and household management. For the purpose of this study, the male marital partner as the breadwinner and the female partner as the household manager is considered the normal pattern, with the male partner assisting around the home with heavier tasks. For the purpose of clarity, effects of illness will be considered separately in the families of male and female patients.

In the Families of Male Patients.-

Earning the living for the family is considered here as the main function of the married man, with assistance in the home with heavier tasks as the secondary function. Since this latter material was not obtained in the interviews, it is not possible to consider this secondary function, although it seems certain that other members of the families will have had to take over many of the household assistance tasks that these patients would normally have been performing, particularly during acute phases of the illness.

From the foregoing section of this chapter, it has been demonstrated that there have been several cases in which the function of breadwinner, ordinarily belonging to the male marital partner, had to be taken over by the community or others in the family, during acute or chronic phases of the illness. To summarize this material, out of

a total of 17 married male patients studied, 9 had not been able to earn the living for the family at some period during their illness. Among these 9, there was one case where no change in breadwinner was made, as the family was able to be supported from insurance and savings. In three of the 9 cases, the community took on the function of supporting the family at some time. In the remaining 5 cases, a family member or a combination of members took over the function of financial support. In the cases where family income was reduced as a result of the illness of the male breadwinner, there is no indication of others taking on partial function of breadwinner to meet this situation, except in the cases where another member, such as a wife, had been contributing before the illness.

In Families of Female Patients.-

In the cases of the married women patients, their main function is considered here as being in the field of household management, which includes housework, cooking, shopping, and the care of children. In some cases, these married women patients also functioned as co-breadwinners. In the cases of single, divorced, separated or widowed women, they became sole breadwinners in some cases. In this study, women living alone are considered as forming single family units, with the same functions as the patients who were living in family groups. Since rheumatoid arthritis is a disease which may become disabling, the third function of looking after personal needs becomes important in all the cases.

To summarize the findings of the previous section in regard to changes in the function of these patients as breadwinners, co-breadwinners, or partial breadwinners, 11 women who were single,

widowed, divorced or separated, who had formerly supported themselves as single family units, became unable to work because of their illness. Of these, social agencies assumed support in 9 cases; family members took on this function in 2 cases. Two married women who had been contributing to their families were no longer able to do so. The families assumed this partial function in both cases.

Among the 8 cases where income was reduced, few adaptations in function were noted, particularly in the cases where the patients had only been supplementing family income. One single woman required social agency assistance whenshe could no longer work; in another case, the brothers took over the function of supplementing her reduced income. In several cases other family members who were already contributing increased their contributions.

In regard to their function as household managers, Table VI shows the number of women patients living in groups of the total 43 in this category, who, at one period during their illness, were unable to perform all or part of their household tasks.

Among the 10 patients who were so incapacitated as to be unable to do any of their housework at one time, 5 were able to do all their own housework at the time of study, 3 were able to do part of their housework and 2 were still incapacitated. Among the 25 patients who were able to do part of their housework at one time, 7 were able to do the major part of it at the time of study while 18 were still doing part.

As demonstrated in Table V, 10 patients, approximately a fourth of the 43 female patients, who were living in groups, had been completely unable to do their housework at some time during the course

TABLE VI

Number of Women Patients Living in Groups who were Unable to Perform all or Part of Their Household Tasks at Some Time During Illness, with Agencies or Individuals Taking on This Function

Agencies or individuals taking on part or full functions of housewives	Total number of housewives totally or partially unable to do housework	Number of housewives totally unable to do housework	Number of housewives able to do only part of housework
Total	35	10	25[a]
Children	11	2	9
Combination of friends and relatives	10	4	6
Husbands	9	2	7
Other relatives[b]	2	1	1
Mothers	1	1	0
Fathers	1	0	1
Social agency[c]	1	0	1

(a) Cases have not been counted where very minor changes have been made. This is purely an arbitrary division.

(b) In one case a sister, in another an uncle.

(c) In this case, a social agency provided a woman to do washing.

of their illness. The following cases are illustrative of this.

> This 58-year-old woman[1] was completely incapacitated during the acute phase of her illness, which lasted for several months. Her husband did all the housework, looked after her and continued to work. She said, "My husband went ahead and did everything without asking - if he hadn't done it that way, nothing would have been done at all. I could barely move, but I wouldn't ask anyone to help."

> This 59-year-old woman[2] had to stop work 8 years before the time of study because she was so disabled. Her mother, close to 80 at the time, had to do all the housework and look after the patient for a period of years. The patient appeared to accept this service as her only way of domination.

> This 47-year-old woman[3] had been unable to do any housework except occasional dusting for 6 months. For a period of weeks she was unable to look after her personal needs. A friend had been coming in every day to do what she could for the patient. The husband did the balance of the household chores. She said, "It's terrible to feel that you're a burden".

> This 56-year-old woman[4] was able to look after most of her own personal needs, but was unable to do much of the housework at the time of study. A married daughter did almost all the housework, and in addition, found it necessary to do her mother's hair, which she was unable to do herself. In order to look after the patient, the daughter had to give up her own work. The daughter said of the mother's

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1 Case No. 72.

2 Case No. 65.

3 Case No. 66.

4 Case No. 6

> attitude towards help, "You can never do things the way she did".

In most of the cases, some of the attitudes towards help illustrated in the above cases came out. Many of these women even when completely incapacitated were unwilling to ask for help, some were critical of the help given them, others seemed overwhelmed at the idea of being dependent, and a few seemed to use their need for service as a means of passive domination.

In the greatest number of cases, a combination of friends and relatives have maintained the family equilibrium by dividing up the function of housewife. In the next largest categories, children and husbands have taken on their function.

Almost all the female patients studied had, at some time during the course of their illness, had to have at least minor assistance with their housework, or needed some assistance in regard to their personal needs. A purely arbitrary division has been made, and only these patients have been counted who at some time have needed considerable assistance.

As shown in Table V, 25 female patients, more than half of the 43 living in groups, were disabled at some time during the course of the illness, so that other members had to take on part of their function as housewives. The following cases illustrate this.

> This 62-year-old woman[1] had been seriously disabled for 8 years, so that she was only able to walk with the greatest difficulty and pain. She allowed her husband to help

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[1] Case No. 61.

> with the heavier work about the house and he did the shopping, but she was insistent on doing the greater part of the work herself, saying, "I want to do all I can even if it hurts. I hate to ask for help."

> This 46-year-old woman[1] had been disabled to some extent for 9 years prior to study and had always had particular difficulty with her hands. Her husband did the scrubbing and most of the heavier housework, but patient was reluctant to ask for help. She said, "The doctor said I should get my family to help. I don't want to ask anybody. I won't ask outsiders".

> This 61-year-old woman[2] had had rheumatoid arthritis for 2 years. Her ankles, hands and shoulders were painful and stiff. A married daughter came in frequently to help, but found that she could not satisfy the patient with what she did. The patient said, "I'm one who won't ask for help - I'd rather do it myself than give people a chance to say 'No'. Nobody ever does things right anyway".

In most cases, children had taken on that part of the function of housewife that the patients could not manage themselves. Husbands were the next largest category, with combinations of friends and relatives being the third largest group to take on this partial function.

These patients, as a general rule, seemed to resist taking help and seemed to tend to be critical of what help they received. The following comments are illustrative of these attitudes, and seem characteristic.

> "I liked to do the work myself, I didn't like to have anyone do anything - it only made me

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[1] Case No. 9.

[2] Case No. 75.

worse, and I felt nervous".[1]

"I must get the house clean and my work done even if I'm up until 2.00 a.m.".[2]

"I wouldn't ask for help. I'm that type".[3]

The patients themselves made ingenious compensations in order to be able to carry on with their work as long as possible. This aspect would be worthy of a separate study in itself. One woman[4] arranged her hair in a different style so that she could continue to do it herself. Another woman[5] managed to continue doing her washing in spite of stiff and swollen hands by means of using the sides and palms of her hands. A third woman[6] could not walk, but managed to do the major part of the housework from a kitchen chair with castors. A fourth[7] had been bedridden for 7 years. Her finger joints were all rigid. In spite of this she had worked out a system which allowed her to manage knitting.

Ten of the women who had been living alone as single family units had needed help with looking after themselves or their dwellings at some time during the course of illness. In 8 of the cases, friends,

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1 Case No. 8.

2 Case No. 10.

3 Case No. 13.

4 Case No. 72.

5 Case No. 70.

6 Case No. 46.

7 Case No. 78.

relatives or neighbours took on part of the function of looking after their personal needs or their dwellings. In 2 cases, the patients moved to another group, where they could receive care.

Summary.-

Among the 53 women patients studied, there were at least 46 cases where illness necessitated some appreciable change in the division of labor within the family. In the group of 43 women who had been housewives, there were at least 10 cases where another member or other members of the family had had to take on this particular function because of the patient's disability. In 25 cases, another member or members had to take on part of the function of housewife. As a group, these patients seemed to carry on as long as they could and to resist giving up any part of their function. In addition to these, there were 10 women forming single family units where at least part of their function had had to be given up to others.

Except in regard to changes in division of labor in regard to their function as breadwinners, there are no findings in this section concerning male patients, as this information was not given in sufficient cases.

This observed tendency of women patients to continue with household tasks in spite of danger of damaging affected joints still further, and lack of rest, which is considered an important part of treatment,[1] has some serious implications in regard to treatment, as noted in the section dealing with financial adaptations. As the

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[1] Holbrook and Hill, op. cit., p. 39.

majority of rheumatoid arthritis patients are women of the age group in which they are most likely to be housewives, the implications here are even more serious as related to treatment. It does not seem enough to see that help is available for them, as their anxiety to keep going does not seem as closely related to a desire for high standards in housekeeping as a strong drive to maintain independence. It would appear to be for this reason also that they tend to be critical of what others do for them. A policy of attempting to frighten them into limiting their activities would seem equally ineffectual as, in some cases, there appears to be elements of masochism. An individual approach in terms of individual personality patterns and drives, and through integrated multi-disciplinary action would seem to be the only effective method of dealing with this situation. This would need to be based on a detailed knowledge and understanding of what the illness meant to the patient.

There are also obvious destructive effects on the families in the cases where the disease has caused changes in division of labor. As in the previous section, there are inevitable emotional stresses for the other family members, to which, in turn, the patient reacts. This kind of chain reaction can have serious effects not only for the patient and his illness but for the equilibrium of the whole family.

CHAPTER V

ADAPTIVE PROCESSES IN FAMILY DOMINANCE PATTERNS

This chapter deals with adaptive processes in the dominance patterns of the families of the patients studied. These reactions in dominance patterns are considered as being one aspect of the broad field of emotional patterns within the families. Although it was not possible to attempt a study of the other aspects of this field, it has been recognized that in rheumatoid arthritis, as in any of the chronic long-term illnesses, there will be inevitable effects on the whole field of emotional patterns within the families as a result of the illness together with increases in emotional tension.

According to Richardson,

> It is not so much the kind of disease as its duration and seriousness which imply a family problem....Chronic diseases not only originate in the family, but also disturb the family equilibrium.[1]

Cooley said,

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[1] Richardson, op. cit., p. 158.

> All of the problems and changes found in the family group as a consequence of illness might well result in emotional tension...we have seen that emotional stress is increased by illness and that the patient and his family are involved in emotional problems. The family will react to changes in the patient's behaviour and to his feelings... his increased dependence will mean more responsibility for someone else. His irritability or dependence will affect those around him. The patient's resistance to a regimen which might be just as difficult for the family may lead to others' resentment of their role in maintaining the regimen.... Any feeling of guilt about the patient will be intensified and lead to tension. The patient may have been the family bulwark of stability, and when he is somewhat shaken by illness, the others, at a loss without his leadership, may resort to quibbling and quarrelling.[1]

Among the patients studied, it has been demonstrated in a general way in regard to adaptations in structure and function of the families that there have been many facets to this stress when rheumatoid arthritis is the illness.[2] Among these families, there have been many deviations from the husband-breadwinner, wife-household manager pattern which is expected in this culture, and in many cases the patient has required physical care. The capricious nature of the onset and course of this illness means that the family equilibrium must be dynamic and flexible to withstand the stress, as there may be many changes in the stress factor. The fact that there can be no guarantee or certainty as to the probable course of the disease, means that realistic long term planning is difficult and sometimes impossible. There may be

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[1] Carol H. Cooley, Social Aspects of Illness, (Philadelphia and London, 1951),pp. 59-60.

[2] Supra, Chapters III and IV.

bewildering exacerbations and dramatic remissions. Treatment may or may not be effective. These factors mean that in many cases this disease exerts a fluctuating type of stress on the family group, and one in which many types of adaptation may be required in order that the group maintain a balance. It seems probable that rheumatoid arthritis would force many changes from what is considered the most desirable type of emotional pattern within the family, that of the husband and wife receiving the major part of their emotional satisfaction from each other.

Concept of Family Dominance

Richardson's concept of family dominance[1] is used in this chapter. This concept refers to interpersonal relationships, otherwise it has no meaning. It is considered in terms of adjustment rather than maladjustment. The content varies with each family. Dominance in the family is considered as being the organization of leadership in the family, either as a separate unit or in relation to the external contacts of the family. "Dominance" is used in the sense of "authority", which term implies some generally acceptable basis of social approval.

This family dominance or authority can be viewed as a pattern which can be concentrated in one individual in the group or distributed among several. It may take place in several ways, such as in competition, delegation of authority, or sharing of responsibility. There may be specializations and divisions of labor. The authority person may assert his dominance to enhance or preserve his own security or in order

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[1] Richardson, op. cit., pp. 77-85, 323-324.

to further the welfare of the family. The dominance pattern may be rigid or flexible. In either case, it may be static or in a state of flux, accepted or contested. It may be weak, resisted, evaded or used for its own sake. For the best results, some one member must exercise enough authority for integration but not too much so as to endanger the integration in the opposite direction. Dominance is considered to vary in its effects, not only according to its intensity but also according to the person who exercises it and the position of that person in the family circle, whether he be parent, child, healthy, sick, adjusted or maladjusted. Every family arrives at its own individual solutions, unless it is unable to solve its problems, in which case, there is a tendency to break up.

The authority person or persons may seek allies and set up factions. The dominance pattern of the family may favor spontaneous development of the individual or tend to repress it. According to Richardson,

> Problems which involve dominance or authority must be solved if the family is to function as a unit. The solution is most effective when the individual who is dominant is the one to whom the authorative role is culturally assigned, but a great variety of aberrations from the usual pattern can be observed, even major ones, which still permit the continuation of family life. Different sorts of equilibrium emerge, according to how much dominance is exerted, and by whom, and according to whether there is one centre of dominance or more than one.[1]

According to this concept, the dominance in the family is

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[1] Ibid., p. 85.

based either on strength or weakness of individual character, and may come about through adjustment or unconscious drives like aggression or need for self-sacrifice. In this way, dominance in the family is not based on the strength or weakness of the individual character per se, but on its influence in the family circle in whatever manner it is exercised. This means that the effect of the dominance varies with the person who exercises it to a considerable degree. In some cases, it is possible for a basically weak or dependent individual to dominate through his very condition of dependency or weakness, as in the cases of children, old people and invalids.

In the interviews on which the studies undertaken by the student social workers were based, particular attention was paid to the dominance patterns of the families, as previous studies had indicated that there seemed to be definite patterns in the patients' handling of aggressive drives.[1] For this reason, an assessment of dominance patterns in the families of which these patients were members seemed to be of importance. Since the interviews were single ones for the most part, however, and since other family members were not interviewed in most cases, this aspect had to be considered in a simplified way, but with a recognition that the patterns could be very complex. One of the three companion studies to this one, which describes the personality structure of the patients, will deal more fully with this aspect of emotional patterns in the families, as revealed in the patients' relationships.[2] A fuller treatment will be possible in this companion study as the focus will not be limited to "adaptive processes" which

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[1] Supra, pp. 3-6.

[2] Supra, pp. 11-12.

the interviews were not structured to bring out.

In order to be able to achieve a sound or valid assessment of the adaptations in dominance patterns in the families, much more intensive interviewing would be necessary, with interviews focussed clearly upon this aspect. For complete validity, it would be necessary for the interviewers to have first-hand knowledge of the families before and after the stress situation occurred, and of the other members of the group in addition to the patient.

In this project, the interviews were not specifically structured to bring out adaptive patterns, but rather to ascertain what the patterns were at the time of the study. There is no evidence, other than the words of the patients, as interpreted by the interviewers in most cases. The material is further limited by the fact that many of the patients were living alone at the time of the study or were not living in the same family group as they had been before they became ill. This means that the sample is too small for the findings to be considered as conclusive, but it has been possible to point out some adaptive patterns which seemed characteristic.

Table VII shows the number of families of the total sample of eighty patients which had to be omitted from this section of the study, with the reasons for their omission.

From this Table, since 18 of the families of the male patients were omitted from this section of the study, only 9 families, or a third of the total sample of males could be considered from the aspect of adaptive processes in dominance patterns. In the families of female patients, since 36 families were omitted from the study, only 17, or slightly less than a third of the total group of females were considered.

TABLE VII

Number of Families Omitted from the Study of Adaptive Processes in Dominance Patterns with Reasons for their Omission

Reasons for omission of families	Total number of families of male and female patients omitted	Total number of families of male patients omitted	Total number of families of female patients omitted
Total	54(a)	18(b)	36(c)
Insufficient information for assessment	29	10	19
Patient not living in same group throughout course of illness	15	5	10
Patient living alone	10	3	7

(a) Total sample was 80.

(b) Total of male patients in sample was 27.

(c) Total of female patients in sample was 53.

This means that this section of the study has been based on 26 cases, approximately one third of the total number of the 80 families studied.

Because of the limitations previously stated,[1] it has only been possible to consider the broader aspects of the dominance patterns of the families, and of the patients' roles in these patterns. In this section, the patients' roles in the dominance patterns of their families have been considered in relation to their marital partners, or in one case[2] of an unmarried woman, to a sister, and in another case[3] of a separated woman to a son. Only those cases have been considered where the patients were seen as being clearly the dominant figures in the groups before their illness; where they have been in clearly passive positions in the families; or where clearly marked contests for dominance were noted. The adaptive processes have then been studied in these three types of pre-illness patterns.

Three broad classifications in dominance patterns have been noted as results of the patients' illness. In some cases, the patients appeared to become more dominating forces in their families as results of their illness. In other cases, the other key members of the groups became more influential in the families because of the patients' illness. In a third group, there appeared to be a marked increase in tensions in relation to dominance patterns where more specific adaptations in dominance patterns were not obvious. It has been recognized that there are many more subtle patterns and adaptations that could not

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1 Supra, pp. 86-87.

2 Case No. 70.

3 Case No. 32.

be touched upon.

Since the stress factor appears to have had different effects and implications in many of the cases, the families of the male and female patients have been studied separately.

Adaptations In Families Of Male Patients

Table VIII shows the various adaptations in dominance patterns that appear to have been made in the 9 families of male patients which could be studied from this aspect, in relation to the patients' pre-illness dominance in the groups. As pointed out in Table VII, there were 18 out of the total sample of 27 where this aspect could not be considered.

From Table VIII, twice as many of the male patients appear to have been in passive positions in the families before their illness as were in dominant positions. In this group of families, there were none in which the patient appeared to have been engaged in a contest for dominance with another member in the pre-illness patterns. While the sample is not large enough to be definite evidence of representing a trend, the two kinds of pre-illness patterns seem fairly clearly defined.

The types of adaptation in dominance patterns of the families will be presented under the headings of the patients' pre-illness roles in these dominance patterns.

In Families in which Patients were Dominant before Illness.-

In the three cases where male patients appeared to have been markedly dominant in their family groups before their illness, there was one case in which this pre-illness pattern seemed to have been

TABLE VIII

Adaptations to the Patients' Illness in Dominance Patterns of 9 Families of Male Patients in Relation to the Patients' Roles in Pre-Illness Dominance Patterns of the Families(a)

Adaptations to patients' illness in dominance patterns of families	Total Patients	Patients' roles in pre-illness dominance patterns in families		
		Patient dominant in group	Patient in passive position in group	Patient engaged in a contest for dominance with another member
Total	9	3	6	
Patients' dominance increased	4	1	3	
Other members' dominance increased	3		3	
Pre-illness dominance pattern unchanged but tensions in regard to dominance increased(b)	2	2		

(a) Classifications in this Table are purely arbitrary.

(b) While it is recognized that other adaptations also had concomitant tensions, these specified cases showed tensions that were more clearly marked.

accentuated by the illness and the patient became still more dominant.

> This 50-year-old man[1] was married and had a son of 20. His arthritis was generalized and appeared to be progressive at the time of study. He was able to work full-time but had considerable pain and stiffness. He had had rheumatoid arthritis for 14 years. He had apparently always been the dominating force in the family, and at the time of study was markedly dominant. He said, "Nobody can say I'm not the head of my own family. I let my wife have her own way when it's not important, but I have the final word in important issues". Since this man had become disabled, it had seemed increasingly important to him to retain and emphasize his emotional dominance. He was very anxious for his son to have a University education and for his wife to be well-dressed, but he appared to have a need to be the giver of these benefits with power to withhold them. His main concern since he had become ill seemed to have been to keep on working in order to retain his financial dominance, as he felt it was "humiliating" to have someone else support his family. As his physical condition deteriorated and the possibilities for his being able to retain his financial dominance diminished, he appeared to be asserting increasing emotional dominance.

In two cases of the 3, where the male patients had been dominant in the family before illness, tensions appeared to increase markedly around the area of dominance with the onset of the illness.

> This 46-year-old man[2] was married with 4 children. At the time of the study, he had not been able to work for about a year because of his illness. He was considered to have been the markedly dominant marital

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[1] Case No. 79.

[2] Case No. 16.

partner. The wife appeared to have been a passive dependent person. Since his illness, the patient had been still more dominating, and the wife had become "nervous". The patient said of the situation, "I can't hide my condition from her and that makes her worse. When I look at her, it doesn't help me". The patient considered that both he and his wife would have been better to have never married. Their dissatisfactions appeared to have been brought into focus by the patient's illness, and the wife's unconscious efforts to resist his dominance and assert her own by being "nervous".

This 38-year-old man[1] was married but had no children. He had had rheumatoid arthritis for 6 years, but had been able to continue working in spite of pain and muscular weakness. He had always been clearly dominant in relation to his wife, and said of his relations with her at the time of study, "I never let her pull a fast one". Since his illness, this patient had been increasingly irritable and argumentative with his wife, particularly during periods when he was having considerable pain and was fearful of not being able to continue to work. Although the wife was not seen, it seemed clear that tensions between the marital partners had increased in the dominance area as a result of the patient's illness. The wife appeared to have begun to try to assert dominance also in indirect ways, which made the patient still more autocratic and argumentative.

In Families in which Patients were in Passive Positions before Illness.-

In six of the 9 cases in which adaptations in dominance patterns of families of male patients could be considered, the patients appeared to have been dominated by their spouses, and to have had passive roles in the families prior to their illnesses.

In three of the 6 cases, this pre-illness pattern appeared

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[1] Case No. 12.

to have been accentuated by the patients' illness, with the wives becoming more dominant in the group and the male patients less influential.

> This 58-year-old man[1] was married with 2 children. His illness had had an acute onset about a year prior to the study, and he had been able to return to work only shortly before the interview. There had been considerable financial anxiety and the children had had to assist financially. During the interview, at which time the patient and his wife were interviewed together, the wife dominated the conversation, which appeared to be a characteristic pattern. Even before the illness, the wife appeared to have derived considerable satisfaction from "mothering" the patient, which included both personal service and directing him, as she would a child with whom she was being protective and dominating. This whole pattern seemed to have been accentuated by the illness. The patient appeared to accept this easily but did not appear to use the pattern to exert authority.

> Another man,[2] aged 49, was married with 2 children. He had had arthritis since 1932. Although he had improved, he was still seriously disabled at the time of study. When his illness had become acute, he had given up his own work and had learned dressmaking from his wife. He was working subordinate to her as a dressmaker at the time of study. The patient appeared quiet and stolid. During the interview, the wife spoke sharply and gave the impression of competence, confidence and authority. It was the interviewer's impression that the wife had always been markedly dominant in the family, and that the patient had always been a passive member of the family. This pattern seemed to have been accentuated

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[1] Case No. 29.

[2] Case No. 49.

> markedly with the patient's illness, which pattern seemed partly a result of his working with his wife as a subordinate.

In three of the 6 cases where the male patients appeared to have been in passive positions in relation to their marital partners before illness, their dominance seemed to have increased through the illness.

> This 47-year-old man[1] was married with no children. His illness had begun about 20 years prior to the study. He had not been able to work for the previous 5 years, and his wife had been earning the living for both. Husband and wife were seen together in interview. He depended on her to give information. This seemed indicative of their basic pattern. The patient seemed to accept the reversal of roles cheerfully, and was quite willing to look after the house while his wife worked. He appeared to derive considerable satisfaction from attention and service, and stated that he sometimes asked friends for food when money was short. It seemed probable that his dominance had increased through his illness.

> This 65-year-old man[2] was married with 4 children. He had been seriously disabled for 12 years, and had not been able to work during that time. He and his wife were then supported by the children. The wife dominated the interview during the study, and spoke as if the patient were not present, with much emphasis on her own difficulties. She said, "I don't know why God should punish me like this. He's had the pain but I've had the trouble". Before the illness, the wife had been the dominating force in the family and had made all the decisions. The patient had been very passive in the group. Since his illness, however, he had needed considerable physical care, and the whole household had had to revolve around him, so that the

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[1] Case No. 36.

[2] Case No. 72.

dominance pattern had reversed.

Summary.-

In the 9 families of male patients studied from the aspect of adaptations in dominance patterns, the male patients had been the centre of dominance in their families before their illness in a third of the cases. In the one case of the 3, where this pre-illness pattern appeared to have been accentuated by the illness, the patient appeared to have been making an effort to compensate for his fear of the possibility of impending financial dependency by asserting more authority in other fields (Case No. 79)[1] after his illness. This seemed to have been accepted by his family. In two of the three cases where the male patients had been the authority figures in the families before the illness, tensions appeared to have increased markedly around the area of dominance with the illness, although the basic dominance patterns remained essentially the same. In one case (Case No. 12),[2] the patient seemed to have had added need to assert authority because of the implied threat to his independence in the illness. In this case, the wife appeared to oppose this added assertion of authority in indirect ways, although she had apparently accepted the pattern as it was before the illness. This situation after the illness had begun a chain reaction in the dominance area, with the patient becoming more irritable and argumentative, the spouse becoming more resistent, and with resultant increases in tensions. In the second case of the two (Case No. 16),[3]

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1 Supra, p. 92.

2 Supra, p. 93.

3 Supra, p. 92.

there also appeared to be a chain reaction with marked increase of tension in the area of dominance. In this case, the patient's illness also seemed to increase his need for using his authority position, and the wife reacted by becoming "nervous" as if this were an unconscious protest, and a means of achieving a more influential position in the family. In this case, the illness of each spouse seemed to accentuate the illness of the other and to create marked tension and dissatisfaction in the other, as a reactive disturbance in the pre-illness dominance pattern.

In six of the 9 families of male patients studied from the aspect of adaptations in dominance patterns as a result of the illness, the patients' spouses had been the dominating forces in the families before the illness. In the three cases where this pre-illness dominance pattern appeared to have been accentuated by the illness, the patients were less seriously disabled and adaptations within the families seemed less marked than in the cases where the patients were severely disabled. In the 3 cases where the pre-illness dominance pattern was changed, and the patients became dominant through illness, the severity of their disabilities and their need for care appeared to make for changes in focus in the dominance patterns as the households became geared to the illness and the needs of the patients. In these cases, the patients who appeared to be basically passive personalities became the centres of influence in the families.

Adaptations in Families of Female Patients

As stated previously,[1] analysis of adaptations in dominance

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[1] Supra, p.87.

patterns of families of female patients could be attempted in only 17 out of the total 53 cases, or slightly more than a third of the cases.

Table IX shows the various adaptations to the illness observed in the dominance patterns of these seventeen families in relation to the patients' dominance role in the families prior to illness. As in the cases of the families of male patients, the dominance patterns are considered in regard to the roles of the patients and of another key member of the family. In most cases, this other key member is the spouse, but in one case is a sister with whom the patient was living[1]; in another, a son;[2] and in a third, a mother.[3] In all of these cases, there was no spouse and no other family members living in the same group. The same classifications have been used as for the analysis of the families of the male patients, for purposes of clarity.

As demonstrated in Table IX, the majority of the female patients were the dominant figures in the pre-illness dominance patterns in the 17 families studied from this aspect. Approximately one quarter of the patients were in a passive position in relation to the other key members, and the same number of patients appeared to be engaged in a contest for dominance in their families before their illness. The adaptive patterns with the patients' illness as stress factors are discussed under the headings of these pre-illness patterns. The adaptive patterns have been classified under the same three headings as the families of the male patients, namely the families in which the patients

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[1] Case No. 70.

[2] Case No. 32.

[3] Case No. 65.

TABLE IX

Adaptations to the Patients' Illness in Dominance Patterns of 17 Families of Female Patients in Relation to the Patients' Roles in Pre-Illness Dominance Patterns of the Families(a)

Adaptations to patients' illness in dominance patterns of families	Total Patients	Patients' roles in pre-illness dominance patterns in families		
		Patient dominant in group	Patient in passive position in group	Patient engaged in a contest for dominance with another member
Total	17	9	4	4
Patients' dominance increased	11	7	4	
Other members' dominance increased	1	1		
Pre-illness dominance pattern unchanged but tensions in regard to dominance increased(b)	5	1		4

(a) Classifications in this Table are purely arbitrary.

(b) While it is recognized that other adaptations had concomitant tensions, these specified cases showed tensions that were more clearly marked.

gained dominance through illness; the families in which another member became more dominant after the patient's illness; and the families in which there were marked increases in tension around the area of dominance, without the basic patterns being essentially changed.

In Families in which Patients were Dominant before Illness.-

There were 9 families out of the total 17 studied where the female patients appeared to have been clearly dominant in their family groups before illness. Out of these 9 cases, there were 7 in which this pre-illness pattern seemed to have been accentuated by the illness of the patients. The following cases are illustrative of this.

> This 63-year-old woman[1] had two married children, but was living alone with her husband at the time of study. She had had arthritis for about 10 years prior to the study, and was moderately disabled. The husband was seen by the interviewer. He appeared as a passive, easy-going man, and left all discussion to the patient. The patient had always been the dominating force in the family. Since the patient had been ill, he had waited on her, and had been doing almost all the housework. The patient expressed appreciation for this in a rather patronizing way, saying, "A man never does things the way you'd do them yourself, but he tries". This basic pattern of dominance seemed to have markedly increased with the patient's need for service.

> This 48-year-old woman[2] had been ill since 1944. At the time of study, she had generalized soreness and stiffness in all her joints and was no longer able to carry on with her former work. She was separated

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[1] Case No. 22.

[2] Case No. 17.

> from her husband and lived with a 20-year-old son. She had always been in the dominant position in the family, and since her illness had become even more dominant. She made many demands on the son, who impressed the interviewer as being lethargic and phlegmatic, and kept close watch on him. When he could not measure up to her demands, she became irritated and let her temper go.

Among this group of families of 9 female patients in which the patients had had the authority positions in their families, there was one case in which general tensions around this area seemed to have increased, although the basic dominance patterns appeared to have remained unchanged.

> This 31-year-old woman[1] was married with 4 children. She was moderately disabled at the time of study but was able to do her own work. At the time of the marriage, 9 years previously, she had been the definite authority figure. She said of herself at that time, "I was too cocky - tried to boss the whole show". The husband was described as a passive compliant man, conspicuously lacking in self-confidence, who had suffered one anxiety attack before marriage. The patient's illness began after the husband had been hospitalized because of another anxiety attack, during a period when she was consciously attempting to repress her hostility towards him. Since that time, tensions had built up in both marital partners, and the dominance pattern appeared to be being acted out in terms of the two illnesses.

In one case of the 9 families in which the female patients were in dominant positions before illness, the spouse achieved a more authoritative position after the illness.

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[1] Case No. 77.

> This 59-year-old woman was married.[1] All her children had married and left home at the time of study. She had had arthritis for 15 years and was severely disabled. The husband was described as being quiet, good-natured and relaxed. The patient appeared to be dominant, aggressive and managing. Before her illness became acute, she and her husband ran a grocery store together. The husband was apparently dependent upon her in this business. In speaking of the business, she said, "I used to have a grocery store - of course, my husband helped me". Since she had become too disabled to carry on with this business, the husband had found outside work and was earning more than they had been able to earn together in their grocery business. This had put him in a much more dominant position than he had had before the patient's illness, although hers was still the dominating personality.

In Families in which Patients were in Passive Positions before Illness.-

In four of the 17 families of female patients which were studied from the aspect of dominance patterns, the patients were in passive positions in the families before the illness, and another key member was in the position of dominance. In all four of these cases, the patients achieved more dominance in the group through illness. The following cases illustrate this form of adaptation.

> This 59-year-old woman[2] had been separated from her husband for 36 years. The patient had supported herself by working as a housekeeper during the period after her separation and before her illness became acute. During this period, she lived with her mother most of the time. The mother was dominating and aggressive, while the patient was timid and retiring. The mother ran the household

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[1] Case No. 41.

[2] Case No. 65.

and held all authority, making decisions for both. During the 8 years prior to the study, the patient had been too disabled to be able to work, and continued to live with her mother. Because of her incapacity and need for service, she had achieved some measure of dominance in the household, and much of the daily routine had to be planned around her disability.

This 46-year-old married woman[1] had 2 married daughters, who were living away from home. Her illness had been moderately disabling for 5 years prior to the study. The husband had the more dominant personality, and had always had the position of authority in the house. This had been particularly marked in regard to the disciplining and making of decisions in regard to the children. The patient seemed to have accepted this authority and to have relied and depended upon it. At the time of study, the patient appeared to have achieved considerable authority and influence in the household through her illness. The daughters frequently came in to help her, and the husband looked after, cooked and did the shopping during acute phases. The household had become geared to her illness, and the patient had become the centre of influence.

This 36-year-old woman[2] was married, but had no children. She had had rheumatoid arthritis for 8 years and was moderately disabled with considerable pain at the time of study. The husband had the stronger personality, and had had the markedly dominant position prior to the illness. He had made all the decisions, and had taken the leadership role. Since the patient's illness, the sphere of influence had changed, and the lives of both marital partners were controlled to some degree by the demands of the wife's physical condition. The patient expected a great deal of service, and exerted considerable control in an indirect way at the time of study. The husband said of her, "I do nearly everything around the house. I'm supposed

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[1] Case No. 24.

[2] Case No. 32

to guess what she wants. If I don't do it, she blames me for not asking her."

In Families in which Patients were Engaged in a Contest for Dominance before Illness.-

In four cases of the total 17 studied from the aspect of dominance patterns, the female patients appeared to have been engaged in a contest for dominance with other key members of the families before they became ill. In all these four cases, tensions in the area of dominance appeared to have increased markedly with the illness with the same pattern of acute competition remaining. In these cases, interviews were not intensive enough to ascertain any changes in the balance of dominance. The following cases illustrate this type of adaptation.

> This 68-year-old woman[1] was single, and had lived for many years with an unmarried sister. At the time of study, her illness appeared to be in remission, but she had been moderately disabled with considerable pain for a period of 5 years prior to this. Before she became ill, the patient had always had the more dominating personality, but the sister exerted considerable influence through a psychoneurotic condition. When the patient developed rheumatoid arthritis, the struggle for dominance appeared to have been acted out in terms of the two illnesses, with both illnesses fluctuating considerably, and with considerable tension being built up in both individuals. At the time of study, the patient's illness was in remission, and the sister's psychoneurotic condition had become more severe.
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> This 46-year-old woman[2] was married with 3 children. Her illness had begun about 9

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[1] Case No. 70.

[2] Case No. 9.

> years prior to the study. Although she had improved by the time of study, her hands were still weak and painful. The patient and her husband appeared to have been engaged in a competition for dominance throughout the marriage, with each marital partner attempting to be the sole authority in the family, and each seeking allies in the children, so that separate factions appeared to have been set up within the family. After the patient became ill, this situation appeared to continue, with increased tensions in this area. The patient said, "Since I've been sick, I fly off and he gives in eventually. I'm so sensitive now - it only takes a word and I go to the bedroom and break my heart. He tries harder than ever to dominate all of us - thinks he can get away with it because I'm sick!"

Summary.-

In the 17 cases where adaptations in dominance patterns of families of female patients could be considered, slightly over one half of the patients had held positions of dominance in the families before their illness. In the majority of these cases, this pre-illness pattern was accentuated when the patients became ill. This adaptation was noted in seven out of the 9 cases where the patient had been the authority figure before illness. In some cases, the patients' influence in the group was more marked because of their need for service. In others, where the patients insisted on maintaining their function in spite of disability, the increased influence was more subtle, and involved guilt feelings in some of the other family members because of the patients' masochistic activities. In one case of the 9 (Case No. 41),[1] the spouse achieved a more dominant position in the family after the patient's illness became disabling, because the patient was no

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[1] Supra, p. 102.

longer able to work with him, and he was able to earn a better living doing outside work. In the ninth case (Case No. 77),[1] although the basic dominance pattern in the family appeared essentially the same as before the illness, tensions in the area of dominance appeared to have increased markedly. In this case, the dominance patterns seemed to have been acted out in terms of the patient's arthritis and the husband's anxiety neurosis.

In four of the 17 cases, slightly less than a quarter of the total cases studied from this aspect, the patients were in passive positions in the families prior to their illness, with another key member of the family, usually the spouse, in the authority position. In all these cases, the patients' position in the family groups became more authoritative after they became ill. As in the cases where the patients had been authority figures before illness, these patients became more dominant through their need for service after illness. In these particular cases, the drive to retain function as long as possible did not appear to be as marked as in the patients who had been dominant before illness, and the more subtle influence though arousing guilt feelings in other members did not appear as marked.

In 4, or slightly less than one quarter of the families of the 17, the female patients appeared to have been engaged in a contest for dominance with other key members of the groups before they became ill. In these cases, the contest for dominance remained unresolved after illness, and tensions in this area appeared to have been markedly increased. It was in these cases that family equilibrium seemed most

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[1] Supra, p. 101.

threatened. In this regard, it is of interest to note Richardson's observation, "This problem of authority versus submission must be settled if the family is to function as a unit and resist the internal tendencies toward disintegration or the shocks of the outer world...if families are unable to solve their problems, they tend to break up".[1]

Since the majority of rheumatoid arthritis patients are women,[2] which trend is demonstrated in the sample used in this study,[3] the adaptive patterns found in the families of the female patients are of particular significance. Although the portion of the sample used in this part of the study was small,[4] some trends appear fairly clear. From the portion of the sample studied, it would appear that the majority of the female patients had either been the dominant figures in their families prior to illness, or had been engaged in a contest for dominance with another key member of the family who challenged their dominance. In the cases where the patients had been authority figures and illness had increased their dominance, it would be expected that there would be destructive effects in the family members and upon the family equilibria. The study was not intensive enough to bring out these effects. In cases where the contest for dominance had not been solved, and tensions were increased with the impact of the illness, the families appeared to be in some danger of breaking up. It would appear that most of these families were in urgent need of skilled

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1 Richardson, op. cit., p. 85.

2 Supra, p. 28.

3 Appendix A, p. 135.

4 Supra, p. 87.

professional assistance, with the focus on the preservation of the equilibria of the whole units.

This portion of the study would appear to indicate that there are many patterns to be found among the families of rheumatoid arthritis patients, and that there are a multiplicity of adaptations. The various adaptations in emotional patterns in the families would merit further study. The trends which seem apparent in adaptations in dominance patterns would need to be tested in a much larger sample in order to be considered valid, but it would appear that even the small sample, in which the more subtle patterns could not be ascertained, there are findings which are of some significance.

CHAPTER VI

GENERAL CONCLUSIONS

Restatement of Purpose and Scope of Study

This specific study has been attempted as part of an assignment given to four student social workers with the purpose of studying the social lives of rheumatoid arthritis patients. This assignment was to include a study of the social field prior to the illness and a study of how this had changed during and after the onset of rheumatoid arthritis. The assignment was a portion of an inter-disciplinary pilot study which was to include contributions from medicine, psychiatry and psychology, and which had as its purpose a study of the medical, psychiatric and social factors which may predispose patients to rheumatoid arthritis. The ultimate purpose of this pilot study was to attempt to discover which of the various possible adjustments between patient and community tended to hasten recovery, and which tended to lead to chronic social illness. As the first of a projected series of parallel pilot studies, an evaluation of the methodology used was considered to be an equally important part of the dual purpose of this study. The pilot studies which are planned to follow the present one will be designed to

investigate other specific disease entities. They are to form the first stage in a comprehensive study. The comprehensive study will attempt to discover the manner in which community life, urban or rural, alters the pattern of illness.

In order to carry out their assignment, each of the four student social workers interviewed twenty patients from Montreal rheumatism clinics who had been diagnosed by rheumatologists as having rheumatoid arthritis. The recording of each interview was done in quadruplicate, so that each participant was able to accomplish a segmental study based on all eighty cases. The four segmental studies, of which the present study is one, included studies of the parent families of the patients, the personality structure of the patients and the effects of the patients' illness. This specific section has attempted an examination of the various adaptive and reactive processes within the families with the patients' illness as the stress factor.

The findings in regard to the efficacy of the methods used in this pilot study are presented in a separate chapter. This material has been included in the hope that it will be of value in planning future inter-disciplinary projects.

Limitations of Study

The sample may not be representative of all rheumatoid arthritis patients, and may represent patients from only the lower economic and social strata, as all the patients forming the sample were drawn from Out-Patients' Clinics. The sample may not be large enough to show truly representative trends. The findings have been given without reference to control groups as originally planned.

In the assignment of the social workers, the segmentation of material has meant over-lapping and gaps in material, and has minimized the possibilities for integration. While some measure of integration has been possible in the four studies completed by the social workers, there has been no possibility of integration with the psychiatrist's reports. Because of the segmentation of material, it has not been possible for the basic hypothesis of the pilot study to be validated or not, and the individual studies completed by the student social workers can offer only the most fragmentary findings in regard to the ultimate purpose of the study, in regard to adjustments between patient and community in relation to illness. This constitutes a severe limitation. In order for this purpose of the study to be achieved, a fifth and integrating project would have to be undertaken using the findings of the psychiatrist, in addition to those of the four separate studies completed by the student social workers.

The individual studies have been further limited by the fact that the interviews in some cases were not specifically structured to bring out material that would be necessary to make valid conclusions. This is particularly true of the chapter of this study dealing with adaptations in dominance patterns. Because of administrative difficulties, the time factor imposed limitations so that the material from the interviews became more superficial in content than had been originally planned. Because of the time factor, too, it was not possible to interview relatives in addition to patients except in a very few cases, so that this means of extending and corroborating material could not be used. The four studies undertaken by student social workers have been dependent on the subjective statements of patients as interpreted by

the interviewers. This subjective factor, however, was minimized to some extent by the fact that the material came from four separate interviewers. Because of the aforementioned limitations, it would seem possible that the complete picture has not been shown in any of the chapters of this unit of the study.

Findings Of Specific Study

The adaptive processes in the families of the eighty rheumatoid arthritis patients as a result of the impact of the patients' illness, were studied from three aspects, as demonstrated in their structure, function and dominance patterns.

Adaptations in Structure of the Families.-

Adaptations in the structure of the families was considered first in relation to dwellings. Although many patients had expressed dissatisfaction with their dwellings in relation to their illness, there was no evidence of major adaptations having been made. None of the families had moved because of the needs of the patient, and there was no evidence to suggest that any of the families had given serious consideration to finding other accommodation. Only the most minimal adaptations were reported to have been made within the dwellings. It was felt that this lack of adaptation was partly due to the economic status of the families, partly due to local housing difficulties, but largely due to what appeared to be strong drives towards independence and self-control observed in many of the patients, with an element of masochism and a tendency to deny the disability or consider it as being less serious than it was.

There were many changes observed in the human structure of the structure of the families because of the patients' illness. These adaptations were generally temporary in nature, as reactions to acute phases of the illness. As a general rule, the patients tended to carry on themselves as long as they could. The assistance of other members of the families necessitating changes in the human structure of the families was generally accepted only when the situation became urgent. When these patients could no longer do without help in caring for themselves or their families, the general pattern was for the patients to arrange for other members to move in with them, rather than for the patients to move to other groups themselves. There were very few instances of the patients moving out of the family group because of the needs of their illness except in the cases of those who required hospital care. In two cases, marriages were broken as a result of rheumatoid arthritis in one of the marital partners. In both cases, the marriages had been unhappy before the onset of the illness, and the illness appeared to exert the final stress which precipitated the separations. There were a few cases where children were placed during acute phases of the illness of mothers, but only two cases where this appeared to be a permanent adaptation. Some indirect effects were observed in the human structure of the families. A few patients stated that they would have had children but for their disabilities; a few felt that they would have married if they had been well; and there was one case in which the interviewer thought the patient married as a result of his illness.

Adaptations in Function of the Families.-

The adaptive processes in the function of the families were

studied firstly in relation to the income of the families, and secondly in relation to the division of labor within the families. In the cases studied the disease had caused much economic loss to the families and to the community, but had not appeared to cause permanent changes in the economic level of the families. The majority of the more serious economic effects had occurred in the families in which the male breadwinners had become incapacitated and unable to work. Some of the patients had had periods of complete loss of income; in other cases, income was reduced. In the majority of cases the support was divided among the families in a variety of ways when the income was stopped; in a few cases the community supported the families when this happened. In two cases, the family income was actually increased through change of job due to illness. The cost to the community was greatest among those patients who had been living alone. When they were no longer able to work, the majority were supported by the community.

In the study of adaptations through changes in division of labor within the families, there was insufficient information to consider the functions of male patients except as breadwinners. It seems probable that in many cases, other family members had had to take over household tasks formerly performed by the male patients, but this information was not obtained. When the male breadwinners became incapacitated, their function as breadwinners was taken over by a combination of members in most cases. In a few cases, one member took on this function, as in the cases where the children left school, or wives earned the living. Among the women patients, a strong tendency to retain their function as household managers as long as they were physically able to do so was observed. The women patients used many

compensatory devices to enable them to retain this independence. This reluctance to give up their function, even in cases where they were severely disabled, appeared to be closely related to the personality factors discussed in connection with adaptations in human structure. Approximately an eighth of the women patients had been completely unable to manage household tasks at some time during the course of the illness. In the majority of the cases, children took over; in some cases, husbands attempted to take on this function in addition to earning the living; in many cases combinations of friends and relations managed between them. Almost all the female patients had required at least minor assistance with household tasks during the course of their illness, so that other members of the family had had to take on parts of the function of housewife. Approximately one half of the female patients had required major assistance from other members in order for the household to be able to function. None of the women who became totally incapacitated had been breadwinners of families. In the cases of the women who had been contributing to the support of the families, few definite adaptations were noted. In most cases, the families managed on the reduced income.

Adaptations in Dominance Patterns of the Families.-

Because of limitations in material, and because many patients had not been living in family groups throughout the course of the illness, this part of the study was limited to approximately one third of the total sample of eighty. Since the interviews were not specifically structured to bring out adaptive processes, only the more obvious patterns were examined. Richardson's concept of family dominance[1]

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[1] Supra, pp. 84-87.

was used, with dominance being considered as the organization of leadership, authority or influence in the family, and based on either strength or weakness of individual members. According to this concept, a member of a family might hold the dominant or authority position because of his very weakness, as in cases of invalids who required considerable care.

An attempt was made in this chapter to assess the patient's roles in the dominance patterns of the families before illness. The adaptive processes, as a result of illness, were then observed in relation to the patients' pre-illness roles in the family dominance patterns. It was possible to treat these complex patterns only in a general and simplified way, and classifications used were purely arbitary.

Among the nine families of male patients in which dominance patterns in relation to the patient could be considered, the majority of patients appeared to have been passive members of the groups before illness, with the spouses or other key members of the group being dominant. In these cases, where the male patients had been passive members of the group before illness, this pattern seemed to have become accentuated when the patients became ill, with the other key member's authority increasing as long as the patients were not seriously disabled. In those cases where the male patients, who had been in passive positions before illness, became severely incapacitated and required physical care, the dominance patterns seemed altered, with the patients achieving more dominant positions through their very incapacity. In some cases, the whole households became geared to the patient and his illness.

In a third of the cases studied, male patients had appeared

to have been clearly dominant in their family groups before illness. In two of these cases, the pre-illness dominance patterns showed no observable alteration with the onset of illness, but tensions in the area of dominance appeared to have increased markedly. In one of the cases, the pre-illness pattern appeared to have been accentuated by the illness. In this case, the patient seemed to have become more markedly dominant. None of the male patients were considered to have been engaged in a contest for dominance in their families before illness.

Among the seventeen families of female patients in which adaptations to the illness in dominance patterns could be considered, more than half of the patients appeared to have had the dominant positions in the groups before illness. In the majority of these cases where the patients had been authority figures in the families before illness, their dominance appeared to have been accentuated markedly by their illness. This group of patients is of particular interest, as they form the largest group of this section of the study, and, if the validity of trends shown in the small sample can be accepted, should represent the most common pattern. In some of the cases, where the patients were severely disabled, their increased dominance in the family group seemed to be a result of their need for service and the need for the households to be geared to the demands of the illness. In the cases where the patients had been able to keep going in spite of varying degrees of disability, they appeared to have achieved increased authority through a kind of martyrdom, which made for guilt feelings and over-compensations in the form of submission in other members of the family groups. In

this particular group, the authority role also appeared to have been accentuated by a tendency in the patients towards greater freedom in expressing criticism, which the status of semi-invalidism appeared to allow them. These findings are in agreement with those of Johnson, Shapiro and Alexander[1] in regard to the personality structure of rheumatoid arthritis patients as discussed in Chapter I.

In one case where the female patient had been dominant before illness, this basic pattern seemed unchanged by the onset of the illness, but tensions in the area of dominance seemed markedly increased. In a second case of this group, the dominance position of another family member became stronger because of the patient's illness.

Approximately a quarter of the female patients appeared to have been engaged in a contest for dominance with other key members of the groups prior to their illness. In the majority of these cases, the contest for dominance continued with added force after the illness and tensions in this area appeared to have increased markedly. This group of families also seems to represent a significant trend.

A small group of female patients appeared to have been in passive positions in their families before illness, with their marital partners or other key members of the group in the more dominant positions. In all these cases, the patients appeared to have achieved more dominance through their illness. In the opinion of the writer, this group is not truly representative, as it does not include those cases where the patients were less physically handicapped and where there was no

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[1] Supra, p.3.

increase of authority because of their needs, as in the case of one group of male patients.[1]

General Significance of Findings

In the area of structure and functions of the families, fewer adaptations were made than might have been predicted from the serious nature of this disease. This would appear to be closely related to some personality aspects of the majority of the patients, which seem fairly typical, such as activity as compensation for fear of dependency, with some masochistic elements. These aspects have been dealt with more fully in another study of this group of four, in which the main focus is the personality of the patients.[2] This generalization appears to have validity in consideration of those aspects of family life in which the patients were able to retain some measure of control, but is not applicable in the area of dominance patterns of the families. In the writer's opinion, these adaptations have been less marked than in other illnesses of comparable seriousness, as in tuberculosis. This opinion could not be validated, however, without the evidence of parallel studies. In our culture a premium has been placed on independence, an ability to be self-controlled, self-sustaining, and on the ability to persevere without asking for help in spite of difficulties. This general attitude appears to have been an element in the attitudes of these patients, and it would appear that there have been tensions and hardships because of this, not only for the patients, but for the families. In many of these cases, the patients and families have been in urgent need of help, but have not received it nor asked for it.

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[1] Supra, p. 116.

[2] Supra, pp. 11-12

Their needs, as a result of the patients' illness and as observed in this study, have run the gamut from acute housing difficulties, through financial needs and necessity for household assistance, to severe tensions and emotional problems. From this, it would seem evident that our culture needs to look to a re-evaluation of some of our social values, in relation to the possibility of their universal application.

In the area of dominance patterns, some of the trends shown in the study appear to have considerable significance, even although the sample is extremely small. Since in two thirds of the families of female patients studied, the patients either held the authoritative roles in their families before illness, or were competing for dominance with other key members, the types of adaptations in these groups are of particular interest for those professional groups who work with rheumatoid arthritis patients and their families. It has been demonstrated that in the majority of these cases, tensions within the family groups were markedly increased in the area of dominance, or the patients, who were already dominant in the groups were strengthened in their authoritative roles because of the illness. In either case, the family balance would appear to have reached a precarious state, and one in which skilled professional assistance might be needed, both to preserve the equilibrium of the whole group, and to assist the patient to deal with the emotional aspects of his illness. The illness in some cases might be providing the patient with some satisfactions, but with professional assistance he might be helped to respond to treatment and give up his illness.

Social Implications Of Rheumatoid Arthritis as Observed In This Study

In the Families.-

Because families are composed of individuals, each with a distinctive personality structure and varying degrees of tolerance to stress, the family balance is always precarious. In order for the family as a group to achieve a satisfactory equilibrium, some pattern must be achieved in which there is a measure of balance of individual needs and satisfactions.[1] Serious illness has effects on the lives of all the members of the family in that satisfactions tend to be diminished and tensions become more acute.[2] Some of these effects have been touched upon in the families of the rheumatoid arthritis patients studied. There has been considerable economic loss; responsibilities rightly belonging to the patient have been thrown on to other members of the family; there has been evidence of considerable tension, anxiety and emotional stress; and in a few cases, families have been unable to maintain an equilibrium, and have broken up. In addition, there have been many more subtle effects on equilibrium of the families, and some indirect effects, such as failure to marry or failure to have children, because of the disease. The uncertainties in regard to the course of the illness, the absence of a specific cure and the fact that rheumatoid arthritis often becomes chronic and disabling[3] makes for a type of stress which is different in impact to

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[1] Richardson, op. cit., p. 86.

[2] Cooley, op. cit., p. 63.

[3] Supra, p.7.

most chronic diseases.

Members of some of the families studied have appeared to react to the stress in neurotic ways, or have appeared to escape from a situation which has become intolerable for them into some other illness. In this regard, it is necessary to remember that, according to Margolis, "...even a neurosis sometimes actually determines individual and family homeostasis".[1] This type of reaction in another family member may have an effect on the patient and his illness, so that a chain reaction is begun, which may well endanger the balance of the whole family. Chain reactions of this kind were noted in several of the families studied in this project, particularly in regard to dominance patterns of the families.[2]

The need for preventive work within the families seems strongly indicated, not only for the preservation of balance in these families, but also in order to safeguard the future families to be formed by children of these groups. The fact, which has been established in another study of this group of four,[3] that many of the patients studied have been shown to come from parent families in which their emotional needs were not satisfied would appear to indicate that this may have been of significance in their illness. The maladjustments of one generation appear to lay a foundation for resultant difficulties in the next, unless this unhealthy chain can be broken.

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[1] H. M. Margolis, The Biodynamic Point of View in Medicine, Paper read to Pittsburgh School of Social Work, Pittsburgh, Pennsylvania, undated.

[2] Supra, p. 96.

[3] Supra, p.12.

In the Community.-

> All ill people and their families are part of a larger community group. Any insecurity, immaturity, instability and unhappiness which are part of their problem becomes the concern of the whole group of which each is an integral part.[1]

If the concept of the welfare of the community being dependent on the welfare of the people making up that community is accepted, it follows that rheumatoid arthritis has created a multiplicity of community problems. Some of these problems have been touched upon in this study. Some of the patients have had to be supported with their families, by community agencies. In some cases, this support has been needed for only temporary emergency periods. In other cases, long-term support has had to be planned. There have also been indirect economic effects on the community. Some members of the families of the patients have had to take over the support of the families because of the patients' incapacities. This frequently has meant that because these relatives have taken over the patients' financial responsibilities, they have no longer been able to continue with other financial contributions which they had been making to the community before this added responsibility. This too has meant economic loss to the community, but is less marked and more indirect than the cases receiving direct community support.

As well as this economic loss, there has been a high loss in service to the community among the patients and their families.

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[1] Cooley, op. cit., p. 63.

Rheumatoid arthritis has robbed the community of workers who had been formerly contributing skills and service. In this aspect, too, there have been chain reactions. Other family members have had to give up work to care for patients, so that these members were no longer able to contribute service to the community. In at least one case, a son had to leave school early to support the family, because of the bread-winner's illness. In this case, it is conceivable that this boy's contribution in service to the community might have been greater in the future had he been able to continue with his education.

In several of the families studied, married children have spent considerable time away from their own homes to care for the patient, or have given up their own homes and moved into the homes of the patients. Although this study was not geared to deal with these concomitant effects of rheumatoid arthritis, it would seem likely that in the cases where the married sons and daughters of the patients had children of their own, the necessity for divided attention might have had serious effects for the children. It would seem possible that this kind of situation too would create future community problems.

Since family balance is compounded of many inter-acting factors, and chronic illness, such as rheumatoid arthritis, can be either symptomatic of family imbalance, or constitute one of the factors contributing to this imbalance,[1] it would appear to be an inevitable cause of community problems. Where, then, does the solution lie, and how can the material of this study be applied? Some applications are suggested in the following section.

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[1] Richardson, op.cit., p. 89.

Some Practical Applications Of Findings

In spite of the incompleteness of the findings of this study, several aspects have been brought out which indicate needs of the arthritis patients and their families which are not being met fully at the present time, and which, if fulfilled,would appear to afford at least partial solutions to some of these problems.

The findings of the study would suggest first that medical and social treatment of rheumatoid arthritis patients must include a full view, not only of the patients, but of the total family situations. Too often the consequences of the illness in the families seems to have been overlooked. It would appear that greater emphasis is required on professional assistance that is clearly family-focussed. This study would seem to affirm the following statements of Cooley, who said,

> It is not sound to achieve the well-being of the patient at the expense of others....In planning programmes, all factors should be taken into consideration, without too great sacrifice to others....What does the cost of treatment mean to the family? How does the programme disturb the plans of others? How does it affect the family relationships? What does it do to the feelings of others? Would an alternate plan be more satisfactory for the family as a whole and as beneficial to the patient? All these aspects must be considered.[1]

In the rheumatoid arthritis families studied, it would appear to be unsound from the viewpoint of community welfare as a whole, and uneconomical of time, effort and expense of service, to allow family

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[1] Cooley, op. cit., p. 65.

problems as a result of the patient's illness to build up to the point where family integration is endangered. The aspect of prevention in a family-focussed programme in relation to preserving the equilibrium of the whole group seems to be of utmost importance. In addition, the reactions and counter-reactions within the family group may be destructive and may be an integral part of the patient's illness. Unless these factors are taken into consideration, and professional assistance is given in these areas, medical treatment of the patient may be ineffective.

It would appear that the only possible means for obtaining this breadth of viewpoint in relation to the illness lies in a well-planned and integrated "team" approach. Only in this way can the patient's illness be seen in relation to the strength and weakness and total equilibrium of the family group, and only in this way can this equilibrium be preserved and strengthened, in relation to the welfare of the whole group and to the patient and his illness. In many cases, as well as being an integral part of the hospital planning, this inter-disciplinary approach requires extension into the community.

In any medical setting, the physician is the only member of the team who is professionally equipped to predict physical stresses and strains of given activities, and is therefore the one member of the team who is professionally competent to make decisions in regard to certain activities, and to assume team leadership.[1] Members of Social Service departments appear to be the members of the team who are best equipped to study the social milieu of the patient and his family

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[1] Caroline H. Elledge, The Rehabilitation of the Patient, (Philadelphia, London and Montreal, 1948), p. 87.

in relation to his illness. It would appear that neither service can function with optimum effectiveness for the welfare of the patient and his family without the contribution of the other. Other disciplines within hospital and clinic settings also have important contributions to make.

In relation to teamwork in rehabilitation, Caroline Elledge said,

> Teamwork...is created through mutual understanding generated by two or more persons offering different though related services to an individual with physical impairment. This understanding stems from two sources: one, recognition of the particular area of competence for which training and experience has trained the given expert to offer specific service, and two, knowledge, understanding and appreciation of the value of that service by other experts may have for the individual. ...Teamwork is spontaneous under such circumstances, but can be enriched through patterns of working together, such as regular conferences, but cannot be produced by virtue of the fact that various experts are housed under one roof....Teamwork flourishes best when a recognized pattern of working together has been established between various experts offering service.[1]

Suggestions For Further Study

In regard to over-all results of the pilot study and the contribution of the social work students, it has already been suggested that a fifth integrating study would have to be made in order to validate the basic hypothesis of the pilot study.[2] This integrating study would require the integration of the psychiatrist's

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[1] Ibid.

[2] Supra, p. 111.

findings with those of the student social workers.

In this study of adaptive and reactive processes in the families of the rheumatoid arthritis patients as results of the impact of the illness, a need has been indicated for a more complete study in adaptations in the emotional patterns of the families, if the total picture is to be understood.[1] In order for this study to be complete and effective, the research would need to involve intensive interviewing and studies of other key members of the group in addition to the patient, with the equilibrium of the total unit being kept in clear focus. For complete validity, the family group would need to have been known before and after the stress situation occurred. Complete validity would also require a parallel study of a control group, with another comparable chronic illness as the stress factor. If such a project were undertaken, the interviews would need to be focussed directly on adaptive and reactive processes, rather than upon the situation as it appeared at the time of study. This could well form a separate and complete project.

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[1] Supra, p. 108.

CHAPTER VII

EVALUATIVE COMMENTS ON METHODOLOGY

As one of the major purposes of the pilot study was formulated as being an examination of the methods used in the study in order to faciliate planning of future projects, some evaluative comments covering this methodology are made in this chapter. General factors concerning the group inter-disciplinary approach are discussed first, in relation to the general advantages and disadvantages of this method. Evaluative comments are made in relation to the main aspects of the assignment of the student social workers, and recommendations are suggested for future projects in the light of the experience gained in the present one.

General Considerations In Regard To The Group Inter-Disciplinary Approach

Advantages.-

It seems obvious that it would not be possible to make a meaningful and comprehensive study of a disease entity, with all its multiplicity of physical, emotional and social factors, from the viewpoint of a single discipline alone. This appears to be particularly true of such a disease as rheumatoid arthritis, since the etiology is said to be multi-factorial.[1] It seems clear that the present project

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[1] Supra, p. 6.

could not have been attempted by the student social workers alone. It seems equally clear that completely separate and individual studies which attempted to deal with any aspect of this topic would have had comparatively little value.

In general a group project of any kind makes the undertaking of a large and meaningful unit of research much more possible, with the probability of more useful conclusions than would an equivalent number of individual studies. This would be particularly true when there is a maximum degree of integration in the separate units of the project with the end results presented as joint conclusions. The inclusion of more than one discipline in such a project would make for more balanced and productive research, providing the topic chosen were within the scope of the professional competence of all disciplines involved.

This type of research project, if managed with skill and adequate planning and organization, should provide the opportunity for complete and balanced orientation to the topic. Since each discipline has the advantage of working with the others, this approach should provide stimulation for all the members of the team. Opportunities for joint discussion would ensure a pooling and interchange of knowledge and skills. In addition to the opportunities for effective handling of the research topic, a multi-disciplinary approach should afford maximum learning opportunities.

Disadvantages.-

In any group project, there are also possibilities of obstructions, time lags and confusion, unless some one individual with skills in group leadership has been definitely invested with this responsibility, and unless preliminary planning has been effective.

Problems can arise from the fact that several individuals are involved. When more than one discipline is also involved, further difficulties can arise through failure to delineate the specific roles of each discipline, and through lack of basic understanding.

It is implicit in the nature of a group project that planning, to be effective, must be done when all members are present. This means that considerable time must be planned for joint meetings. As it is frequently difficult to arrange meeting times when all participants are available, time may be lost and delays become inevitable unless careful planning has been done.

Since each participant is partially dependent upon all of the others, it may not be possible for each to proceed at his own rate. This may mean a slackening off of interest for some participants and a feeling of pressure for others. These factors may constitute a definite problem in the planning of the whole project, when there is a time limit imposed for its completion.

Evaluation of Methods as Applied to the Assignment of the Student Social Workers

The methods used in this study have been outlined in Chapter II. The efficacy of these methods as applied to the assignment of the student social workers must be considered from three aspects: one, as an opportunity for individual learning, both in regard to research techniques and in regard to the subject matter of the topic; two as an experimental study in methods; and three as a means of contributing to knowledge of the topic.

In spite of, and to some degree because of, administrative and management difficulties, this project provided valuable learning

experience in research techniques. Because the student social workers had the stimulation of direction, instruction and interpretation of various factors in rheumatoid arthritis from the two psychiatrists, the project also afforded excellent learning experience in relation to the topic.

Although there was some weakness in the sample and the resultant statistical findings, the results of the studies have made some contribution in that certain other studies have been supported, and certain significant trends have been shown. It would appear that the amount of reliance that could justifiably be placed on quantitative measures in a dynamically oriented study of people would be doubtful.

The greatest value in the project would seem to be in its "pioneering" aspect, as an experiment in methods which should prove useful to other similar projects. It is the opinion of the student social workers who participated in the project that the experience gained should facilitate the projects to follow. It is from this viewpoint that the following recommendations are offered.

Recommendations For Future Projects

1. The investment of some one individual with definite responsibility for group leadership appears to be of basic importance. This individual should possess leadership skills, so that maximum integration might be possible.

2. Clear delineation of supervisory responsibility appears to be of equal importance.

3. Full understanding and agreement is necessary in advance of the research design on the part of those members of the research team who are to carry supervisory responsibility.

4. The structuring of a definite time sequence for the project and the setting of target dates should ensure an effective apportioning of time. This should be accomplished in the preliminary planning stages.

5. Full and early exploration of resources for case finding should be undertaken to avoid the possibility of later management difficulties.

6. Complete orientation of all participants to the topic, the research design, and the contribution expected of all disciplines, should be accomplished.

7. A careful delineation of the roles of the respective disciplines and individuals appears to be of importance.

8. Definite planning and defining of the information to be extracted from the interviews should be done before the structuring of the interview schedule.

9. Trial interviews should be undertaken after the preliminary interviewing schedule has been agreed upon. Adjustments could then be made in the form of the schedule on the basis of the experience gained from these interviews.

10. A uniform method of recording should be worked out from the

material obtained in the trial interviews.

11. Since interviewing time is limited, every effort should be made to reduce the more time-consuming aspects of management phases. If possible, cases should be screened and patients prepared for participation in the project in advance, so that interviewing time would not have to be used in this way. If this cannot be done, this should be taken into consideration in planning the research design, and a more limited unit of research should be planned

12. Student social workers require some instruction in techniques of interviewing, since the methods used in research differ from those in which social workers are trained.

13. If possible, presentation of the project should be undertaken in a single integrated unit, with joint introduction and joint conclusions.

APPENDIX A

CHARACTERISTICS OF PATIENTS USED IN STUDY

I. Number of Patients Studied - 80.

II. Sex Distribution of Patients - Male 27
Female 53

III. Marital Status of Patients at Time of Study -

TABLE A1

Marital Status at Time of Study

Marital Status	Total	Male	Female
Total	80	27	53
Married	45	17	28
Single	12	5	7
Divorced	2	1	1
Separated	8	3	5
Widowed	12	1	11
Common-law	1	0	1

The greatest proportion of both males and females were married at the time of this study. The next largest

group of men were single; of females, widowed. One ninth of the total neumber of men were separated; more than one seventh of the women were separated. The same numbers were divorced. One woman was living in common-law relationship. None of the men was living in common-law relationship. Almost a fifth of the women were widowed but only one man out of the 27 was a widower.

IV. Numbers of Children per Patient -

TABLE A2

Numbers of Children per Patient

Numbers of Children per Patient	Patients		
	Total number having children	Male	Female
Total number of patients having children	80	27	53
0	24	12	12
1	12	3	9(a)
2	18	3	15
3	12	5	7
4	11	3	8
5	1	1	0
Over 5	2	0	2(b)

(a) Two of these children were born of common-law relationships.

(b) One patient had 10 children, another had 7.

Thirty-six patients had no children. The next largest group (18) had 2 children. Twelve patients had 1 child

and 12 had 3. Only 2 patients had more than 5 children Six of the 7 single women had had no children. Six of the women who had been married at some time had had no children.

V. Age at Time of Examination -

TABLE A3

Ages of Patients at Time of Examination

Age group	Total number of patients	Patients	
		Male	Female
Total number of patients	80	27	53
16 - 25	3	3	0
26 - 35	9	4	5
36 - 45	20	7	13
46 - 55	23	10	13
56 - 65	18	3	15
Over 65	7	0	7

Female patients tended to be an older group than the male patients. The largest number of female patients was in the 56-65 age group, with an equal distribution coming next in the age groups 36-45 and 46-55. The largest number of male patients was in the 46-55 age group, with the next largest number falling into the 36-45 age group. Three male patients were under 25. There were no female patients in this age group. Seven of the female patients were over 65. There were no male patients in this age group.

VI. Degree of Disability of Patients at Time of Study. -

TABLE A4

Degree of Disability at Time of Study

Degree of disability(a)	Total number of patients	Patients	
		Male	Female
Total number of patients	80	27	53
Bed-ridden(b)	5	1	4
Confined to house but requiring care(c)	11	7	4
Confined to house but able to do light work(d)	17	3	14
Able to work part-time	17	4	13
Able to work full time(e)	30	12	18

(a) Degree of disability is considered here in terms of social function. Classifications are purely arbitrary.

(b) Patients are considered here as bed-ridden when most of their time is spent in bed.

(c) Patients are considered here as being confined to house when they must have help to leave the house.

(d) Some women were confined to house but performed light household tasks. The two men in this category were able to leave the house although their disability was quite marked at the time of study.

(e) Women patients are considered here as able to work full time when they perform household tasks with minimal assistance or require no assistance.

APPENDIX B

STRUCTURE OF THE INTERVIEWS

I. Dynamics of Parent Family

A. Distribution in time and space

1. When and where did the individual marry?

2. How often and through what localities have the parent family moved since marriage until the present time?

B. Disruptive and cohesive tendencies of parent family

1. Was it the first time the individuals had been married?

2. Have the marital partners ever separated since their marriage?

3. If so, on how many occasions?

4. For what cause?

5. History of movement of additional members if they were not direct siblings. Peak size of family.

6. Was the family considered free from unpleasant emotional tension? If not, what were the causes and how did it show itself?

7. At what age did each sibling leave the family?

8. For what cause?

9. What was the emotional relationship at the time of leaving?

10. Have any siblings ever returned to the family after leaving?

11. If so, for what cause?

12. If so, how many times?

13. What was the emotional relationship between them and the family on their return?

II. Patterns of the Family at the Time of Study

A. Dwelling

1. Type.

2. Condition.
3. Number of rooms.
4. Sleeping arrangements.
5. Heating.
6. Lighting.
7. Water supply.
8. Washing facilities.
9. Proximity to shopping centres.
10. Social level of neighbourhood.

B. Human structure

1. List the number of individuals living together as a family and give their legal relationships.

2. State the division of labor within the household.

3. State the work history of each family member who is gainfully employed.

4. Enumerate each source of the total income of the family. What is the total income of the family?

5. What is the social level of the family?

6. Which member of the family is financially dominant?

C. Emotional patterns of family

1. Have the parents such a close relationship with each other that all other relationships can be regarded as secondary?

2. If this is not so,

   (a) Does either parent derive the major part of his emotional satisfaction from an adult relative?

   or

   (b) Does one or both derive his major satisfaction from the children?

   or

   (c) Do the children derive their major satisfactions from each other to the exclusion of the parents?

3. Describe any other pattern not included in the above.

4. Who is the emotionally dominant member?

5. Who is the intellectually dominant member?

D. Personalities of adult members of the family

Describe all the adult members of the family in the following fields:

1. Family.
2. Occupational.
3. Recreational.
4. Cultural.
5. Political.
6. Religious.

In such of these fields, describe the individual in terms of the following characteristics:

1. Self-reliant or dependent.

2. Having more evidence of self interest or concern and consideration for others.

3. Domineering in attitude or usually anxious to avoid trouble.

4. More inclined to gain his ends by active competition or indirect means.

5. When he is under emotional strain or frustration, is he more likely to bottle up his feelings, or become irritable and explosive?

III. The Patient's Illness

1. Circumstances of onset.

2. Course of illness.

3. Treatment received from viewpoint of patient.

4. Degree of disability.

5. Attitude toward illness:

(a) Did he accept fully the implications of illness or did he tend to regard it as less serious than it was?

(b) What were his reactions in regard to effort?

(c) Is there any evidence of his using the illness to get his own way?

(d) How does he feel that his friends, associates, neighbors,

families and representatives of social agencies are reacting to his illness? Is he satisfied with this reaction?

6. Description of the personal habits of the patient before and after illness in the following fields:

(a) Mental.
(b) Body activity.
(c) Business.
(d) Social.
(e) Recreational.
(f) Cultural.
(g) Religious.

APPENDIX C

SAMPLE CASE HISTORY

Case Number - 77

Age - 31

Sex - Female

Marital Status - Married

Social Level - Low

Extent of Disability at Time of Study

Patient has swelling in her wrists and the back of her knees, but has had little pain for last two years. She is able to do her own work with some modications. She uses a mop instead of getting down on her knees to wash the floor, etc.

Appearance

Patient is a very thin young woman. She has delicate features and delicate coloring. In spite of hardships, she keeps a fair standard. She is dressed neatly. The house is very drab but clean.

Attitude to Questioning

"I'm glad to help - I've been helped myself - I enjoy talking to people - glad to tell you anything that would help anyone else". She discussed all aspects of her life freely.

Sources of Information

1. Interview with patient.
2. Interview with sister.
3. Medical chart.

I. Dynamics of Parent Family

A. Distribution in time and space

1. Married 1911, Montreal, (Mother from England, Father born in Montreal).

2. Remained in Montreal.

B. Disruptive and cohesive tendencies

1. First marriage for both parents.

2. Parents never separated.

3. Parents never separated.

4. Parents never separated.

5. No additional family members at any time. Peak time 8. Mother, father, 6 children.

6. Patient - "Our family was as happy as most, I think, in general - never much money, but we lived decently and kept eating. Mother was very strict with the girls - boys could do anything".

   Tension points.- Mother died of a heart attack when patient was 17. She had had arthritis for 10 years before death. She was bedridden for the last 3 years. The father lost his job at time of the mother's death. There was financial worry. The oldest sister spent 2 years in T.B. sanatorium. On her return, the mother "gave up and went to bed". The sister became head of the family. The patient resented her at the time.

7. Age of leaving family
   1. Sister - 20 - away at T.B. sanatorium 2 years (1932). (Mother died 1935).
   2. Brother - 23 - married (1939).
   3. Patient - 21 - married (1942).
   4. Sister - 23 - married (1948).

   Attitude of family at leaving.- Family was upset and worried when the oldest sister went to T.B. sanatorium. (Patient was 14). After the mother died, the father was very possessive of children. The family very close. "It was hard to leave - everyone was sad. The worst was when my youngest sister got married - everyone missed her so".

8. Comment.- None of the siblings ever returned to the parent family after leaving to get married. This family was always close-knit. The father "lived for his work" (manager of chain grocery store). He appeared to be very passive in his relationships with family - "we hardly knew he was there". Mother appeared to have been an efficient, hard working, rather rigid woman. She dominated the whole family. She appeared to be closer to the oldest sister and 2 boys than to the father. When she became bedridden and the oldest sister came home from sanatorium, the sister took over the mother's role, with the same kind of dominance in family.

   The patient expresses resentment at her mother's and sister's

strictness. She states that she was never close to her mother. "She treated me as if I was dopey or something". According to the sister, she frequently said that nobody in the family understood her - all her recreations and pleasures were outside the family. (Sister - "Away from the family, she didn't seem to have a care in the world - lots of friends, parties, week-end trips, etc.".)

The sister feels that she resented the twins, four years younger, that she felt they received more attention than she did. She frequently teased them. "She always seemed to feel like 'the odd man out' in the family".

9. Siblings

1. Sister - 38. At home - unmarried. She stayed at home from time of her return from T.B. sanatorium to look after the family until 1944. She has worked in factory since that time. "She gave up her chances for the rest of the family". She leads a very active life now. She still runs the house, but has many outside activities, Women's Clubs, etc. She had read a great deal - "has acquired more culture than anyone". She is said to be self-reliant, and is considered domineering. She appears to obtain satisfaction by active competition, but shows much concern for others. She is considered more tense than relaxed.

2. Brother - 36. Never married. He was in the navy during World War II. He has never been the same since. "He was very bright at school, won scholarships, but never seemed to get on his feet - seems bitter, discouraged - keeps things in - working part-time at Post Office". He is considered dependent, anxious to avoid trouble, and likely to gain his ends by indirect means. He shows more evidence of self interest than concern for others, and is said to be more likely to bottle up his feelings than to explode under stress.

3. Brother - 34. Married. He is working full time at the Post Office. "Easy-going, takes things in his stride - always on the go - good health". He is considered self-reliant, but anxious to avoid trouble. He appears to have some competitive drive, but shows concern and consideration for others. He tends to become explosive under tension.

4. Patient - 31.

5. Sister - 27. Married - "very kind, good-natured, honesty, very important - sympathetic - always avoid argument". She has had fairly severe asthma. It has improved since marriage. She is considered more

dependent than self-reliant, and appears anxious to avoid trouble. She shows little active competition and shows more concern and consideration for others than self interest. She tends to bottle up her feelings if under stress.

6. Sister - 27. At home, unmarried, working. "Strong personality, very determined, but quieter - not friendly - plans ahead, thinks in logical way". She is considered self-reliant and tends to be domineering. She shows more evidence of self interest than concern for others. She tends to gain her ends in indirect ways and bottle up her feelings under stress.

Illness in Family

Mother, maternal aunt - arthritis (aunt now bed-ridden).
One sister - T.B. - 20 years ago - good recovery.
One sister - asthma - improved.

Parent Family at present Time

Father
Sister - 38 - unmarried.
Brother - 36 - unmarried.
Sister - 27 - unmarried.

II. Patterns of Family at Time of Study

A. Dwelling

1. Type.- Ground floor flat.

2. Condition.- Poor.

3. Number of rooms.- Kitchen, livingroom, hall, 2 bedrooms, bathroom.

4. Sleeping arrangements.- Children (4) share 1 bedroom, patient and husband share the other. When the husband is away, the youngest child sleeps with mother.

5. Heating.- Coal heater in hall - all rooms open - heat circulates well.

6. Lighting.- Electric lights but the general effect is dark and dull.

7. Water supply.- Running cold water, but not hot. Flat has toilet but no bath tub. For baths, water has to be heated on the gas stove. The family tin bath in kitchen.

8. Washing facilities.- Patient sends out as much of her washing as possible to the laundry. She has no washing machine, and all water has to be heated on the gas stove.

9. Proximity to shopping centres.- There is a small store across street - otherwise, patient has to take street car to larger stores. The closer store more expensive.

10. Social level of neighbourhood.- Low.

This family have lived in the present flat since 1945. Patient is sensitive about the district, and finds the flat "depressing, hard to keep up, dark, dull". She described it as being much worse when the family first moved in - "It was filthy - the walls and ceilings were black - it was over-run with mice - we caught over 200 in the first few months - I'm terrified of mice". Rent $22.00.

B. Human structure

1. Patient (mother) - 31.
Husband (father) - 30. (At present in psychiatric ward D.V.A. Hospital. Diagnosis - Anxiety Neurosis.)
Children - Son - 9 (premature). School.
Daughter - 7. School.
Daughter - 6. School.
Daughter - 3. Home.

2. Patient - housewife.
Husband - outside work (never regularly employed since marriage).

3. Occupation
Husband.- Husband was still in the army when they were married. He had been sent back to Canada from Overseas because "his nerves cracked up". He was given his discharge shortly after marriage. He has never held a job since. He always left because "he couldn't stand something about the job. He tried everything, his last job was at Canadair. He left this to go to hospital, November 19, 1951". He is now earning spending money at the hospital by doing woodwork. He hopes to be able to start a small woodwork business of his own on discharge. (He had tried welding, work at the Post Office, etc.; this employment was interrupted by hospitalization 3 times in last 3 years.)
1949 - 8 months Psychiatric ward, D.V.A.
1951 - 4 months Psychiatric ward, D.V.A., January - April.
1951 - November to present date.
Patient.- Patient attempted to work at a laundry for a month in 1943. She left because she was nauseated in

in the mornings.

4. Income.- Present income $20.00 per week from group insurance (this expires end of February 1952) plus $23.00 per month Family Allowance on March 1st. Social agency to pay rent ($22.00), light ($4.00). $17.50 a week to be paid for food, clothing. Social agency has given financial assistance on and off for past 3 years.

5. Social level - low.

6. Financial dominance - husband, when able to work.

C. Emotional Pattern of Family

At the present time, the patient appears to have a closer emotional tie with her sisters than with her husband. This appears to have been a gradual process and has evolved during the past 3 years, since the husband has had frequent hospitalizations. The patient appears to have always been the emotionally and intellectually dominant partner. Patient said, "When I was married first, I was too cocky - felt I was my own boss, could do as I wanted - put down payment on furniture - caused lots of debts - then when my husband began to be ill, I thought I'd been too dominating, aggressive, so I tried to be helpless and dependent - nothing made much difference - for the past 3 years, I have decided it's better to be myself - can't expect to do for my husband what the best psychiatrists haven't been able to do - now I just try to accept the situation, and leave it to the people who are trained in psychiatry. I did finally find out that my husband thought I depended too much on my family - we've always been very close, so I tried to keep my troubles to myself, and concentrate on him - that didn't seem to make much difference either".

The sister said - "She wore herself out, trying to be six different people to help her husband".

D. Husband.- (At present in the psychiatric ward, D.V.A. hospital. Diagnosis - Anxiety Neurosis).

The patient's sister said - "He's a very obliging, timid person - the sort of person you hardly notice in a room - contrast to my sister - before any sickness in their family she was "the life of the party" - anything for a laugh - you never noticed him".

The patient said - "He's afraid of everything - no self confidence - shy - hard for him to make friends - pretty dependent - gets discouraged easily - when he's getting sick loses

interest in other people and gets wrapped up in his own feelings - can't express them - hates argument - always tries to avoid trouble - can't face competition - gives up easily."

"When he is getting sick he is frightened, worried, fidgetty - can't sleep - reads all night - keeps phoning doctor".

Until the patient's illness, the patient and her husband went out together fairly frequently. The husband's mother or patient's sisters looked after the children. There were also frequent evenings when patient's sisters and husbands or friends spent evening at patient's home. There were few extra-marital contacts for either partner, aside from these evenings.

Patient

Before illness.- Sister said, "When we were all home together, she was the independent kind, 'nothing bothers me'. She spoke her mind and pretty freely. She felt nobody understood her at home. She was pretty resentful sometimes - but she was pretty popular, and made friends easily. She was 'the life of the party', and was always going some place - away from home more than others - not 'bossy' but knew her own mind. She was very generous and was always buying things for us kids when she started to work - she would do anything for anybody and seemed sure of herself. She was very competent - at 17 she was looking after a family of 4 children. Always liked nice things - made $2.50 a week doing housework when going to high school - saved it - bought clothes, but always willing to help us too - always on the go".

Interview impressions

1. Self reliant.
2. Concern for others.
3. Domineering rather than anxious to avoid trouble - (not marked).
4. No marked evidence of active competition or of using indirect means to gain her ends.
5. Under emotional strain she tends to be irritable and explosive - (not marked).

Since illness.- The sister said, "She didn't seem to change so much after she got sick until her husband got sick too. We still used to have parties at her place after she was sick, but now she seems different. She lives on sympathy and doesn't seem so sure of herself somehow. She gets bitter and resentful and tries to hide her feelings. She pretends things are better than they are - now she seems more anxious to avoid trouble. It's kind of as if she's beaten down, and seems more because of her husband than because of her own illness, though".

The patient said, "I've changed quite a lot, I guess - had

to grow up, learn to live differently, keep my troubles to myself, do without things, accept things. I have learned a lot. It was terrible to have to ask for financial assistance. When I have to phone the social agency again, I feel sick, but I have to face it and go through with it".

III. Patient's Illness

1. Circumstances of onset

The patient said, "About 5 years ago, I was pretty run-down - it would be about April, 1947, I started having stray pains. Sometimes, they were pretty severe, but it would pass off. There was no swelling or stiffness, I could do everything. That summer the 3 children and I went out to my brother's place in the country for a holiday. There was no conveniences, like running water; we had to walk a long way into the village for groceries. The pains got worse, then my wrists started to swell. I thought I'd sprained them at first, carrying the babies so far. I knew what it was as soon as my fingers began to swell. I remembered how it was with my mother".

2. Cause of illness

"It kept getting worse steadily - by January, 1948, when I went to St. Mary's Hospital under observation, all my joints were affected and I had terrible pain in my legs, knees, neck and shoulders. The nights when I went to bed were terrible agony. I couldn't go to bed because of the children. I could walk only with awful pain and getting dressed was torture. I had to get food ready for children, but couldn't open cans or cut bread. I tried to do dishes but broke many. My husband worked all day at job, then came home and did housework, washing, etc., at night. The children were able to do quite a lot even if they were little. I was really not able to dress, undress, comb my hair. After a few months of this, my husband told me I didn't know how to relax. He tried to teach me. He said I was all tensed up. He said take each limb and pretend it was soft like dough. Sometimes he would rub my arms and help relax me. Sometimes, I'd be covered with sweat I'd be trying so hard. I finally learned, though. I have never had so much pain since. There has been a gradual improvement.

Two summers ago it got pretty bad again. Now I think it was more nerves than arthritis. I went to a Convalescent Home. My husband had just had another breakdown. He was in the hospital again. It seemed as if I just went to pieces, gave up, and couldn't face anything. It was my husband's psychiatrist who wanted me to go to a Convalescent Home. My husband was worrying about me. I was bad like I'd been a year before - maybe not as bad as

I thought then, though - maybe just because I gave up. The children all had to go into foster homes - both parents were in hospital at the same time. It was hard on them, too.

I gradually got better again and have been about the same for the last year or two. There has been little pain but much swelling of my wrists, the back of knees, and occasional pain in my upper arms. I can't get on my knees. I use floor mop but can't squeeze it out. I can't wash much or little finger 'locks'. I can do pretty well everything for myself and around the house. The stairs are hard. I have to pull myself up by hand-rail, but can make them - hard to get up step on to bus or streetcar - not much control and have fallen a lot but I do get out. I keep trying to see how much I can do - if there is too much pain I stop."

3. Treatment received from viewpoint of patient

"I have tried all sorts of things myself before I went to hospital - anything to try to get relief. Sloan's liniment helped a little at first, then it was not strong enough, then soaked Thermogene in liniment, used mustard poultice - lived on aspirins, went to St. Mary's Hospital for observation. I was in about 15 days (January, 1948). I had no treatment, but had X-rays and had my teeth out. I had thought I might be pregnant. They verified this and told me to come back after the baby was born. I didn't think they could help, so never went back. I got better shoes, this helped my posture. It's not so hard to walk now.

I had 14 injections of gold at the clinic, one course of treatment. I don't want any more. My finger never locked before I had it. I have noticed the same thing in other people who have had it. I'm afraid of it. I asked about Cortisone. People seemed to have been helped so much. I was told it was so expensive and that it was only used for people who are the worst. I was disappointed but I can understand that".

4. Degree of disability

Never bedridden - confined to house in 1947 and 1949 for a few months each time.

Present.- All activities are restricted, but she is able to do her housework and go out. The disease appears to have been stationary for the past year or year and a half.

5. Attitude to illness

(a) "I justgave up in the beginning. I thought I'd just get

worse and be bedridden like Mother, I was so scared I couldn't do anything. If my husband and sisters hadn't given me so much courage and encouragement, I don't know what would have happened. I guess I'd have just sat there forever. The children made me get going too. I was so frightened, I was afraid to try anything in case I got worse. I got that way again 2 summers ago. Now I feel there's hope. I used to be very bitter and depressed. My sisters have helped me a lot".

(b) "I gave in to it right away, then sometimes tried to fight it. My husband taught me to accept it, but relax. I know for sure that being emotionally upset makes a difference. That's why I'm trying to accept my husband's illness as it is and leave it up to the doctors. When I begin to fuss and try too hard to help him, I get worse right away."

(c) The sister feels she had needed and obtained much sympathy through her illness. "She lives on sympathy". No direct evidence of using it to gain her own ends.

(d)"Everyone's been awfully good to me - my husband, the family, social agencies, I hate to have to ask for help, though".

6. Personal habits

Before illness	Since illness
(a) Very little reading.	Increase in reading - pocket novels, popular psychology, child care, etc.
(b) Much body activity - "full of pep - always on the go" - walked a lot - walked to work - always ran upstairs - as child "loved running", roller skating, basketball - "had to keep going".	No activities that are not necessary now - "glad to be able to crawl upstairs". No increase in body activity in beginning of illness - "afraid to try".
(c) Did housework week-ends while attending school - when left school, packed tobacco, continued housework week-ends after school.	Tried to work at laundry, fall of 1947, half day - nauseated in morning (illness had just begun).
(d) "Always liked to get around, do things, see people". Sister - "Lots of friends, full of fun - Loved parties".	Social contacts almost completely restricted (feels due more to husband's illness and financial situation than to own condition).

(e) "Used to love shows, parties, some dances - still able to do a lot together first few years of marriage - no patience with inactive things, like cards, reading - always lots to do".	Learned to play cards, reads - goes to card parties occasionally. Cannot be comfortable in movies - but could not attend regularly because of lack of money. Little recreation.
(f) No cultural activities.	Some reading.
(g) Attended church regularly (R.C.).	Attends only occasionally - self-conscious, unable to kneel.

V. Summary

Physical.- Patient has never been bedridden, but has had moderately severe arthritis since the summer of 1947. At worst, the periods, both motility and eye-hand-mouth activities were severely restricted. She could walk only with greatest pain, and required help in dressing and eating.

Environmental.- Change in general environment seems to be more due to husband's illness (Anxiety Neurosis - frequent hospitalization) and unstable work record than to patient's illness.

Her activities have been severely restricted, partly because of husband's condition and economic condition, partly because of arthritis. She was previously very active socially - "always on the go", now has almost no social activity. She has learned to substitute some activities within her scope as reading, playing cards.

Emotional.- Patient and sister both recognize considerable changes in her. This was felt to be also partly due to husband's illness. She was described before illness as being "often generous, anything for a laugh". Since her illness, "She's different - sort of quieter as if she's been beaten down - sometimes bitter, sometimes pretends things are all right - lives for sympathy". The patient herself considers that she has matured and learned acceptance.

Both patient and sister feel there is a close emotional tie-up in the arthritis - definite exacerbation with each new anxiety attack of husband's.

APPENDIX D

MAIN ACTIVITIES OF INTERVIEWER IN REGARD TO CASES

All cases studied by the writer were obtained from the Royal Victoria Hospital Out Patients' Arthritis Clinic.

A. Reading and Summarizing Medical Charts

In each case, before any attempt was made to make contact with the patient or a relative, the medical charts were read and summarized, in order to obtain identifying information, and any other information which appeared to be useful in corroborating some of the patients' statements. This was also one method of screening the cases.

Number of medical charts read and summarized - 44.

Number of cases discarded from reading medical charts - 9.

TABLE A5

Reasons for Discarding Cases from Medical Charts

Reasons for discarding cases	Number of cases discarded
Total cases discarded	9
No diagnosis of rheumatoid arthritis	1
Under psychiatric treatment at time of study	1
Transferred to other interviewer	7

Number of cases retained after assignment and reading medical charts - 35.

B. Attempting to Arrange Appointments with Patients and Relatives

After cases were screened through the medical charts, and charts were read and summarized, the interviewers attempted to arrange appointments with the patients.

Number of cases where attempts to arrange appointments were made - 35.

Number of cases where appointments could not be arranged - 15.

TABLE A6

Reasons for Discarding Cases after Attempting to Make Contact

Reasons for discarding cases	Number of cases discarded
Total cases discarded	15(a)
Not interested	0
Patient dead	1
Language difficulty	3
Already interviewed by other interviewer	4
No longer at address given	7

(a) In 9 of the cases, home visits had to be made in order to establish whether or not the cases could be used. In 6 of the cases, letters or telephone calls were used for this purpose.

C. Home Visits

Home visits were arranged in every case possible. In some cases further screening was done at this time.

Number of home visits made - 46
Number of home visits without interviews - 14
Number of home visits with interviews - 32

TABLE 7A

Reasons for Lack of Interviews
During Home Visits

Reasons for lack of interviews	Number of visits
Total	14
Visits for arranging appointments	5
Patient dead, no longer at address given, interviewed by other or not able to speak English	9

D. Office Interviews

In a few cases, where it was not possible for patients to be seen in their own homes, office interviews were arranged at the Royal Victoria Hospital.

Number of appointments kept by interviewer - 5
Number of appointments not kept by patients - 2
Total number of office interviews - 3

E. Interviewing

TABLE A8

Numbers of Interviews with Patients and
Relatives and places of Interviews

Individuals interviewed	Total home and office interviews	Place of interviews	
		Home	Office
		Total home interviews	Total office interviews
Total individuals interviewed	35	32	3
Patient interviewed alone	25	22	3
Patient interviewed with relative	4	4	0
Patient interviewed alone	6	6	0

F. Arranging Appointments for Patients with Psychiatrist

Ten appointments were arranged between patients and psychiatrist. In most cases, this was done by means of telephone calls.

General Remarks

As the public transportation system was used, and some of the patients lived in the outskirts of the city, travelling time was sometimes excessive. In a few cases, three hours would have to be allowed for a return trip; in many others, two hours was required. This factor, together with the limited time at the disposal of the interviewers made for some difficulties.

APPENDIX E

SAMPLE KEY CARD FOR ABSTRACTING INFORMATION COVERING ADAPTATIONS IN DWELLING AND HUMAN STRUCTURE OF RHEUMATOID ARTHRITIS PATIENTS

Case number _____ Age _____ Sex (male, female) Marital status (married, single, divorced, separated).

Degree of disability (able to work full time, part-time, unable to work).
Nature of disability (locomotion, hand-eye co-ordination, both).
Duration of disability in years _____.

Dwelling.-

Is patient satisfied with his dwelling? (Yes, no).
If not, is he dissatisfied because of needs of his illness? (Yes, no).
If he is dissatisfied because of his illness, state specific reason. ___

State any other reason for dissatisfaction with dwelling _____

Was interviewer satisfied with dwelling? (Yes, no).
If not, state reason _____
Is present dwelling considered cold, damp or both? (Yes, no).
If so, indicate whether cold, damp or both. (Cold, damp, both).
Did patient live in present dwelling at the time illness began? (Yes, no).
If not, was the dwelling cold or damp? (Yes, no).
Has family ever changed dwellings because of patient's illness? (Yes, no).
If so, what was the specific reason in relation to illness? _____

Have any modifications ever been made within dwelling because of patient's illness? (Yes, no).
If so, state what specific modications were _____

Remarks _____

Human structure.-

State present human structure of family _____
Has this structure ever been known to have changed during course of illness as an adaptation to illness? (Yes, no).
State specifically what these adaptations were _____

Remarks _____

SAMPLE KEY CARD FOR ABSTRACTING INFORMATION COVERING ADAPTATIONS IN FUNCTION OF FAMILIES OF RHEUMATOID ARTHRITIS PATIENTS

Case number _____ Age _____ Sex (male, female) Marital status (married, single, divorced, separated).

Degree of disability (able to work full time, part time, unable to work).
Nature of disability (locomotion, hand-eye co-ordination, both).
Duration of disability in years _____.

Human structure of family. _____

Function.-

A. Income
Has the patient ever contributed to the family income? (Yes, no).
If so, has the illness ever affected his contributing? (Yes, no).
Has his income ever stopped because of illness? (Yes, no).
If so, what adaptations were made to meet this? _____
_____
Has his income ever been reduced because of illness? (Yes, no).
State the manner in which income was reduced (change in job, no longer able to work full time, gave up part time work, long term, expensive treatment).
If income reduced how did the family meet this _____
_____
Has the income ever been increased because of illness? (Yes, no).
If so, state reason _____
_____

B. Division of labor
State divisions of labor in family at time of study _____
_____
Has the patient's illness been responsible for present pattern? (Yes, no).
If so, state adaptations made _____
Have other changes in divisions of labor been made at any time because of illness? (Yes, no).
If so, state adaptations made _____
Remarks _____
_____

SAMPLE KEY CARD FOR ABSTRACTING INFORMATION COVERING DOMINANCE PATTERNS IN FAMILIES OF RHEUMATOID ARTHRITIS PATIENTS

Case Number _____ Age _____ Sex (male, female) Marital status (married, single, divorced, separated).

Degree of disability (able to work full time, part time, unable to work).
Nature of disability (locomotion, hand-eye co-ordination, both).
Duration of disability in years _____.

Human structure of family _____
Who is financially dominant in family?
Who appears to be intellectually dominant in family?
Who appears to be emotionally dominant in family?
Has the patient lived in this group throughout course of illness?(Yes, no).
If so, does present pattern appear to be result of illness? (Yes, no).
If so, how did it appear to differ before the illness? _____
_____
Have any other adaptations to the illness been noted by the interviewer? (Yes, no).
State what these adaptations are _____
_____
Remarks _____
_____

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