McGILL UNIVERSITY

FACTORS AFFECTING THE REHABILITATION OF TUBERCULOUS PATIENTS

A Study of Forty-three Patients Discharged with Medical Approval from the Grace Dart Hospital within the Period from May 1951 to November 1952 with reference to Their Psychological, Social, Economic and Familial Adjustment

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This thesis was written on the assumption that there are many factors which affect the rehabilitation of tuberculous patients, and that present facilities are inadequate to insure maximum adjustment. The study is based upon 43 patients who had been discharged from the Grace Dart Hospital in 1951-52.

The thesis is submitted by four students as a group project. Each student has been responsible for one of the four sections into which the material has been divided: the psychological adjustment of single patients to the illness; the psychological adjustment of married patients to the illness; the effect of hospitalization upon the economic status of patients and their families; and the adaptive processes in the families of tuberculous patients. Each section has been presented in two chapters, and contains an examination of the data compiled in relation to the topic under consideration.

The findings of this thesis show that there are many factors within the patient, in the hospital and in the community which affect his rehabilitation, and that the services and facilities which are now existent for the use of tuberculous patients are not extensive enough to ensure optimum rehabilitation.

PREFACE

This study was carried out as a group project, by four students in their second year at the McGill School of Social Work, as partial fulfilment of the requirements for the M.S.W. degree. The research was begun in the autumn of 1952 and continued during the winter of 1953, following recognition on the part of medical authorities that further rehabilitation services to the tuberculous were required. It was considered important to interview discharged patients themselves, and to study their hospital and clinic records in order fully to assess their problems.

The thanks of the writers are due to their Advisory Board which included Dr. Eric Wittkower, Dr. Jack Rubin, Miss Eva Younge, and Dr. G. R. Howell. To Dr. Howell, Medical Director of Grace Dart Hospital goes special appreciation for his interest and co-operation throughout the study. The writers also wish to express their gratitude to the Board of Directors of the Grace Dart Hospital for their permission to carry out this project and to the clerical staff of that hospital who were patiently helpful throughout a trying period of selecting records and materials. The group is particularly grateful to Miss Helen Tuck whose continued interest and support has made it possible to complete this, one of the first group theses successfully completed at the McGill School of Social Work. Lastly, thanks is extended to the patients interviewed who were, without exception, co-operative and willing to give of time and experience.

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CHAPTER I

INTRODUCTION

Within recent years the whole concept of illness and treatment has undergone radical revision and emerged with a shift in emphasis and a broadening of its base. It had been accepted practice to concentrate on the diseased organ which was treated as an entity existing independently of the patient. Gradually, however, came the recognition that the emotional and social together with the physical features of illness enter into the disease process and should be considered together in order to restore the individual to full health. It had become apparent that all the fears and worries which have plagued the patient throughout his previous life, those occasioned by his illness, and those which the illness engenders in terms of the future, play an important role in the course of the disease, his response to treatment and degree of recovery.

This amplification of the concept of illness has repercussions in the area of treatment. Hatfield says , "A patient cannot be divided into parts. He must be looked upon as a whole human being".[1] The significant trend in

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[1] L. W. H. Hatfield, Handbook on Tuberculosis. Provincial Board of Health of the Province of British Columbia, 1944, P. 49

the treatment today therefore is the consideration of the personality of the patient in relation to his social milieu rather than just the isolated disease entity.

In line with this thinking rehabilitation is now considered to be an essential part of the treatment process. Although physical recovery may be complete, psychological invalidism may nullify all the work of the medical team. The goal of rehabilitation has been defined as "the restoration of (patients) to the fullest physical, mental, social, emotional, vocational and economic usefullness of which they are capable".[1] To be effective, rehabilitation should begin at the time of onset of the disease, and it is a continuous process of adjustment requiring a number of services and resources operating together and concurrently.

Especially does this goal seem relevant for the patient who has been hospitalized with tuberculosis, for his illness, by its very nature makes inroads into all departments of his life. Frances Upham states that "the patient with tuberculosis is faced with more facets of personal and family adjustment than most other sick people".[2]

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1. Caroline Elledge, The Rehabilitation of the Patient. (Philadelphia, 1948), p. 2.

2. Frances Upham, A Dynamic Approach to Illness. (New York 1949), p. 110.

It is financially costly, because it demands that he relinquish his job, for months or maybe years, and thus resign himself to economic dependency which, in turn, often gives rise to feelings of failure and inadequacy. His illness may have brought about changes in family structure and family patterns. After hospitalization he may find his same job waiting for him; often he will not. Sometimes physical inadequacy may make a return to former employment impossible. The patient may find that the role he once played in his social group is no longer open to him.

In addition, these problems have been prefaced with the patient's own reaction to his diagnosis and need for hospitalization. There is no specific and permanent cure for tuberculosis. In the past, it had been a hopeless disease, and while it may now be arrested or improved, many fears and anxieties about the outcome of the illness persist. The fact that it may become reactivated at any time, is a worry that may follow the patient even after he has been discharged from the hospital with his condition arrested. As it is also an infectious disease, the patient may consider himself a menace to his family and friends, and while much has been done in the way of educating people about the nature and treatment of tuberculosis, a social stigma has still persisted. The treatment of the disease requires long periods of bed rest which preclude normal activity and gives the individual little

chance for the outlet of energy. Specific treatment techniques such as surgery may be threatening to the patient. Above and beyond the fears and anxieties which are occasioned by illness, his reaction to his disease and to hospitalization are influenced by the hopes he entertained for the future and which may no longer be possible.

Hatfield describes the social, economic and psychological aspects of tuberculosis in this way:

> "With tuberculosis the social factors likely to be present are indicated by the very nature of the disease itself; the duration, the uncertainty of cure, the kind and degree of incapacitation (economic, professional, social, and recreational, etc.), the separation from the family group, the public health aspect of infection, the stigma and fear of the disease. Tuberculosis hits at the roots of family life, it undermines economic independence and hope for the future; and since these are fundamental needs for mental health the most frequent of the social ills of tuberculosis is the underlying anxiety."[1]

All these factors enter into the rehabilitation picture and should come under scrutiny as soon as possible in order to be dealt with constructively.

The necessity of an over-all plan for treatment and a consideration of rehabilitation in its broadest sense not only helps the individual and his family in their adjustment to the illness, but also helps the larger community in terms of the individual's social and economic usefulness and productivity. The growing awareness of public responsibility towards the

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1. W. H. Hatfield, Handbook on Tuberculosis, Provincial Board of Health of the Province of British Columbia, 1944, p. 90

eradication of tuberculosis has resulted in the government assuming the greater part of the cost of the treatment, a responsibility which involves a large investment of public funds. Since the government of the Province of Quebec is now beginning to allocate more funds to the assistance of tuberculosis patients, there is interest at the presemt time, both on the part of health departments and hospital personnel in knowing what facilities are now lacking within the hospital and the community in achieving the goal of maximum restoration for the tuberculous patient.

The purpose of this study is to assess those factors within the patient and the family, the hospital and the community which affect the rehabilitation process along the lines already defined. The problems patients have had in terms of their rehabilitation and the factors that affected them may come under consideration. The services that are required to facilitate over-all adjustment and the adequacy of the available services already existant within the hospital and the community have also come under scrutiny.

This study was undertaken with the assumption, derived from observations and readings on the subject, that the tuberculous patient encounters various impediments to satisfactory adjustment. These result from the fact that tuberculosis, because of its particular characteristics and treatment will tend to have an adverse effect on his economic and social status, with resulting repercussions in his personal

and family life. The very fact of being afflicted with tuberculosis, and undergoing the necessary treatment adds to the strains imposed upon him. Also in the community and the employment field he is likely to encounter attitudes which will impede his resuming a normal role in these areas. Even more intimately concerned with his progress will be the attitude of his family to his illness and all its implications and his response to that attitude. In general, it is questioned whether within the hospital and later in the community, he will have met with or will meet suitable and adequate resources to help him effect the desirable adjustment.

The study as a whole was undertaken by five students, and was divided into five related parts, each student being responsible for one of these parts. These were:

1. Psychological Adjustment of Single Patients to Illness.
2. Psychological Adjustment of Married Patients to the Illness.
3. Effect of Hospitalization for Tuberculosis on the Economic Status of Patients and their Families.
4. Adaptive Processes in the Families of Tuberculous Patients.
5. The Effect of Hospitalization for Tuberculosis on the Vocational Adjustment of the Patient.

However, the fifth part which dealt with the Vocational Adjustment of the patient has not been completed. As a result it has been omitted from this study and it will be carried through as a single project at a later date.[1] Therefore findings and recommendations for the vocational aspects of rehabilitation

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1. The time limit for the completion of this single study expired in August, 1955. The analysis of the vocational aspects of rehabilitation is, therefore, not available.

have not been included in Chapter X.

The study is based on a group of forty-three tuberculous patients who, following hospitalization at the Grace Dart Hospital for varying periods of time, have been discharged into the community, with their condition arrested or improved. The Grace Dart Hospital is a small non-sectarian tuberculosis sanitorium of about 150 beds, on the outskirts of the city of Montreal. At the time the study was undertaken the hospital had no Social Service Department. It was a valuable setting to study because, while the medical staff did a great deal to help the patients, there was no concerted rehabilitation programme. The patients themselves set up a council which arranged for several recreational programmes, but there was no provision made by the hospital for any form of occupational therapy.

This study is confined to a group of patients who were discharged from the hospital between May 1951 and November 1952. The student group originally hoped to interview 80 patients but several limitations did not allow for that number. As none of the five students spoke any language but English fluently enough to conduct an interview, all patients who could speak no English were excluded from the records which the hospital made available to the group. From the potential sample, further screening was carried out by the students in relation to the patient's medical condition, residence, age, time spent in the sanitorium and length of time out of the hospital following discharge.

Only those patients who had been discharged with medical approval with their disease arrested, apparently arrested or improved were selected. This eliminated 26 patients who had been discharged irregularly or who had been transferred to other sanitoria. It was felt that the latter patients would still have physical limitations to their rehabilitation. For reasons of facilitating interviewing, only those patients with residence in Montreal and its environs were choseen. This necessitated the elimination of seven patients with residence outside the city limits. The age group studied covered patients from 16 to 60 years of age. The lower age limit was imposed by the setting since this hospital did not accept patients under 16 years. The upper limit was selected since it represented the oldest age at which it is considered, in our society, that individuals may be rehabilitated vocationally. It was also felt that those patients who had been in hospital under two months should not be included, because their short period of hospitalization did not give them the long-term experience of hospitalization and separation from family and community which was being sought in this research project.

The selection began with patients who had been discharged from the Sanitorium during the month of November, 1952 and those, within the limits described, who were discharged in preceding months until sufficient patients were obtained. November, 1952 was chosen as the starting point for selection in order to allow

for a period of at least three months after discharge before an attempt was made to assess their post-hospital adjustment. A further limitation was imposed by the fact that five patients within the group selected refused to be interviewed and twelve individuals had moved out of the city and were no longer available for interview purposes. Finally a lack of time necessitated a further deletion of 13 patients from the selected group. For these reasons the sample group was reduced to 43 patients.[1]

Data were obtained from medical records of the Grace Dart Hospital from which identifying information, medical diagnosis, treatment and recommendations were taken. This was followed by a perusal of out-patient clinic records for information about the medical progress of the patient following discharge, and any pertinent observations by the doctor or nurse. The clinic records were obtained from the Royal Edward Laurentian Hospital, Bruchesi Institute, Laurier Clinic and the Grace Dart Hospital Clinic, depending upon where the patient received his post-discharge follow-up.

The main source of data was the interview. Each patient was interviewed during the post-discharge period and another member of the family was interviewed where possible.

The early thinking and reading for the project was done by the seminar method of study in order that the research workers could become familiar with the literature in the field of tuberculosis and rehabilitation. Following preliminary planning

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1. See Appendix Table No. [redacted] p. 263

and the development of a tentative schedule which would help to to define the limits within which the study would be undertaken, the group members shared the work of abstracting material from the medical and clinic records. The interviewing of these patients was carried out by the five students with each being responsible for one fifth of the total number. Process records of all interviews were typed in quintuplicate and added to the common pool of material. It was recognized that the one interview was a limitation, in that it was not possible to cover the broad scope of the material as fully as desired or to evaluate the situation as deeply as was intended. Each interview lasted from two to three hours and an attempt was made to keep the discussion spontaneous. A schedule was prepared as a guide to the information required and as much as possible, direct questions were avoided unless factual material was desired. It was also felt that the material collected could be quite subjective, yet the fact that the total number of interviews was done by five students would offset the subjectivity that occured. These interviews also depended to a large extent on the memory and honesty of the patient bringing out feelings and reactions which he had experienced some time previously.

In compiling data, three methods of analysis have been employed. The statistical method has been used in order to assess the relationship and relative importance of factors under consideration. Descriptive anaylsis, in the form of case

illustrations, has been used to point up and illustrate the various aspects of the problems, and the patients' adjustment to these problems. Library research has provided a background against which to evaluate or assess the understanding of information gathered.

This study is being presented in four parts. Within each part the individual writer will make introductory comments about the material pertaining to her own section and will draw conclusions from the data analyzed within the particular section.

Parts I and II of the study are concerned with the psychological adjustment of tuberculous patients to their illness. Since this subject was considered to be too broad to be dealt with by one student, it has been divided into two parts, one dealing with the psychological adjustment of the single patients, the other with that of the married patients. The two parts of the project cover the same aspects of the material and therefore analysis of data within each section follows the same pattern. The first chapters in each section, namely Chapters II and IV, will present some consideration of the emotional problems related to the illness itself and the hospitalization period. These chapters will include a discussion of the reactions of the patients to having tuberculosis and their feelings related to the treatment involved during their hospital stay. In Chapters III and V some aspects of their personal adjustment during the post discharge period will be examined such as attitudes to

restrictions imposed by the illness and the effect of the illness on social and recreational life.

In Part III, the effect of hospitalization for tuberculosis upon the economic status of patients and their families is considered. Chapter VI will deal with the nature of the financial impact and the adjustments made necessary by the impact. This chapter will also include a discussion of the problem of spending money while in the hospital and of the effect of illness upon housing. Chapter VII will contain an examination of the attitudes of the patients toward their changed financial status and the effect of this changed status upon family relationships. The effect of changes in financial dominance in relation to the breadwinning group will also be considered.

Part IV of the study deals with the adaptive processes in the families of tuberculous patients. Some of the repercussions brought about by the illness of the patient and the separation from his home and family will be discussed. Chapter VIII will consider structural changes in the family brought about by the illness of the patient. Chapter IX will be concerned with changes in the status of the patient and the effect of the illness on the marital relationship of the married group.

Finally, in the last chapter, the implications of the four areas will be considered together in order to arrive at general conclusions and recommendations.

PART I

PSYCHOLOGICAL ADJUSTMENT OF SINGLE PATIENTS TO THE ILLNESS

CHAPTER II

EMOTIONAL PROBLEMS RELATED TO ILLNESS AND HOSPITALIZATION

Introduction

Illness has a different meaning for each individual depending on his particular personal experiences and environment. It can be said that all illnesses are bound to create some anxiety on the part of the individual suffering from them. However, the degree of disturbance varies and the reactions to a disease can range from mild to excessive concern. In some patients the emotional state is apparent and in others it lies beneath the surface. Some individuals may welcome illness as an escape from an unbearable situation, while to others the experience can be quite devastating. The illness itself does not explain entirely the behaviour of the patient.

Frances Upham describes illness as representing "an attack upon the person by a hostile, malign, and often unknown force".[1] This is particularly true of tuberculosis which has been regarded for many years as a threat to life and status. The emotional components of illness are bound to be exaggerated in tuberculosis because of its particular characteristics and treatment.[2]

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1. Frances Upham, A Dynamic Approach to Illness (New York, 1949), P. 15

2. Supra p. 3

The tuberculosis patient has to pass through at least three difficult periods of adjustment in relation to his illness. One is at the time of diagnosis when he has to accept the fact that he has the disease and that he needs to be hospitalized for a comparatively long time. Dr. G. R. Howell, Medical Director of the Grace Dart Hospital, calls this "a period of anxiety during which the patient gradually adjusts himself to the apparent devastation of his life".[1] The second stage of adjustment occurs during the period of hospitalization when the patient is faced with a new environment, during which time the disease is the center of interest and may create renewed feelings of despair, and when the actual treatment may be threatening to the individual. When the patient is ready to leave the hospital and returns to the outside world, he has to adjust to living within the limitations imposed by the disease and perhaps he has to make a radical change from the way of life he had known before his illness. William Tollen states that:

> The authorities have generally agreed . . . that the very fact of being afflicted with tuberculosis and undergoing hospitalization for treatment adds to the strains upon personality to a degree unequalled in most other diseases.[2]

It is therefore becoming apparent that a consideration of the emotional aspects of the illness is essential for an

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1. G. R. Howell, M. D. "The Role of Emotion in Tuberculosis", Unpublished paper, p. 3.

2. William Tollen, Irregular Discharge: The Problem of Hospitalization of the Tuberculous (Washington, 1948), P. 9

effective treatment programme since personal problems surrounding the illness may be disturbing enough to give rise to serious difficulty in treatment. Also, although tuberculosis may present various emotional and social problems, the ability and degree to which the patient can cope with the situation depends upon his pre-morbid personality and an individualized approach in rehabilitating the patient is necessary to effect an optimum state of health.

This part of the study will deal with the attitudes, reaction and behaviour of the single patients in the sample group in relation to the disease as they pass through the three aforementioned stages of adjustment. It is not the purpose of this study to ask why the patients reacted the way they did but to learn how they reacted under the strains, and to evaluate their emotional and behavioural responses in terms of degree of feeling and acceptance. The assumption is that behaviour and attitudes are symptomatic and may furnish clues to underlying problems with which the patient may need help. Some categories have been developed to make comparisons within the group and have been defined in the particular sections under analysis.

This part of the study is concerned with twenty patients, fourteen male and six female, who were single or who were considered as single for the purposes of this area, at the time of diagnosis and hospitalization for tuberculosis.

These include seventeen patients who were unmarried, one patient who was legally separated, one who was divorced and one who was widowed prior to being hospitalized. It is interesting to note that out of this group, only one patient's marital status has changed since the hospitalization period, namely the widower who remarried shortly after he was discharged.

It was arbitrarily decided that the last mentioned patients should be included in the single group for this section of the larger study since their living arrangements and family life seemed closely related to those of the single patients. Eleven patients in the single group, including one who was divorced, had been living with at least one parent. Four patients, one of whom was a widower, had been living with a brother or a sister, and the remaining five patients, including one who was legally separated, had been living alone or apart from any member of their family.

At the time of interviewing these patients ranged in age between 18 years to 47 years. Over fifty per cent, 14 out of 20, were under 35 years of age. The actual age of these patients at the time of hospitalization was less than those stated, since these patients had been home from the Sanitorium for a period of time ranging from three months to two years. The majority had been home from the hospital for about one year at the time the study was undertaken.

The medical diagnosis of the single group, at the time

of hospitalization, included five patients with minimal lesions, fourteen patients with moderate lesions and one patient who had an advanced lesion. Five of these patients had had relapses and had histories of previous hospitalization at other sanitoria. For the remaining fifteen patients, hospitalization at Grace Dart followed their first breakdown with tuberculosis.

Length of time in the Grace Dart Hospital ranged from two months to twenty-four months with the exception of one patient who was under hospital care for only one month. However, this patient had had the experience of a previous hospitalization at another Sanitorium for one year, and he was therefore included in the group under study. Seven of the patients were in the Grace Dart Hospital between two to six months; eight patients were in between seven to twelve months making a total of fifteen patients who were at the Grace Dart Hospital for a period of less than one year. Of the balance of five patients, four were in the hospital between thirteen to eighteen months and one remained there for two years. It must be remembered that many of these patients rested at home for a period of time while waiting for admission to the Sanitorium. Also, treatment was not completely terminated on discharge since patients were advised to keep their rest hours for varying periods of time at home and some continued to receive treatment at clinics. The time spent at the sanitorium, therefore, is an indication of the length of time

treatment was carried on away from their normal home environment.

This chapter will include a discussion of the patients' reactions to diagnoses and their need for hospitalization. The patients' feelings about their illness while they are in the hospital will also be considered. This will be followed by an evaluation of their attitudes to treatment procedures and medical authority.

Reaction to Diagnosis

At the time of diagnosis, the individual receives the first impact of the meaning of the disease for him. Frances Upham states that, "The discovery by an individual that he has tuberculosis is always traumatic".[1] Actually, the reaction to the diagnosis differs with the individual person and is received with varying degrees of shock and understanding, the most common one being anxiety, depression and fearfulness.. Eric Wittkower[2] agrees that tuberculosis is a dreaded disease, yet he found in his study of the behaviour of 785 tuberculous patients, that thirty-five per cent of those examined seemed little concerned about their diagnosis. However, as he concludes, in many of these patients the disturbance was not apparent at the time of diagnosis.

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1. Frances Upham, Op. cit. p. 110

2. Eric Wittkower M. D., A Psychiatrist Looks at Tuberculosis (London, 1949) P. 19.

William Tollen points out that:

> The fear which is so common among the tuberculous is a fear not only of the disease itself - the physical damage wrought by tuberculosis and the possibility of death - but also of the social and personal consequences of hospitalization.[1]

The way in which the individual reacts to his diagnosis may be an indication of the problems which the person will encounter in his rehabilitation process. Dr. G. R. Howell of the Grace Dart Hospital feels that, "The onset of a state of mind leading to eventual irregular discharge may in fact take place at the time of diagnosis".[2] Therefore the importance of the patient's attitude at that time should not be underestimated and an awareness of the problems that are likely to exist is essential to those who offer services to the patient.

Table 1 indicates the various reactions to the diagnosis of tuberculosis among the twenty single patients under analysis for this section. Three broad headings were used to group the reactions. One is "shock" which includes those patients who showed marked anxiety or depression over the illness itself. Another type of reaction is "incredulity" in which the predominant feature is either conscious disbelief on hearing the news of the diagnosis or a temporary numbness

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1. William Tollen, Op. cit. p. 6

2. G. R. Howell, M. D., "Irregular Discharge of Tuberculous Patients", Unpublished paper, p. 11

which seems to convey an unconscious "shutting out" of the illness. Under the term "slight concern" were grouped those patients who seemed only mildly upset or who were not obviously perturbed by the diagnosis of tuberculosis.

TABLE 1

Reaction to Diagnosis of Twenty Single Patients Discharged with Medical Approval from the Grace Dart Hospital, Montreal, between May 1951 and November 1952.[1]

Reaction to Diagnosis	Total	Male	Female
Total	20	14	6
Shock	10	6	4
Incredulity	3	3	-
Slight Concern	7	5	2

Of the twenty single patients interviewed, ten patients or fifty per cent, indicated that they had experienced a marked degree of shock on hearing that they had tuberculosis. Among them six were men and four were women. It is interesting to note that a higher proportion of women reacted with shock, four out of six, whereas only six out of fourteen males admitted they were severely upset by the diagnosis. In this connection

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1. All tables in part 1 of this thesis refer to patients in this sample group. Therefore no further references will be made to the hospital, place, date and year in subsequent tables.

this small sample group concurs with Wittkower's[1] observations of reaction to diagnosis of 785 patients.

The following examples illustrate the reaction of shock to the diagnosis which include elements of feeling about the illness itself:

> Case 36. Miss N., a 38 year old woman disclaimed any preconceived ideas about tuberculosis. However, this is her account of how she felt when told the news. "When the doctor told me I was completely surprised. It never entered my mind and I cried all day and all night. I couldn't sleep and I couldn't eat. I was a wreck. I felt it was something I wouldn't get over and that I'd die".
>
> Case 43. Mr. J., a 39 year old divorced man had this to say about his reaction. "I was shocked when the doctor told me. Everybody has feelings about tuberculosis Some of my friends died of it. Before I went into the hospital I thought it was a real sickness like cancer or leprosy".
>
> Case 4. Miss J. a 26 year old nurse who had suffered two relapses stated that when her illness was first diagnosed at the age of sixteen she felt "that the end of the world had come. I didn't want to live any longer. I felt people are going to be scared of me. The doctor said it would take six months and at that time it seemed like a lifetime".

Three patients, all male, reacted with some degree of incredulity to their diagnosis. One of these patients said he was surprised but did not feel anything at first. The other two patients actually experienced some shock together with their disbelief. The following exerpt is a striking example of this reaction:

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1. Wittkower, op. cit. pp. 19-20

> Case 27. Mr. J. a 26 year old man "just about dropped" when he was told of his illness at the clinic. This was immediately followed by the feeling that there must be some mistake. He went to several doctors, including a specialist, and the fact that he had tuberculosis was confirmed but he still could not see that he had it. He said, "I felt well, I know the doctors should know as they are smarter than I am". This patient never fully accepted his diagnosis although he followed through with his treatment.

In the group of seven patients who seemed slightly concerned, were five males and two females. Two of these patients indicated they had no fear of the disease and consequently were not upset. Two other patients stated they did not know the seriousness of the disease at the time. One patient said she was "brought up to take things as they come". Only two patients in this group showed by their statements that they were mildly depressed. They remarked that they "felt bad" or "felt gloomy".

Reaction to Need for Hospitalization

In addition to, and concurrently with, the patient's reaction to the illness itself, is his need to accept hospitalization. Tollen sums up the patient's possible fears in this regard as follows:

> . . . the tuberculous patient, confronted with the prospect of a long period of hospitalization, fears the loss of his economic security, separation from and possibly rejection by his family and friends, the suspicion in his own mind that he is a hopeless failure . . .[1]

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1. Tollen, op. cit. p. 6.

For the single patient, the need for hospitalization and long, "drawn out" treatment can be a real threat to his future. Carol Cooley explains some of the implications as follows:

> Unmarried young people who must leave their families and friends for a year or two suffer real hardships. The period may be the most critical to the patient who sees hospitalization as a block to education, a job, friendships and marriage.[1]

All the patients in the group under study did accept hospitalization but their attitudes in relation to this need were diversified. Seven patients, three female and four male, expressed marked fear or apprehension about going to the hospital. To some of these patients, the length of time required in hospital as estimated by the doctor, was exaggerated in their minds and "six months seemed like six years". Others associated the sanitorium with death. For example, one patient asked if he were "going to that place to die". The doctor's reply that everyone did not die was not very reassuring to him. One patient did not like hospitals generally, and had excessive fear of doctors and nurses.

Two patients, one male and one female, resisted hospitalization until they were too sick to carry on any longer. The following case will serve to illustrate the type of problem which can exist in accepting hospitalization:

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1. Carol Cooley, Social Aspects of Illness (Philadelphia, London, 1951), p. 232.

> Case 25. Mr. F. a bachelor, 42 years old, was, as the medical record stated, "an old chronic who resisted sanitorium care and operation". He had been under the care of a private physician and had been receiving medication until he developed a cavity and hospitalization was imperative. Mr. F. said he had not been upset about having tuberculosis, but he resisted hospitalization for two years because he was worried about leaving his job and losing his chance of promotion. When he was reassured that his employment status would not be affected, he was able to accept hospitalization readily. The patient summed it up this way, "This was my main worry and had I known things would turn out so well, I would have never resisted going in the first place".

Four patients, three male and one female, reacted passively to the need for hospitalization. They said that at the time they "did not mind going", or did not question the need for hospitalization. They did not express any fears about having to leave their usual environment, nor did they show any apprehension about going to the hospital. These patients showed marked dependency in relation to their families, and it would seem that to a certain extent hospitalization meant a continuation of this role in relation to authority.

The remaining seven patients, three male and one female, accepted hospitalization realistically in terms of their illness. At least two of these patients worried a little about leaving employment, but on the whole their main concern was to get into the hospital and have their disease cured. Typical responses were, "I felt something specific would be done" or I figured I should go in as soon as possible to have it cleaned up".

It is interesting to note that in this sample group of single patients, concern over the illness itself or feelings about hospitals seemed, on the whole, more significant in determining the patient's reactions to the need for hospitalization than such factors as separation from family, friends or employment. It is felt that the seemingly mild concern over separation may be partly due to the fact that the Grace Dart Hospital is situated comparatively close to the city and that these patients believed they would have frequent visits from friends and family. Also, for the most part, the single patients had no major financial responsibilities and worry about employment was not a big factor.

Adjustment to Illness during Hospitalization

Once the patient is admitted to hospital, a second major period of adjustment begins. This involves a gradual orientation of the patient to the hospital atmosphere and surroundings. Here the full awareness of the nature of tuberculosis as a disease is thrown sharply into relief for new arrivals by their observation of other tuberculous sufferers.

Because of the particular psychological and social implications of tuberculosis, - that is the stigma attached to the disease, fears of death, long period of treatment and and isolation required, and uncertainty of outcome, - a mood of anxiety or depression following diagnosis is to be expected for a period of time, until the patient is able to adjust to the idea of having the illness. Wittkower emphasises this

point in the following manner:

> During the initial stages patients should be allowed to experience feelings of depression and to pass through a phase of it without much interference, for after all they have good reason to feel depressed . . . anxious patients who frantically try to conceal their anxiety should be tactfully encouraged to admit their fears without shame. By condoning it the chest specialist helps his patients to tolerate their anxiety and thereby eases their emotional tension.[1]

At least twelve single patients out of twenty stated they were quite severely anxious or depressed during their first few weeks of adjustment in the hospital. Some of these patients had been very upset by the diagnosis, and their mood in the hospital was partly a carry-over from this earlier period. The majority, however, intimated that the onset or increase of their anxiety was caused largely by the hospital atmosphere. Seeing other patients in various stages of the disease was frightening, and other patients often seemed to delight in telling newcomers lurid stories about tuberculosis, its treatment and outcome. Discussion of a case will illustrate this further:

> Case 3. Mr. G., a 34 year old man, claimed he had had no particular fears about tuberculosis before he contacted the disease. He was mildly upset at the time of diagnosis. However, he had this to say about his first month at the Sanitorium. "The patients discourage you in hospital. They frightened me stiff for about a month and I didn't know whether to stay or not. The man next to me who had been in hospital many times kept telling me stories about tuberculosis". He added that he felt "a little low about being locked in there".

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1. Wittkower, op. cit. p. 39.

The remaining eight patients in the sample were mildly depressed, anxious or resigned during the initial hospital period.

Dr. Howell[1] estimates that it takes from three to six weeks for a patient to settle down in the hospital. He feels that if the patient's mood of depression or anxiety lasts beyond this period, there is good cause for inquiry.

Table II shows the degree of adjustment to the illness made by the twenty single patients after the settling-in period. The reactions of these patients were grouped under four headings as illustrated in the table. Realistic acceptance was attributed to those patients who, although they may have been markedly anxious or depressed about their illness at the beginning of hospitalization, were able gradually to face the illness more realistically and adjust in a comparatively short time. When the anxiety or depressive state was prolonged beyond the settling-in stage and lasted throughout the whole hospitalization period, the patient was considered to be severely concerned. Patients who were predominately over cheerful and defiant were classed under the heading of apparent lack of concern. Under passive acceptance were included those patients who seemed mildly concerned or in whom secondary gains derived from hospitalization seemed to compensate and overshadow any deeper concern the patient may have had.

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1. G. R. Howell, M. D., "The Role of Emotion in Tuberculosis", Unpublished paper p. 5

TABLE II

Adjustment to Illness during Hospitalization of 20 Single Patients Classified According to Degree of Concern.

Degree of Concern	Total	Male	Female
Total	20	14	6
Realistic Acceptance or Concern	8	5	3
Severe Concern	5	5	-
Apparent Lack of Concern	3	2	1
Passive Acceptance or Mild Concern	4	2	2

Eight patients, five male and three female seemed to have assessed their situation in a realistic manner and made a comparatively good adjustment to their illness. Some of these patients were helped by verbalizing their fears and receiving the assurance and understanding of the doctors or nurses. This was particularly evident in the following case illustration:

> Case 30. Mr. V., a 49 year old man was extremely concerned about his illness when he first entered hospital. This is his account of how he felt. "I was very depressed after I got into the hospital, very depressed! I felt that this is terrible, just the thought of it. You hear stories of the place and you look at the patients and think 'this is the finish of me'". Mr. V. then saw Dr. Howell, the Medical Director, and told him of his fears. The patient said that "after I had a talk with him I felt better. He said they would put me on streptomycin and what I needed was just rest and proper care".

A few individuals stated they were helped by talking to other patients as shown in the following example:

> Case 38. Miss D. who is 27 years old, felt "pretty low" at first. She was placed in a room with an elderly woman who was very sick and coughing and this upset her further. However, within a few days she met some other patients and particularly one girl who had lived in her neighbourhood as a child. Miss D. stated that "she helped me a great deal and I never felt particularly down about it after".

Although proportionately fewer male patients had shown marked upset over their diagnosis, a higher proportion seemed to have problems in adjusting to the illness during the hospitalization period. Mary S. Brooke has said that, "It is during the long period of hospitalization that the meaning of the disease for the patient manifests itself".[1]

Throughout their stay in the hospital five male patients showed some evidence of excessive anxiety over their illness. None of the female patients fitted into this category. No attempt was made, for the purposes of this study, to estimate whether the anxiety was justified or not. It was felt that in any case pronounced anxiety or depression constituted a problem for the patient and that it could possibly influence the course of his disease and

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1. Mary S. Brooke, "Psychology of the Tuberculous Patient", Journal of Social Casework, Vol. XXI, No. 2 (February, 1948), p. 58.

his total rehabilitation. Dr. Howell makes the following assertion:

> At present there is evidence to suggest that emotional states . . . influence the course of a tuberculous lesion. We are not yet able to demonstrate this relationship yet most observers believe that it exists. For example, we cannot show the effect of emotional tension on the lesion. Nevertheless from what we know of the effect of rest on the lesion, we are entitled to infer that tension inhibits healing.[1]

The following example demonstrates quite clearly how an anxiety state over the illness contributed to the patient's poor adjustment in the hospital:

> Case 35. Mr. M., a 35 year old man, had been shocked by the diagnosis as he "didn't know what he was up against". He did not like his first impression of the hospital because nobody from the medical staff greeted him at the door to "explain things" to him. Mr. M. said he was very depressed for the first while, could not sleep and kept the windows wide open. He used to lie in bed and wonder if he would ever get out of the building. He felt neglected by the doctors, thought they should come around more often, and felt the routines should be more strict. He was nervous about the treatment and finally, when an operation was recommended, his anxiety reached its peak. Up to this point, the patient stated, he got along fairly well but in the surgery ward he drank, broke rules and stayed up late.

A severe emotional disturbance such as illustrated here, could conceivably be detrimental to the patient's recovery.

Three patients were seemingly lacking in concern and

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1. Howell, op. cit. p. 6.

four patients fell under the classification of "passive acceptance" or "mild concern". It is recognized that the two attitudes exhibited by the groups were in large measure psychological defenses against underlying emotional problems. Wittkower observed that in some patients their "air of slight concern was little more than a pose behind which they concealed depressive and anxious thoughts and feelings".[1]

There were three patients who apparently lacked concern about the illness. It was noted that overcheerfulness, defiance and resentment characterized their mood and behaviour and seemed particularly in these cases to be defenses against underlying tensions. However, their behaviour on the surface indicated a lack of acknowledgement of the seriousness of the disease. The following illustrates apparent lack of concern about the illness:

> Case 31. Mr. W., a young man of 27 years, said he was more upset about having to go to the hospital than about his diagnosis. His main concern at the time was leaving his social group and "missing good times". After a week at the hospital, he "turned the place upside down and had a heck of a good time". This patient claimed he was in a "good frame of mind" and kept himself very active in hospital activities. Actually, Mr. W. had many underlying social problems. While he was at the hospital, his father died and his mother was hospitalized for a short while. Both of these occurences upset him very much. This patient defied hospital rules and was a behaviour problem in the hospital.

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1. Wittkower, op. cit. p. 31.

Frances Upham points out that "some defensive mechanisms have more constructive value to the person . . . than others".[1] She adds that they should be regarded as useful because they are a means of handling anxiety. For example, regression which creates increased dependency may be helpful in facilitating treatment.

The four patients who accepted their illness passively seemed quite content during their hospital stay. It would seem that passive acceptance of a disease like tuberculosis would be beneficial to the patient since peace of mind is important in the treatment of the illness. These patients would seem to have strong dependency needs. Wittkower observes that, "Individuals with marked overt dependent trends make good invalids. They take to bedrest, enforced dependence and idleness, like a duck to water".[2] A typical example of such a patient is the following:

> Case 18. Miss C., 30 years old, had a stoical attitude. She claimed she had been "brought up to take things as they come" and was not upset by the diagnosis, nor did her mood change when she entered the hospital. She blamed any feelings of depression she may have had on the weather. This patient was not at all bothered by the treatment, did not find the routines irksome, ate well, and seemed to enjoy her dependency in the sanitorium.

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1. Upham, op. cit. p. 19

2. Wittkower, op. cit. p. 59

Harold Nitzberg points out that it is important to "avoid the pitfalls of fostering dependency".[1] Pauline Miller explains this as follows:

> Life in the sanitorium is seductive, and the maintenance of a balance between giving up responsibilities and carrying some of them is all important if the illness is not to destroy the individual as a person and impair or undermine his relationships as well.[2]

It is felt, too, that patients who are passive and complacent may, to a certain extent, be underrating the seriousness of the disease. The encouragement of both over-complacent and over-defiant attitudes are not in the real interest of the patient.

Reaction to Treatment Procedures

The patients in the group studied here successfully completed their course of treatment at the hospital and were eventually discharged with medical approval. This would seem to indicate, on the surface at least, that they made a comparatively satisfying adjustment to hospitalization. One could easily assume that for the most part their emotional problems were not as severe as those of patients who leave the hospital before the termination of treatment. Nevertheless, although these

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1. Harold Nitzberg, "Rehabilitation of the Tuberculous - A Casework Process", Social Case Work, Vol XXXI, No. 2 (February 1950) p. 64.

2. Pauline Miller, Medical Social Service in a Tuberculous Sanatorium, Federal Security Agency, Public Health Service, Division of Chronic Disease and Tuberculous, 1951.

patients did remain in the hospital and were able to accept the treatment, they did so with varying degrees of difficulty and acceptance.

The importance of the patient's feelings about and reactions to his treatment has been brought to light by Tollen's study[1] of the reasons for irregular discharge amongst tuberculous patients. Among the basic causes were dissatisfaction with hospital rules and procedures and fear of surgery or other treatment techniques.

For the purposes of this study, treatment procedures were divided into three categories as shown in Table III. One is bed rest and adherence to hospital rules. Bed rest and hospital regulations were considered together in this analysis since the attitude and reaction to both were interrelated and therefore similar for individual patients. It was noted, for example, that hospital rules were in the interest of the patient's treatment and a defiance of these rules was always accompanied by a rebellious attitude to bed rest.

Another category was minor treatment techniques. This included medication such as Streptomycin and PAS.[2] Pneumothorax and various tests such as bronchos copies and

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1. Tollen, op. cit. p. 19.

2. The initials PAS designates Para-Aminosalicylic acid.

gastric lavages were also considered in this grouping.

The third type of treatment was surgery. The various kinds of surgery grouped here are pneumonolysis, phrenic crush and thoracoplasty operations.

Table III

Reaction to Treatment Procedures of Twenty[a] Single Patients According to Emotional Response.

Types of Treatment	Total Reactions	Reaction to Treatment				
		Realistic Acceptance	Passive Acceptance	Over Conscientious	Rebellious	Excessively Fearful
Total Reactions	48	18	13	5	4	8
Bed Rest and Hospital Rules	20	8	5	3	4	-
Minor Treatment Techniques	20	7	8	-	-	5
Surgery	8	3	-	2	-	3

a) Some patients manifested several types of reactions and therefore the total reactions exceeds the number of patients in the sample.

Bed Rest and Hospital Routines:

Sufficient bed rest and acceptance of hospital regulations are essential elements of the treatment programme, as passivity is the core around which treatment for tuberculosis is based. Some individuals are able to surrender to this life of

restraint and regimentation quite easily, while others find the long drawn out periods of inactivity and the necessity to stay where they are, difficult to bear and the latter often have rebellious attitude towards it. William Tollen states that:

> Prolonged rest, the basic technique in treatment of tuberculosis, involves a negation of one of the most essential tendencies of human nature: the tendency to seek release of emotional and psychic energy when the personality is super-charged with feeling.[1]

As shown in **Table 3**, eight out of twenty single patients, five male and three female accepted their bed rest and hospital restrictions realistically. This group included the patients who may have been somewhat irked or bothered by the restrictions and restraints, but who followed them, nevertheless, with a minimum or moderate amount of discomfort because of the necessity of doing so. Such statements as "sometimes I didn't feel like resting but I knew I had to, and everybody else was doing it" or "when anybody is sick the doctor has to be strict" indicates their attitude.

Five patients, three of whom were male and two female were passive in their attitude; that is they did not seem to be the least bit bothered by continuous bed rest and fitted in quite happily with routines. Typical

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1. Tollen op. cit p. 6.

responses were that "treatment and routine life were no bother to me" or "I was glad to be able to sleep all I wanted". Characteristically, these patients on the whole did not complain about the food at the sanitorium although it was a common "gripe" among the patients. Some thought the food could have been improved but they made no complaints and a few of these patients said it was very good and they enjoyed it.

Under the heading of over-conscientious, are included those patients who conformed scrupulously to hospital restrictions and bed rest or who took more rest than was necessary. Three patients, all male, fitted into this category. Actually, both the passive and the over-conscientious patients, eight in all, did not seem to have a normal attitude to the usual frustrations of hospital life and showed strong dependency needs. G. E. Daniels and E. Davidoff have arrived at the following conclusions about the "good patient" in their pilot study of Tuberculous patients in a Veterans' Hospital:

> . . . the so-called good patient who yields, is submissive and does not verbalize his complaints may be considered well adjusted to his prolonged hospital stay because of a deep-seated desire to remain in the hospital and not face the outside world. Such a person is often more in need of psychotherapy than the aggressive restless individual . . .[1]

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1. G. E. Daniels and E. Davidoff, "The Mental Aspects of Tuberculosis", American Review of Tuberculosis, Vol. 62 (Nov., 1950) P.537

The over-conscientious patients, in contrast to those who were passively accepting, showed some underlying anxiety and excessive concern about the illness which was met by a too careful adherence to bed rest. The following is a striking example of the "good patient" who was considered over-conscientious:

> Case 17. Mr. W., a man of 47 years, was very shocked when he was first told about his illness. He could not believe that he was so ill (he was far advanced) but he did not question the need for hospitalization. He said that in the hospital everybody thought he was a "wonderful patient". He obeyed all the rules "like school", thought the doctors and nurses did all they could for him, and found no fault with the food. His attitude to medical authority was one of submission in order, it seemed, to gain acceptance. He also seemed over-accepting of hospital restrictions. This patient was "sorry to leave the hospital" as he was "a stranger when I came and now everybody was my friend". Mr. W. said he"slept about twenty hours a day" and kept this up for about seven months. He appears to have met the anxiety around the illness by withdrawal into sleep.

Rebellious patients included those individuals who found the passive and relatively inactive life required in the sanitorium hard to bear. Four patients, three male and one female, broke rules periodically, found bed rest extremely tedious and generally were complainers. The following case illustrates this attitude:

> Case 31. Mr. W. had led what he called "a real ragged life" before he was hospitalized for tuberculosis. He said the most difficult thing for him to endure about his illness was the

necessity of staying in bed. He considered the regulations "too strict" and thought the patients were made to "feel like cripples" because of the constant "nagging about rest" and not letting them exert themselves at all. This patient said he constantly complained about everything, including the food, and was known as the instigator at the Sanitorium. Mr. W. felt like "walking out" many times but he wanted a medically approved discharge for practical purposes. However, he did go out several evenings when he was not supposed to and once he jumped through the window to get home for a holiday.

It is evident from the above illustration that this patient was not utilizing his treatment to the best advantage and his behaviour indicated underlying problems.

Minor Treatment Techniques:

Some apprehension is usually felt by patients who are receiving treatment for the first time, particularly if there is the possibility of some pain being inflicted. But even the minor treatment procedures may invoke disproportionate fears in some individuals. In the treatment of tuberculosis, the various types of medication are usually administered by injection and "needle phobia" may as Wittkower[1] observed, arouse excessive fears in the patient. This is particularly true of pneumothorax as this treatment involves the injection of a long needle into the pleural cavity . A test such as a bronchoscopy may conceivably arouse visions of choking or gasping for air.

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1. Wittkower, op. cit. p. 46

Seven patients, five male and two female, found the treatment unpleasant or seemed mildly anxious about it, but they put up with it because they felt it was good for them. These patients made remarks such as "it was unpleasant but I wasn't frightened by it" and "I felt kind of leary about the treatment but I thought if it had to be, it had to be". It was felt that these patients faced their treatment realistically.

Eight patients, five male and three female, accepted their treatment passively and indicated no fear or discomfort in this area. A typical response was that "treatment did not bother me at all".

The remaining five patients showed excessive fear of minor treatment procedures. This constituted twenty-five percent of the single patients. This reaction seemed mainly related to dread of the needle. It is interesting to note that although "needle phobia" has been mainly attributed to women, in this sample group a higher number of men showed marked fear in this regard. Four out of fourteen men in the sample group and one out of six women reacted in this manner. The following examples indicate the degree of anxiety experienced by these patients:

> Case 42. Mr. L., 31 years old, showed anxiety around his illness and took more bed rest than was necessary. He had pneumothorax and said he was very nervous about the needle. He added, "I took a nervous and physical shock after my first pneumo. I couldn't control myself."

> Case 16. Mr. P. a young boy of 18 years, said, "I didn't know what pneumothorax was and was shocked when I first heard about it. I always think of the worst things; I never got used to pneumo." This patient claimed he had always been frightened of needles. He also did not take as much PAS as he needed because he did not like it.

Surgery:

In the Sanitorium, surgery is sometimes recommended and this may add to the patient's anxiety toward treatment. Surgery has many emotional implications for the individual, both conscious and unconscious, which may affect his reaction to it. Upham says that:

> The patient in the Sanitorium often has to accept surgery, which, because of fear of mutilation, anesthesia, bleeding, pain, and death, creates difficult problems for him.[1]

Out of the selected group of twenty single patients, eight patients, seven male and one female, had undergone some form of major surgery during their hospitalization. Two of these patients had had their operations at other Sanitoria previous to admission to the Grace Dart Hospital. In all, four patients had had a thoracoplasty, two had a phrenic crush and the balance of two patients had had a pneumonolysis performed.

Three patients, two male and one female, although obviously frightened by the prospect of having an operation, were able, with the support from their families to modify

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1. Upham, op. cit. p. 113

their fears and face surgery with less apprehension. These patients were grouped under "realistic acceptance."

Two patients, both male, were classified as over-conscientious. These patients, both of whom, had had thoracoplasties were emotionally upset when they heard they needed the operation and may have had some fears of disfigurement. However, as Wittkower observed in his study, some patients may welcome surgery because they regard it as a step-up because they have seen others do well and because they hope that the operation will speed up their own recovery. This seemed to be true of the patients in this group. It was noted in this study that these individuals seemed very optimistic about the outcome, and they tended to feel that this was a cure-all for the disease. This was particularly true of the following patient:

> Case 25. Mr. F., aged 42, was according to the medical record, "emotionally upset when told he would have seven ribs out". However, Mr. F. felt this was the quickest way to get better and be discharged from the hospital. This patient said he had no fears of relapse and stated it in this manner. He said that "there are two kinds of patients, one who has had an operation and is not afraid of relapse and the other who has not had an operation and is always concerned about getting sick again."

The other patient, although he had had an unsuccessful thoracoplasty operation elsewhere, was according to the medical record "willing and anxious to have an operation,

particularly a resection "if it should be necessary.

In contrast to this attitude, three male patients expressed marked anxiety over the surgery which was to be performed, and showed some resistance to having it. One of these patients said "the knife scares me" which expressed his fears of operations in general. A striking example of feelings around disfigurement and death was evident in another patient:

> Case 35. Mr. E., had a left arterial thoracoplasty performed. When he found out he was to have the operation it "scared hell out of me. I knew some died and I also noticed the lopsided shoulders of some of the patients". He talked to other patients, found out more about the operation and learned there were exercises that could be taken, but he still felt he did not need it. He finally made up his mind to undergo the operation when the doctor told him he would get out of the hospital sooner this way. However, this patient said he had now made up his mind not to go back for another operation if he ever needed it.

A certain amount of anxiety felt by the patient seems inevitable in surgical procedures. Some operations involve more risk than others in terms of mutilation and death. However, the reaction of the patient to the operation differ with the individual personality and is not necessarily related to the type of surgery to be performed.

Reaction to Medical Authority

When a patient enters a hospital for medical treatment he has to, at least temporarily, give up some of his

responsibilities and independence. A certain amount of faith in the doctor and reliance on his decisions and recommendations is necessary so that the individual will follow the required treatment toward recovery. Particularly in the illness of tuberculosis, a passive dependent attitude is a desirable pre-requisite to successful treatment. Upham discusses this in the following way:

> Regression, a common defense in illness, has the value of enabling the patient to use his physical resources for recuperation and, through his increased dependency, to accept from others the healing assistance he requires. When the defense no longer serves this useful purpose, the individual usually is able to relinquish it and gradually to resume activity appropriate to his reality situation.[1]

Some patients because of their particular personality make-up find it difficult to accept their dependent role and have a resentful or aggressive attitude to medical authority. Others may become extremely dependent on their physician, have supreme confidence in him and will submit almost completely to his authority with something like a blind faith.

Of the twenty single patients under study, thirteen individuals seemed to have a realistic trust in and reliance on the doctors who were treating them. These patients indicated they had confidence in the medical staff and were able to follow advice and recommendations in keeping with

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1. Upham, Ibid, p. 175.

the reality of their physical condition nor did they have any problems in accepting medical authority.

Three patients were very submissive, thought the doctors were "wonderful" or had "all the faith in the world" in them and conformed to their suggestions without question. It is interesting that these individuals got along well with other patients in a superficial way but did not make any close friends in the hospital. Their closest ties were with the nurses or authority figures and they seemed overly eager to please and gain their acceptance. The following example demonstrates this point:

> Case 30. Mr. V. was very depressed and anxious about his illness when he first came to the hospital. After speaking to the doctor he felt better and placed full trust in his skill and knowledge. He said "The doctors and nurses told me not to worry about things, just relax and rest. They were just wonderful." He thought the food was very good and he would get "a great kick" out of helping and encouraging other patients who felt anxious or who complained all the time. He added "I was always willing to help the nurses and doctors in anything they wanted to do after I got up and around".

It would seem that underlying this submissive attitude are strong dependency needs and anxious self concern.

The balance of four patients were somewhat aggressive and had difficulty accepting the doctors' advice even though they had confidence in the medical staff. This attitude was largely related to their negative feelings about routines and hospital regulations. These patients felt the doctors

were "too strict" and they had difficulty in adhering to restrictions that the hospital environment demanded.

In this chapter there was a discussion of the patients' emotional reactions to the illness and the hospitalization experience. The various steps and procedures that the individuals encountered from the time of diagnosis and through their sanitorium stay and the personal problems they experienced in relation to them were observed. It was noted that individuals reacted to a given situation in various ways and that difficulties in adjustment to the illness or within the hospital were created by the particular characteristics of the disease and its treatment as well as by factors in the individual personality.

The following chapter will deal with some personal aspects of the patients' post hospital adjustment.

CHAPTER III

PERSONAL ADJUSTMENT OF SINGLE PATIENTS DURING POST DISCHARGE PERIOD.

The tuberculous patient actually has a difficult reality situation to face when he leaves the sanitorium and goes back to his accustomed surroundings. He may have feelings of dependency, anxiety around his illness, fears of rejection and isolation, and he has to live within limitations imposed by the disease.

This period of adjustment may prove to be the most trying one for the patient. As Wittkower points out, he has to readapt himself to being healthy and to living in a healthy environment. He adds:

> . . . difficulties arise for ex-patients on return to a healthy environment . . . from their reduced wage-earning capacity, from their lowered physical strength and vitality, and from their re-entry into the family circle, the circle of previous friends and society in general.[1]

The ex-patient has to compete with others while as yet he does not feel at par with them physically and this may create feelings of inadequacy and inferiority. Added to his own personal feelings may be the resentment of his family because of his reduced capacity and the negative attitudes he may encounter when he comes in contact with individuals in the community. Edith Seltzer refers to this aspect of the patient's difficulties as follows:

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1. Eric Wittkower, M. D. "The Psychological Aspects of after-Care", Presented before the Regional Conference on Chest Disease, March 7, 1952. p. 4.

> Personal adjustment can help the individual only up to a certain point - he cannot be expected to adjust to a hostile, unfriendly world which, in a sense, punishes him for his illness, and will not give him a suitable opportunity for pursuing as normal a way of life as his condition permits.[1]

This chapter will deal with some personal aspects of the patient's post-hospital adjustment. Firstly, the patient's reaction to leaving the hospital will be discussed. Attitudes to restrictions and limitations imposed by the illness in the post-discharge period will follow. The relationship of the patients to their hospital friends and former social group will be considered and finally there will be some consideration of the effect of the illness on the patient's social and recreational life.

Attitude to Leaving the Hospital

Having to leave the protective atmosphere of the sanitorium after a long period of separation from his normal environment also may arouse different reactions within each individual. Upham remarks that the patient "may have conflicting feelings and anxiety about returning to the family and community".[2] Seltzer notes that some patients are "terrified at leaving the sheltered atmosphere of the sanitorium; some fear they may not be welcome at home;

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1. Edith Seltzer, The Personal Problems of the Patient as a factor in the Treatment of Tuberculosis. (New York, 1943) p.7

2. Frances Upham, A Dynamic Approach to Illness (New York, 1949), p. 115.

old friends and associates have drifted away or may shun him".[1] In anticipating his return to the world outside, the patient may need help in order to meet the new circumstances and adjust to a new pattern of living.

The attitudes of the twenty single patients under study, to leaving the sanitorium have been categorized in table IV. The patients were grouped into three categories to indicate their emotional response to leaving the hospital. Those patients who were able to accept the doctor's recommendations for discharge without undue anxiety were placed under the heading of "realistic acceptance". Patients who seemed reluctant to leaving the hospital were considered to be apprehensive about discharge. Individuals who had pressed for an earlier discharge than was thought advisable by the doctor were considered to have been "over-anxious" to leave.

Table IV

Attitude to discharge of 20 single Patients According to Their Emotional Response

Attitude to Discharge	Total	Male	Female
Total	20	14	6
Realistic Acceptance of Discharge	10	7	3
Apprehension about Discharge	5	3	2
Over-anxious for Discharge	5	4	1

2. Seltzer, op. cit. p.7.

Ten patients, seven male and three female, indicated that discharge from the hospital presented little or no conflict for them. The majority of these individuals said they were "happy to leave" or they "couldn't get out fast enough" when the doctor told them they could go home. They were not apparently threatened by the prospect of leaving the sanitorium and gradually assuming their responsibilities. At least two of the patients in this group had been somewhat worried over finances since they were not allowed to work for several months after being discharged. However, this did not constitute a major problem for them at the time of discharge as they had somewhere to stay in the meantime. The following example illustrates this type of situation and the manner in which it was handled realistically without much conflict.

> Case 30. Mr. V. said "it was a wonderful feeling" when the doctor told him he could go home. This patient had lived alone prior to his hospitalization, but his nieces planned to look after him after he was discharged. His brother-in-law also asked him to stay with him in the country for several months. Mr. V. said he was worried about not being able to work for six months as "you feel your money is going". However, his nieces and brother-in-law would not let him spend any money during that time and did everything for him until he went back to work.

It is recognized that many of these patients may have had underlying fears at the time of leaving the hospital that were not expressed during the interview. However, these

ten patients were placed in the category of "realistic acceptance" because any conflicts they may have had did not seem to make them unduly apprehensive about going home, nor did they indicate that they had any inner or outer pressure that would motivate them to seek and earlier discharge than the doctor recommended. Also, some realistic plan seemed to have been made by the individual or his family for his discharge.

Five patients, three male and two female, showed some anxiety or apprehension about leaving the hospital. These patients did not mind staying on at the sanitorium,,upon the doctor's suggestion, longer than they really needed to or they said they enjoyed their stay at the hospital and were sorry to leave. An example of this attitude is the following:

> Case 6. Mr. W. T., 24 years old, said he did not care how long he would have to be in the hospital as he "didn't have any responsibilities" holding him down. He claimed he had enjoyed himself at the hospital and if the doctors would have asked him to stay on for a few more months, he would not have minded. This patient had suffered a relapse and this was his second period of hospitalization. It seems evident here that Mr. W. T. felt more secure within the confines of the hospital.

Dr. Howell[1] discusses the patients who seem to prefer the sheltered life of the hospital to the struggle for existence outside it. He says that "they must therefore persuade themselves that they still require hospital care even when they are told that their disease is healed". The following

example demonstrates the feeling one patient had about his discharge where the underlying anxiety was evident:

> Case 16. Mr. P., who is 18 years old, was told he could leave the hospital on a Thursday but he did not leave until the following Saturday. He expressed resentment at not having been placed "on exercise" at the sanitorium before he was discharged. He repeated several time that he should have been put in the "last class" before going home. Mr. P. claimed that he was worried that his mother would not know what to do "if anything happened" while he was home.

In contrast to this attitude were those patients who were considered "over-anxious" for discharge. These five patients, four male and one female, said they had "nagged" or "kept bothering" the doctors about when they could leave the sanitorium. Although, in some instances, the doctor felt they would benefit from a few more months of sanitorium care, they refused to stay in the hospital longer than was absolutely necessary. It was felt that in these cases personal or social problems were creating pressures for a speedy discharge. The following examples illustrate both personal and social difficulties which induced the patient to seek an early medically approved discharge.

> Case 37. Miss D., a 23 year old girl, had been a behaviour problem in the hospital, rebelled against routines and refused to eat the food. She said that the doctor confined her to the ward and told her that if she behaved herself she could go home at Christmas. Miss D. said that "at first he was rather

reluctant to let me go, but I kept after him. I was very anxious to go home". Both her parents died while she was in the hospital and she had identified closely with the patient group and had a fiancé at the sanitorium. However, it would seem that this patient could not tolerate the restrictions and regimentation of hospital life.

Case 31. Mr. W. was advised by the doctor to stay at the hospital for the rest of the summer but he did not want to stay because of conditions at home. This patient's brother contacted tuberculosis a month before Mr. W. was discharged. His father had died while he was at the hospital and his mother was having a difficult time managing on her own.

Attitude to Limitations Imposed by the Illness

When the patient leaves the sanitorium with medical approval, his disease is either apparently arrested or improved. Usually the individual has not completely recovered enough and would not be discharged so early if there were hospital beds. He therefore has to adhere to his rest periods at home or continue treatment and regular checkups at the clinic. In any case, a certain amount of restriction is necessary because of the possibility of reactivation of the disease. Upham points out that, "One of the outstanding characteristics of tuberculosis is its recurrent nature".[1] The illness, therefore imposes more or less permanent limitations. The individual cannot always resume the type of life he led previously and often has to adapt himself to a new

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1. Upham, op.cit. p. 108

pattern of living. Carol Cooley comments on the necessity for a limitation of activities:

> To gear all his activities to a slower pace, to restrict voluntarily his social life, to carry over the habits learned in the sanitorium, are real challenges to the patient's perseverence and desire to stay well.[1]

The ability of the ex-patient to accept the limitations imposed by the illness depends largely on his personality and his particular social environment. It is also closely tied up with his concern about the illness and fears of relapse. Wittkower brings this out in the following statement:

> Some of them are so much afraid of a relapse . . . that they avoid the slightest exertion, sometimes in an absurd manner. More often than not these patients fail to respond to reassurance because their anxiety, although apparently concerned with and related to their illness, really arises from another source which requires exploring. Conversely, there are other patients who at an early date, defiantely and against their own interests, keep away from their doctors because they want to forget all about their illness.[2]

Table V indicates the attitudes of the twenty single patients to the restrictions of activity and the necessity for continuation of rest routines.

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1. Carol H. Cooley, Social Aspects of Illness (Philadelphia, London, 1951) p. 232.

2. Wittkower, op. cit. p. 4.

Table V

Attitude to Limitations Imposed by the Illness following Discharge of 20 Single Patients according to Degree of Acceptance.

Attitude to Limitations	Total	Male	Female
Total	20	14	6
Acceptance of Limitations	10	5	5
Under Concern with Limitations	6	5	1
Over Concern with Limitations	4	4	-

As shown in the Table, half of the patients, or ten out of twenty, were able to accept their limitations with little or no difficulty. At least three of these patients accepted the restrictions easily and showed no resentment at having to lead a comparatively quiet life. To illustrate this attitude, the following example is given:

> Case 34. Miss R., 24 years old, had been hospitalized twice for tuberculosis. She was glad to follow the rest routines at home since she was anxious not to have another relapse. She hoped that in the near future she would go back to a more normal routine but in the meantime she had worked out a regime which was satisfactory to her. Miss R. spent a great deal of time knitting, sewing and doing handicrafts from which she derived a great deal of satisfaction.

The balance of seven patients who accepted their limitations, did so with some degree of irritation. However, they were able to see quite realistically the necessity of

of following a regime because the nature of the illness. Their chief complaint was that it was much more difficult to accept restrictions at home than at the hospital. Wittkower points out that it is in the home that "the difference and the cleavage between the situation of the unfit and that of the fit make themselves strongly felt".[1] One patient summed this up in the following way, "It was much easier to follow routines at the sanitorium where everybody else was resting as well and it seemed the natural thing to do."

Six patients, five male and one female, were considered to be "under concerned" with limitations. These patients restricted themselves very little, did not follow the doctor's recommendations and developed their own regime of rest. The majority of patients in this group showed no apparent fears of relapse. It is recognized that their defiance may be a defense against inner anxieties. However on the surface they were considered to be insufficiently concerned about their limitations, and it was felt that their behaviour and attitude could be detrimental to their well-being. Several of these patients admitted they derived some comfort from their periodic clinic checkups. Such was the case of the following patient:

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1. Eric Wittkower, M. D., A Psychiatrist Looks at Tuberculosis (London, 1949) p. 81.

Case 26. Mr. G., 22 years old, said it bothered him a great deal to stay behind when his friends went out. He said "I can't stay at home, I always felt this way and I still do". This patient felt he was actually doing more than before he went to the sanitorium. He reasoned that "being active seems to be doing good". Although he admitted that the doctor did not want him to be too active, he said he did it just the same. He commented that he had no fears of relapse but it was a comfort to go for checkups once in a while because "you fool around and start worrying".

Two of the patients in this category, both male, did not report back to the clinic for checkups as they were supposed to. In both these patients there was evidence of an underlying concern about relapse and a desire to forget about the illness. Further discussion of these cases will serve to illustrate this attitude:

Case 9. Mr. R., aged 20, was discharged from the clinic because of failure to return for checkups. During the interview, this patient said he did not feel he had to restrict himself anymore, he had no fear of relapse and never thought about it. He believed that if you think about it too much, you will get it. He also said that he tried to forget that he was ever at the sanitorium.

Case 35. Mr. E. T., aged 45, got married a month after being discharged from the hospital. He did not report back to the clinic and felt he was all right and could look after himself. His married life was very happy and he seemed to want to shut out anything that might interfere with his present state. Mr. E. T. had been very concerned about his illness during his hospitalization.

Those patients who restricted themselves more than seemed necessary were considered to be "over-concerned"

with limitations. They took "extremely good care" of themselves or took "double precautions" and seemed particularly fearful of relapse. Four patients, all male, fell into this category. Analysis did not reveal any relation between severity of diagnosis and concern over limitations. For example, among the patients who seemed over-careful about restrictions, one had been diagnosed as a minimal lesion, two were moderately advanced and one was far advanced.

Various writers have pointed out the effect that tuberculosis may have on the personality. Bellack[1] and Wittkower[2] mention that illness gives rise to hypochondriacal concern, self observation and anxiety. Several of the patients who were "over-concerned" about their limitations showed evidence of what Bellack refers to as "secondary narcissism". The following is an example of this effect on a patient.

> Case 30. Mr. V. said, "If I get a little pain I wonder if this is coming back again. I have a decided fear of relapse and when I get a little cold it worries me. I'm afraid I might overdo it and bring it back again so I keep check on myself".

Attitude to Relapse:

Since there is always some danger that the disease may be reactivated, the patient who has been treated for tuberculosis

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1. Leopold Bellack, M. D. "Psychiatric Aspects of Tuberculosis", The Family, Vol. XXXI, No. 5 (May, 1950), pp. 183-189.

2. Wittkower, op. cit. pp. 21-37

usually has some fears of relapse even though his illness has been arrested. Of the twenty single patients analyzed for this study, fifteen of them expressed definite fears of relapse. One of those patients said he could not believe that he would be healthy again. Several patients stated they were anxious about going to public places or hearing other people cough. The majority were not so concerned about getting the disease from others but felt they had to be careful themselves. While the balance of five patients said they had no fear of relapse, nevertheless, three of them seemed to get some relief from attending the clinic regularly. The remaining two patients did not attend clinic but there was evidence of underlying concern as noted previously in the illustrations.[1]

Relationship with Social Group

During the patient's prolonged absence from his normal social group, his friends may have developed new ties and new interests. Feelings of stigma about the disease or fear of infection may result in rejection and ostracism of the ex-patient by his former group. The necessity for restrictions and limitations in activity may further hamper his re-entry into the circle of his previous friends. Wittkower comments

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1. Supra, p. 58 (Case 9 and 35)

on this problem:

> While the patients were away, their contemporaries may have forged ahead, may have fallen in love and may have married ..... Loss of friends may be due to many reasons; tuberculous patients are apt to think it can be due to only one reason - the illness.[1]

During his long stay at the hospital the patient has often developed a new philosophy of life which is incompatible with the ideas held by his former associates. He may have more in common now with his hospital friends, identify closely with them and more or less withdraw from his former social relationships. The individual may not only lose his former friends, but the above mentioned factors may also be instrumental in limiting his further social contacts in the larger community.

The single patients under study were analyzed in terms of the degree of identification they had with the patient group in their post-discharge period. It was felt that the patients who "withdraw into a world of fellow sufferers"[2] have felt keenly the rejection by friends or other members of the community, are apprehensive about competing with their healthier contemporaries and seek the security and comfort of those who share many of the same problems.

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1. Eric Wittkower, M. D. "The Psychological Aspects of After-Care", Presented before the Regional Conference on Chest Disease, March 7, 1953, p. 6.

2. Ibid., p.6.

Table VI

Degree of Identification with the Patient Group of 20 Single Patients during the Post Discharge Period.

Degree of Identification	Total	Male	Female
Total	20	14	6
Close Identification with patient group.	7	1	6
Partial Identification with patient group.	4	4	-
Complete Withdrawal from patient group	7	7	-
Withdrawal from both patient and former social group	2	2	-

It is interesting to note that the six women in the single group all identified closely with the patients. Only one male patient fell into this category. All these patients had experienced some definite rejection by former friends and had lost all or most of their former associates for one reason or another. They stated they had "more in common with hospital friends" or they felt "some bond in knowing everybody had the same thing". In some instances their previous friends had drifted away, got married or they did not seem to have the same interests anymore. Two patients in this group, one male and one female, had identified completely with their hospital friends and did not keep in touch with their former social

circle at all. The remainder of this group saw some of their old acquaintances but their main interest was with the patient group. The following examples will illustrate the degree of attachment to the tuberculous patients and partial or complete withdrawal from former social relationships:

> Case 38. Miss D., 27 years old, said she was more interested in the group from the hospital than her former friends. She had been very upset about one friend who never visited her at the hospital and the family did not want her to visit the patient now either. Many of her friends were now married and she saw them once in awhile but she felt they did not have the same interests any more. This patient said she had changed her outlook as far as friends were concerned; she now looked for character and sincerity whereas formerly she had sought the friendship of those individuals with whom she could enjoy herself in sport activities.
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> Case 31. Mr. W., 27 years old, led a rather wild life before his illness. He now had no friends left from his previous social group as "they only came up to see him once or twice in the hospital". His former fiancée left him because of pressure from her family. This patient felt he lost all his former friends on account of his illness. He now associates only with the hospital group and has not made any other friends since discharge. He plans to marry a girl he met at the sanitorium.

Four patients, all male, kept in touch with the patient group on a casual basis while they still maintained their ties with their former friends. Only one patient in this group said he experienced some rejection by a former acquaintance. Nevertheless he felt he had more in common with his previous circle of friends than with his"patient"friends. These patients were considered to have only partially identified with the patients

from the hospital. On the whole they were still active with their old crowd, and they also kept in touch with some hospital friends.

At least seven patients, all male, withdrew completely from the hospital group once they were discharged and retained their former friends. With two of these patients there seemed to be a conscious withdrawal and it seemed as if they wanted to forget the whole hospital experience and those associated with it. Five patients gradually drifted apart from hospital friends and returned to their former social circle. This group of patients said they had not been ostracized by any of their former group and still had their old friends.

Two patients withdrew from both the patient group and from their former acquaintances. They made no lasting friendships at the sanitorium and seemed unable to keep pace with their usual circle of friends or else they felt they could not. The following illustration indicates the feeling of one patient in this regard:

> Case 30. Mr. V. said "I seem to have gotten away from my friends. I felt they knew I had tuberculosis and I should not interfere in their lives. I'd rather live more to myself. I want to be more quiet and do the things I like by myself. I'm contented this way".

It seemed that the above patient had some fear of rejection and was not actually rebuffed or slighted. The withdrawal in this case would seem to be a defense. This

attitude may be reflected in the patient's feelings about forming close personal ties.

Indirect Effect of Illness on Personal Relationships:

For the single tuberculous patient, his illness may be a real threat to his future in terms of marriage. First of all, he may experience or fear rejection by personal acquaintances and therefore be unable to enter into a permanent relationship. Also because tuberculosis is relapsing in character the patient himself may be apprehensive about assuming the responsibilities of marriage and family life.

In the group of twenty single patients under study, five individuals of whom three were men and two women, had some reservations about getting married. Their statements revealed concern over possible relapse and some fear of rejection. They seemed particularly worried about becoming a "burden" if they got sick again. This was particularly evident in the following example:

> Case 36. Miss N., 38 years old, said that her illness had affected her outlook on marriage. "I had a friend before I went to the hospital - - I still have, but he was scared of me although he came to see me. I think his sister put ideas into his head. She told him he was a fool to be coming to see me and I talked to him about it and said I'd rather he did not come. I still see him but I feel now that I won't get married. He tells me that's silly but I know he feels it. If I should get sick again I'd be a burden if I were married".

Four patients, three men and one woman, were planning to be married in the near future. One of these patients said he would wait for the doctor's permission and added, "I'm run by the doctor more or less". Another patient had been told to wait two years before getting married, but she planned to marry earlier as she felt "a year and a half was sufficient". There was no information available about the other two patients in terms of doctor's recommendations or the patient's feelings about it.

The remaining number of patients in the single group said they had no fear of getting married or having children. One patient had married since discharge. Three patients said they never intended to get married and that this decision was not connected in any way with their illness.

Effect of Illness on Social and Recreational Activities.

The patient who has had tuberculosis cannot always resume the type of activities he pursued before his illness. If the patient had always led a quiet life, the limitations and restrictions which are necessary for his well-being in the post discharge period will not disrupt his former pattern of existence to any great extent. However, many persons prior to illness have led a rather active social life and participated in some form of recreation, such as athletics, hobbies, clubs

and so on. Often, the individual has to curtail some of his activities or develop new fields of interest which are not so strenuous. Cooley remarks on this aspect of the effect of illness on the individual:

> A social result often observed is that illness has interfered with or prevented a normal way of life. The usual outlets for self expression found . . . in recreation may have had to be modified or given up temporarily.[1]

For purposes of analysis, the twenty single patients were grouped according to three main types of social and recreational interests they had been most active in prior to their illness. One category were those who had led an active social life. This group of patients had enjoyed going to night clubs, social gatherings, drinking, dancing and generally keeping late or irregular hours. Another group were those patients who had participated actively in outdoor sports. Also included in this category were a few individuals who belonged to recreational clubs which took up a great deal of their time and energy, A third group of patients was considered to have followed mainly sedentary pursuits. This included individuals who had enjoyed reading, going to shows or visiting friends and so on. It was felt that they led a comparatively quiet life and had not been engaged in social or recreational activities which required much physical exertion. Many patients enjoyed various types of activities

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1. Cooley, op. cit. p.6

but an attempt was made to classify individuals according to the type which seemed most characteristic of them.

As shown in Table VII, five persons did not change their activities and were participating in them to the same extent as they had before their illness. The majority of patients, ten in all, still had the same general interests but the degree of participation was lessened or the type of activity was modified to meet their present state of health. Five patients completely changed the type of activity they had pursued previously.

Table VII

Post Discharge Adjustment to Social and Recreational Activities of 20 Single Patients according to Degree of Change.

Activities Prior to Illness	Total	Degree of Change after Discharge		
		No Change	Modified	Complete Change
Total	20	5	10	5
Active Social Life	7	-	5	2
Participation in Sports and Recreational Clubs.	7	1	3	3
Sedentary Pursuits	6	4	2	-

Seven patients had led an active social life prior to their illness. Of this group, five patients still enjoyed this type of recreation but they did not go out as much as they had before and to a large extent modified their activities. A

typical response was as follows, "Before I was at a night club practically every night. Now I go to the movies, read and take in a night club once in awhile". Some patients seemed outwardly resigned to the fact that they had to modify their activities but a few showed marked resentment and found it extremely difficult to curb their usual modes of outlets. The following patient's response indicates this clearly:

> Case 43. Mr. J. said "Since I've been sick there's no more bowling with the boys. I've played a few games but it played me out. I used to go swimming but you're not allowed to take the sun so what's the use of going! I used to jitterbug but I had to give that up. Now I do the slow dances. When there's a party I come home about 1 or 2 o'clock and I'm itching to stay but I have to go home. Sometimes, if my parents or sister are not there, I don't leave when I'm supposed to.

Two patients completely gave up their former active social life and turned to more sedentary interests. The following is an example of a complete change in major form of activities which the patient had pursued.

> Case 37. Miss D., 23 years old, was fond of dancing, movies, night clubbing and parties prior to her illness. She now felt that she had quieted down very much and was not interested in this type of entertainment. Her main interests now were reading, knitting and visiting friends she had made at the sanitorium.

It can be seen that all the patients who had led this type of life either modified or completely changed their activities. None of the patients in this group had resumed their previous activities as they had left them before hospitalization.

Of the seven patients who had been very active in sports or clubs, only one patient seems to have resumed his old activities with his crowd. He felt there were no restrictions and had taken up "Boxing for fun" after discharge. Three patients had given up the more strenuous sports but still enjoyed outdoor activities. For example, one patient said he used to play hockey, ski, bowl, and do a lot of fishing and swimming. He hoped eventually to resume some of them but won't "Rush into them" and has dropped most of them in the meantime except fishing. The remaining three patients gave up their sport activities entirely, as is evident in the following illustration:

> Case 42. Mr. L. V. used to play hockey and baseball in small local league and also enjoyed bowling. He liked to sing as a hobby and participated in local musicals and church choir. Since his hospitalization he gave up sports, does hardly any public singing and does a lot more reading at present. This patient said he was now much quieter and felt he "played around too much" prior to his illness.

Of those patients who had been interested in more sedentary activities, the majority, four out of six, still had the same interests and there was no apparent change. Two patients seemed to have modified even these pursuits on account of their illness. An example will serve to illustrate this:

> Case 16. Mr. P., 18 years old, used to "live in the movies" before he took ill. He also enjoyed playing the piano and had taken lessons for awhile. Movies were still his main interest but he did not go as often because he was very conscious of "coughing that is heard in public places". He has neglected the piano a great deal because he felt that practicing would get him too tired.

It is evident from the above illustration that excessive concern over the illness and fears of relapse affected this patient's attitude toward his recreational activities.

An attempt was made in this chapter to observe some personal and emotional phases of the single patient's postdischarge adjustment. It was seen that leaving the hospital and returning to the community created a variety of difficulties for the patients. In many instances the pattern of social and recreational activities which the patient had pursued prior to illness was changed or modified. Limitations imposed by the illness, fears of relapse and apprehension about the future in terms of marriage added to the strains that the tuberculous patient had to bear.

Findings

The psychological adjustment of the 20 single patients to their illness was viewed from three aspects as demonstrated in their reactions and attitudes from the time when diagnosis was made and hospitalization recommended, through the period of hospitalization, and during the postdischarge period until the time of the research interview.

About two-thirds of the patients were markedly upset when their illness was diagnosed. These patients reacted with a great degree of shock and a few were incredulous when they heard the news. A higher proportion of women as compared

with men admitted they were severely upset. Fears of death and feelings of stigma seemed to be the predominant concern of patients at the time of diagnosis. In almost half of the cases studied, there seemed to be a great deal of apprehension or resistance to going to the hospital. This showed evidence of underlying problems which existed which were making it difficult for the patients to accept sanitorium care. Misconception about the illness and sanitoria seemed to invoke more fear than the separation factor.

After they entered the hospital, more than half of the patients were severely anxious or depressed for the first few weeks. Following the "settling-in period" only a little over one-third of the single patients seemed to have assessed their situation realistically. One-fourth of the 20 individuals studied showed severe concern and anxiety about their illness throughout the hospitalization period. Among the balance of patients, some of whom apparently lacked concern or others who were only mildly upset, it was seen that their attitude was in many instances a defense against underlying anxiety.

Treatment procedures as a whole presented obvious difficulties for at least one third of the patients under study. It was also felt that among the patients who were very passive about treatment, strong dependency needs were evident. This could present a problem in terms of resuming former responsibilities after recovery. A proportionately higher

number of women than men showed concern about their illness at the time of diagnosis. But more men than women seemed to have difficulties during the hospitalization period in accepting the various treatment procedures and in having a realistic attitude to their illness.

In half of the 20 cases studied, personal and social factors were instrumental in creating problems with regard to discharge from the hospital. In some instances the patients were too anxious to leave, and in others they seemed to prefer the sheltered atmosphere of the sanitorium. During the postdischarge period, the majority of patients showed some irritation with limitations and restrictions imposed upon them by their illness, yet a substantial number accepted these drawbacks. However, a little more than one-quarter of the 20 single patients studied here had severe difficulties in accepting their restrictions and four patients seemed to be over-anxious and restricted themselves too much. The majority of patients expressed definite fears of relapse and in a few cases some apprehension about reactivation of the disease was apparent. from their behaviour.

At least half of the 20 single patients experienced some rejection or felt ostracized by former friends and acquaintances. About one-third of the patients identified closely with the patient group because of this, and two of these patients identified completely with their hospital friends. Two other

patients withdrew completely from both patient and former social group because of their illness. A third of the patients stated that their former relationships were not affected by the illness at all. It was noted that the female patients tended to draw away from their former social circle and identify with the patient group more than did the male patients.

One-quarter of the single patients indicated that the illness had affected their future plans or hopes for marriage and raising a family. This feeling seemed to be based on fears of relapse because of the increased responsibility that marriage entails and fears of being rejected because they had been ill.

The majority of the 20 single patients had to modify or completely change their former social and recreational activities on account of their illness. Patients who had led an active social life or who had participated in sport activities were mostly affected in this area. For patients who had led a quiet life before illness there was either no change or very little modification in former pursuits.

Although the patients in this study completed their course of treatment in the hospital and were discharged to the community with medical approval, they did so with varying degrees of difficulty. These patients may have made a comparatively satisfactory adjustment in that they were able to withstand the strains imposed by the illness and carry through at least to

their physical recovery. However, in the process of adjustment, during the various stages of their illness and treatment, they showed by their reactions, attitudes and feelings that they had emotional and social problems for which they needed support and help.

PART II

PSYCHOLOGICAL ADJUSTMENT OF MARRIED PATIENTS TO THE ILLNESS

CHAPTER IV

EMOTIONAL PROBLEMS RELATED TO ILLNESS AND HOSPITALIZATION

Introduction

It is undeniable that it is disturbing to an individual to learn that he has a serious, chronic, disabling disease. When this disease is tuberculosis, it is equally apparent that he responds, not only to the tuberculosis bacillus which is doing physical damage, but also to the meaning which the illness has for him in terms of social stigma, hospitalization, medical care, discharge, and his eventual re-establishment in the community.

Illness, and particularly serious or prolonged illness, is viewed differently by every individual, according to his life experience. To some, it is a manifestation of weakness and they deny this frailty, or evidence a lack of concern with it. To others, illness is a terrifying thing which threatens to deform them, - to change the body image which they have of themselves. To still others, serious illness is so menacing that they cannot face it and they become very depressed or withdraw into such comforting states as sleep.

Each phase of tuberculosis and its treatment may make it more difficult for the patient to move on to the next. For example, insufficient explanation and understanding at the

time of diagnosis may engender unwarranted fears at the time of admission to the hospital. This may make it impossible for the patient to adjust in a healthy way while he is hospitalized, which in turn may bring about difficulties at the time of discharge and re-assimilation into the community.

Dr. G. R. Howell, Medical Director of the Grace Dart Hospital makes the following statement regarding focus in the treatment of tuberculosis: "the tuberculous lesion and the emotional or individual factor should be studied together and should be considered as a single medical problem".[1] Although a great deal has been written about tuberculosis and its physical effects, comparatively little attention has been given to the emotional problems concomitant with the disease. This section of the study concerns itself with these problems and with the difficulties involved in the patient's return to his normal social milieu. No effort will be made to set forth causal factors, since the underlying purpose is to emphasize the problems experienced by the patients. These will be evaluated in terms of degree of intensity. For example, the reaction to diagnosis will be measured according to shock or distress, incredulity, and slight concern.

In studying the emotional aspects of this illness, it is important to give some attention to the personality of

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1. G. R. Howell, M. D. "The Role of Emotion in Tuberculosis, "Unpublished Paper.

the tuberculosis patient. "Investigations have failed to detect a uniform personality type prevailing in tuberculosis patients....[1]." It is important, however, to note that tuberculosis does not effect a change in the personality. The patient uses the same emotional equipment to face his illness, that he has used to deal with all his life problems. If this equipment has proven inadequate to the task of helping the patient adjust to his other problems, then it is reasonable to expect that he will have considerable difficulty in making a good adjustment to his illness.

This chapter concerns itself with the emotional adjustment during hospitalization of the 23 married patients in the study. Of these, 13 were male and 10 female, with an age-range at the time of interviewing of from 23 to 57 years. Six males and seven females, or a total of approximately 56 percent of the patients were 35 years and under. Of the males, one was separated from his wife shortly after discharge from hospital but he has been classified as married since the separation did not become effective until he had left hospital.

Of the 23 married patients, six had a diagnosis of minimal tuberculosis, 15 were moderately advanced, and one was classified as far advanced. There was also one case of pleurisy with effusion, which was included in the study since

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1. Eric Wittkower, M. D. "Psychological Aspects of After-care in Pulmonary Tuberculosis". Unpublished Paper.

medical authorities expressed the opinion that the pleurisy was tuberculous. The shortest period of hospitalization was two and one-half months, and the longest, two years and five months. Two patients were hospitalized for over two years and five for more than one year. However, 15, approximately 65 percent of the total number, were in hospital less than eight months. These figures relate only to the most recent hospitalization of the cases under study, although five had previously been hospitalized for tuberculosis. Of these five, two had had two relapses, two had had three relapses, and one had had only one recurrence of the illness.

In order to deal in an organized fashion with the material secured, they will be discussed under the following headings: 1) Reaction to Diagnosis. 2) Reaction to Need for hospitalization. 3) Reaction to Illness During Hospitalization. 4) Reaction to Treatment Procedures. 5) Reaction to Medical Authority and Dependency.

Reaction to Diagnosis

In examining the reaction of the married patients in the present study, to their diagnosis of tuberculosis, considerable individual variation was found. However, on further analysis, it was seen that responses could be divided into

three broad categories. The first, "shock or distress," is defined as meaning a response of agitation, fear, or anxiety regarding diagnosis. The second category, "incredulity," is used to include patients who were, for a time, unable to accept either intellectually or emotionally, the fact that they had tuberculosis. The third group is classified under "slight concern," and consists of those who expressed only a small degree of anxiety over their diagnosis whether it was serious or relatively mild. The following table illustrates the feelings expressed.

Table VIII

Reaction to Diagnosis of 23 Married Patients, Discharged with Medical Approval from the Grace Dart Hospital, Montreal, Between May 1951 and November 1952.(a

Reaction	Total	Male	Female
Total	23	13	10
Shock or Distress	17	8	9
Incredulity	3	3	-
Slight Concern	3	2	1

a) All subsequent tables in Part II of this thesis, refer to patients in this sample group. Therefore, no further reference will be made, in tables, to hospital, place, date, and year.

The figures in this table indicate that 17 out of 23 patients responded to diagnosis with shock or distress.

Ninety percent of the women fell in this category, while there were only approximately 53 percent of the males who felt this way or felt free to admit their feelings. The response was expressed in many ways during the interviews and at times the reaction was so strong that patients found it difficult to find descriptive phrases. The following excerpts will perhaps serve to emphasize the above statements.

> Case 33. Mrs. O., a young married woman of 25 years who, at the time of her diagnosis as moderately advanced tuberculosis, had a two-year-old son, said, "It's hard to describe what it's like when somebody tells you you've tuberculosis." This patient was very much disturbed and frightened and brooded over her possible prognosis.
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> Case 2. Mr. R., a 34 year old man with three children said, "When I first heard the diagnosis it was a terrific shock. Have you ever been hit by a streetcar? I was flabbergasted and couldn't think straight."

Only three patients, all males, responded with feelings of incredulity. Each of these found it difficult, because of his feelings about himself and about the illness, to accept the fact that this shattering experience had come to him. The illustration given below, is typical of this group.

> Case 7. Mr. P., a 56 year old man with a large family, expressed his feelings as follows: "I couldn't believe I had tuberculosis when they X-rayed me at work. They sent me up to the clinic for more investigation and when they told me I had it, I began to believe it a little but I didn't really believe it until I was right in the hospital."

Another man was incredulous of his diagnosis and maintained throughout his interview that he had never had tuberculosis.

Of the three patients who expressed only slight concern at the time of diagnosis, two were male. The one female appeared to accept her diagnosis rather passively. The example cited below, describes the response of a man who responded by projecting his fears.

> Case 23. Mr. M., a married man of 28 years, expressed only very slight concern since he appeared to be projecting his real feeling onto his wife. In the interview he said, "The doctor told my wife and I'd rather he had told me. I was worried for my wife. For myself, if I was going to die I was going to die and if I was going to live, well -- I'd live!"

These reactions to diagnosis do not necessarily set the pattern for reactions throughout the illness and hospitalization. They merely indicate how this group of patients has reacted under the stress of an upsetting and sometimes totally unexpected announcement. It is important to note that some patients whose response seemed unhealthy in this area, were later able to make a very good adjustment to their illness.

Reaction to Need for Hospitalization.

As well as reacting emotionally to their diagnosis, tuberculosis patients fre quently react strongly to the need

for hospitalization. Hospitalization means many different things to each different individual. It entails separation from the family which is dependent upon him, or upon whom he may be dependent. It brings with it anticipation of a great many difficulties, including dread of treatment, feelings about medical authority, and apprehensions regarding the final outcome of the illness. To the predominantly active, independent person, it carries the threat of firm restrictions on activity which convey to him feelings of imprisonment. To the individual who does not understand his disease and its treatment, the sanatorium may be tantamount to a death cell.

Four broad groups of reactions to need for hospitalization were seen in the group of patients interviewed in this study. Of 22 patients whose reactions were secured, 15 revealed themselves as having accepted hospitalization realistically. That is, they felt that although the thought of hospitalization might involve separation from their families, loss of income, and painful treatment, still this was the surest way to a speedy recovery and they must accept it as an unpleasant necessity. Of this group 11 were male and only four female.

Four patients reacted to the question of hospitalization with emphatic expressions of fear and apprehension which they were not able, at that time, to rationalize in terms of the contribution which the hospital might make toward their eventual

recovery. Three of these were female and one made the following statement. "I felt I was doomed if they sent me to the san. and I thought if I was going to die, I would rather die at home."

One patient resisted admission. This woman had rested at home for some months and when it was finally made clear to her that she should enter hospital, she resisted. When she was informed that a hospital room was available to her she would not accept it. It was only after her doctor refused responsibility for her condition that she finally accepted the admission.

Two patients gave evidence of having been over-eager for admission. Both expressed a desire for hospitalization which was projected onto feelings regarding the spouse. One, a female, was anxious for hospitalization since she felt that she would be close to her husband who was already hospitalized with tuberculosis.

In this married group most patients expressed some concern as to what hospitalization itself might bring and fears regarding separation from family were very common. A young man who had suffered two relapses said, "The other times I didn't mind so much but this time it was different. I was married and it (the necessity for admission) nearly broke my heart!" A married woman with six children exclaimed, "I thought the bottom would come out of the world! I thought of the children

and how they would get along without me." As indicated here, the need for hospitalization brings with it so many threats both from within the hospital and with regard to home, work, and economic situations, that it places a great strain on those individuals who must accept it.

Adjustment to Illness During Hospitalization

Tollen makes the following points regarding tuberculosis:

1. Tuberculosis is a disease for which no specific, sure, and permanent cure has yet been developed.
2. Treatment of tuberculosis generally required a relatively long period of hospitalization.
3. Tuberculosis is a dreaded disease with fear, open or disguised, as an almost universal concomitant.[1]

It is apparent that the tuberculosis patient, if he gives vent to his real, underlying feelings, cannot help but have a great deal of apprehension regarding this disease which he has contracted. His feeling is, to some extent, heightened or decreased according to his understanding of his illness.

In an effort to gain a picture of the variety of responses to illness of the 23 married patients, the analysis of reactions was done in terms of four headings. The first, "Apparent Lack of Concern" was defined as including those patients who gave little outward sign of fear and worry, or

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1. William B. Tollen, "Irregular Discharge" U. S. Public Health Service, Tuberculosis Control Issue, Vol. 63, No. 45, Nov. 5, 1948, pp.1443.

used a psychological defence such as withdrawal or defiance. "Passive acceptance" was used to describe patients who expressed little feeling about the illness but appeared to welcome it since the dependency which it fostered was gratifying to them. Those grouped under "Realistic Concern" showed feelings which seemed justified by the severity of their diagnosis but were also apparently able to make a healthy adjustment to the illness. The category "Severe Concern" covers those individuals who evidenced great anxiety about the illness, its symptoms, and what it meant for them, it was felt that the feeling in these cases involved unhealthy emotional aspects. A table to show the number of individuals, who fell into each group, is given below.

Table IX

Adjustment to Illness During Hospitalization of 22 Married Patients Classified According to Degree of Concern.

Emotional Response	Total	Male	Female
Total	22	13	9
Apparent Lack of Concern	4	3	1
Passive Acceptance	4	1	3
Realistic Concern	8	4	4
Severe Concern	7	5	2

Only 22 of the 23 patients could be categorized in this table since one female was diagnosed as an "anxiety hysteric" and was unable to give any definite picture of her feeling about the illness. She was heavily sedated during more than one-third of her hospitalization period and although there were elements of severe concern in her reaction, it was impossible to separate them from her feelings about her total life situation.

Of the twenty-two cases, only four were classified under the heading of "Lack of Concern". Three were male, and one female. Some defence mechanism was used in each case as a protection from the actual feeling engendered by the illness. The following will serve as an illustration of this response:

> Case 22. Mrs. R., a 29 year old woman with two small children, showed considerable defiance while she was ill. In her own words, "I went laughing to the hospital. I got all my crying over with when they told me my diagnosis." This patient said that although she frequently felt depressed and upset while in the hospital, she always "laughed on the outside" so that no one would know how she was feeling.

Four patients were classified as passively accepting their illness. These were all patients who seemed to have marked dependency needs and for whom the illness appeared to fill a definite need. Three of the four were female. Perhaps the best example of passive acceptance is the one which follows:

> Case 24. Mrs. R. was a 29 year old woman, whose husband was hospitalized at the Grace Dart Hospital. This couple also had a six year old daughter. It was apparent that she had no feelings of aversion toward the disease and, in fact, was rather pleased to be in hospital. She said, "In a way, I was glad to go in. I really liked the hospital. If I had to go back I wouldn't kick!"

Eight patients showed realistic concern over their illness. That is, although some were very much upset at first, they were able, eventually, to adjust themselves to their situation in a realistic fashion, early in the illness. The ensuing case illustration is typical of this type of response:

> Case 32. Mrs. W. was a young married woman of 31 years, who had one child at the time of admission. Mrs. W. said, "The first day in hospital I started to make my will and then the nurse gave me a good talking to. She said that if every patient looked as good as I did they would have no worry. After that -- it's crazy, but I was quite happy: I felt the quicker in the quicker out! I had to learn to stand on my own feet."

Seven of the twenty-two patients showed severe concern over their illness. These individuals gave evidence of feeling which was exaggerated and out of proportion to their symptoms. The following is an example:

> Case 41. Mr. V. was a 44 year old man who had recently come to Montreal with his wife. Mr. V. said that he was nervous when he went into the hospital and nervous when he got out." He was frequently so terrified about his condition and prognosis that he could not sleep and the sight of other patients who had had surgical operations upset him so badly that he became nauseated and vomited. Mr. V. was so

concerned about the contagion of the disease that he would not permit his wife to go near any other patients on visiting days and was perpetually afraid that the results of his X-rays and tests would indicate that he required surgery.

Reaction to Treatment Procedures

According to Tollen, "Prolonged rest, the basic treatment for tuberculosis, contradicts one of the elemental needs of human nature: the need to seek release of emotional and psychic tension in action".[1] Routines make each day almost the same as the one preceding it and the intensity of the boredom is felt particularly by those who have previously discharged their tensions primarily in physical activity. If bed rest is the only treatment the patient is receiving, he may, if progress is slow, have heightened feelings of anxiety since he will see others making apparently rapid strides following a surgical operation or the use of drugs. This will again increase his feelings of impatience regarding the apparently interminable bed rest.

Many of the minor treatment procedures and tests are fearsome and annoying to patients. The hypodermic needle may be very frightening to an individual who has feared it from childhood. For example, one patient, who was questioned about treatment said, "I'm a big man, but I'm small inside." Tests,

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1. Ibid, pp. 1444.

such as bronchoscopies, may be terrifying to patients who do not always understand the procedure and are afraid that they will smother or choke. Gastric lavages and X-rays are inevitably attended with feelings of misgiving, fear and hope. The recommendation that a patient receive pneumothorax is received with deep, inner feelings of terror on many occasions.

While it has been apparent in the preceding paragraph, that the minor treatment procedures and tests elicit a response of fear and apprehension, it is usually when a patient is faced with a surgical operation that his anxiety becomes strongest. The suggestion of a thoracoplasty or lobectomy intensifies the patient's feelings of fear regarding the treatment. According to Wittkower;

> This is not only because a thoracoplasty is a much more serious operation but also because its effects ..... are irreversible, and because the presence of a scar, as a blow to the patient's vanity, aggravates their sense of inferiority.[1]

In the group of twenty-three patients studied, feelings regarding treatment procedures were seen to fall into five categories. Under "Apathetic" were included those who passively accepted treatment and rest routines without expressing real feeling about them. "Realistic Acceptance covered those whose fear seemed proportionate to the treatment given and who were able to accept it as a necessity directly related to their eventual improvement. "over-conscientious"

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1. Eric Wittkower. A Psychiatrist Looks at Tuberculosis. London, National Association for the Prevention of Tuberculosis, 1949, p. 46.

was used to describe patients who were over-anxious to be co-operative and to accept treatment or rest routines. These individuals had the appearance of always trying to be "good". The "Rebellious" were those who continually questioned treatment and routines and who habitually evaded the regulations or recommendations. "Excessive Anxiety" referred to patients whose fear regarding treatment was out of proportion to the seriousness of their situation.

The following table illustrates a breakdown of the group under the above headings:

The term "Minor Treatment" covers such procedures as the administering of streptomycin and PAS,[1] pneumothorax, or pneumoperitoneum, as well as tests including X-rays, bronchoscopies, and gastric lavages. "Major Surgery" is defined as referring to operations such as pneumonolysis and the more serious thoracoplasty and lobectomy. "Bed rest and Routines" is self-explanatory and in this category has been included treatment routines which are directly related to the patient's physical well-being. Rest hour regulations and week-end leaves are examples of the latter. The following table illustrates a breakdown of the group under the above headings.

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1. These initials are commonly used to designate Para-aminosalicylic acid.

Table X

Reactions to Treatment Procedures of 23 Married Patients According to Emotional Response

Response	Total Response	Minor Treatment	Major Surgery	Bed Rest & Routines
Total Responses	47	22	4	23
Apathetic	2	1	-	1
Realistic Acceptance	23	10	2	11
Over-Conscientious	11	5	-	6
Rebellious	9	4	-	5
Excessively Fearful	4	2	2	-

The above table includes data on all 23 cases. However, no information was available regarding the feelings of two female patients with reference to their surgical operations. One woman had had a thoracoplasty and the other, a pneumonolysis. In another case, there was no information regarding the attitude of a male patient to minor treatment.

Minor Treatment:

One patient was apathetic or passive with regard to minor treatment. Her response to queries regarding any phase of the treatment or hospitalization was that it was "O.K." Her feelings seemed never to be strongly negative or positive

and she accepted her situation with no complaint, but also with little expression of pleasure.

Ten patients were able realistically to accept minor treatment procedures. That is, although treatment and tests were often distasteful or somewhat painful, these individuals were able to recognize the need for them. Although they might at times be fearful, or a little rebellious, they could, on the whole, take the treatment procedure as a matter of necessity. A common response was, "You get used to that like everything else, and if it is to make you better, you don't really mind too much".

Five showed over-conscientiousness and a desire to please medical authorities, in their response to minor treatment. One patient, typical of this group, was a rather dependent man who expressed his feeling in the statement, "I tried to co-operate in every way. I really took every rule they made. When I had my bronchoscopy I tried to be co-operative because I knew it would go better and I wouldn't feel as much." These individuals were very much concerned about their illness and frequently seemed to look to the doctor as an oracle whose word was law.

Four patients reacted in quite the opposite way to the above. This group became antagonistic and rebellious regarding treatment, and endeavoured either to avoid it or to become

aggressive toward those who were responsible for it. They tended to make many complaints about the hospital and the progress they were making and made such statements as, "I was a fighter. I was a hard character to kill and I'll fight everything under the sun before I'll give up!"

One patient expressed strong fears over treatment procedures. This 23 year old woman was very fearful regarding the whole of her illness and hospitalization. She was also immature in her attitudes and was very dependent on her husband, friends and the doctors who spent a great deal of time with her, helping her to accept treatment.

Major Surgery:

Only six patients in the group had surgical operations. Two of these accepted the surgery in a realistic fashion. Of these two, one was male and one female. The male had a pneumonolysis about which he said, "I wasn't worried about it. The others told me exactly what it was like and I was only in bed for a day." The female had a pneumonectomy, a thoracoplasty and a lobectomy about which she had considerable feeling but which, eventually, she had been able to accept. Her comment was, "It didn't make much difference to me. I was married. It was hard on the single girls, though. I thought the operations were the quickest way to get well!"

Two patients expressed excessive fear over the necessity

for surgery. Again, one was male and one female. Each had a thoracoplasty and was very much concerned over it. The following example will throw into relief the vivid fear felt by these patients.

> Case 15. Mr. A., a young married man of 30 years, refused the operation at first. When he was finally able to accept it, he said that he "Didn't like the idea of being carved up." Mr. A. said that the operation was a shocking experience and that he thought he would never get up from the operating table. Even at the present time, the thought of this experience is very painful to him.

The fifth and sixth patients in this group have already been mentioned since no information was available regarding their feelings.

Bed rest and Routines:

Bed rest, the basic treatment for the tuberculous, was realistically accepted by eleven of the group studied. Although they found this aspect of treatment as well as hospital routines, very trying at times, these patients were able to accept it as necessary for their recovery. One patient said, "If you're anxious to get well, you co-operate." Another remarked, "I felt that they (rest and routines) were part of the treatment and I had to do it."

One patient was apathetic regarding rest and routines. This woman had a passive, dependent attitude throughout hospitalization and enjoyed her period of rest and dependency.

Her case stood in marked contrast to a group of six patients who were over-conscientious in observing rules regarding bed-rest and other aspects of treatment. One 44 year old man, in this category, complained at length that the rules were not enforced strongly enough. He felt that he should be getting much more rest than he was and that there should be no radios to distract patients from concentrating upon resting.

Five patients expressed strong feelings of rebellion against their confinement to bed and to a set routine. Comments such as, "I can't be ruled, " were common. Prolonged bed rest was intolerable to one woman who said, "I told my doctor that unless he let me get up to go to the bathroom, I would go behind his back. They'd want you to rest two hours morning and afternoon. I couldn't cope with it although others could." Another young woman commented that she did not find the routines troublesome as long as she was confined to bed but she rebelled against them as soon as she was given some freedom and was allowed out of bed for a time.

The category "Excessive Fear" did not apply to any of the patients with regard to their attitude to bed rest and routines.

When a patient is hospitalized, he is forced, to a greater or lesser extent, depending upon individual circumstances, to become dependent upon those who are placed in

positions of authority over him. To the rebellious individual who has never completely resolved his feelings about his parents, doctors may be aggressors who have set themselves to create rules which cannot be kept, and to devise treatments which are not only useless but which also involve physical and emotional pain. Four of the twenty-three patients studied fell into this category. One of them said, "I'm not a saint, - I just can't be ruled."

Still other patients enjoy the security and attention which this dependent situation affords. These are usually the "good patients" who accept the restrictions of invalidism and follow, often in an exaggerated way, every rule set down for them by the medical authority. They do this, ostensibly because they feel that it will bring about a speedy recovery. Actually, these individuals are finding the answer to many of their needs in submission and while they are in the care of doctors and nurses they have recreated a secure and satisfying family situation. Of the group studied, four patients out of 23 (two males and two females) showed marked tendencies toward dependency on medical authority. One man made such statements as, "Over the long haul, the doctors are right." He said also, "All patients like being looked after, if the truth be known." Each of the four patients who seemed over-dependent on medical authority, also gave evidence of being dependent with regard

to hospitalization as a whole. Wittkower[1] claims that, "Despite all protestations to the contrary, these patients seem to feel no urgency to get better and, in fact, in some of them, one is inclined to wonder whether they want to get well at all." The accuracy of this statement has been borne out in the four cases in this study which fall into the over-dependent category.

Reaction to Medical Authority

The threat of hospitalization often carries with it fear or anxiety concerning medical authority which patients cannot always relate to any previous traumatic experience. Such statements as "I get frightened as soon as I see a white coat," are elicited from these individuals whose fears appear to be deep-seated and at times quite out of proportion to the situation. In the group of 23 patients, three came under the heading of "Disproportionate Anxiety" regarding medical authority. Each of these patients, (2 males and 1 female) regarded those in medical authority with mixed feelings of apprehension and fear. One patient said, "I hated the sight of doctors and nurses, - I was afraid of them." Another exclaimed, "I never knew what the doctors were thinking but I was always sure they wanted me to have an operation!"

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1. Ibid, p. 60.

However, twelve of those interviewed were able to accept it in a realistic way, although they may have had some feeling around the question of medical authority. That is, they saw the doctor as an authority figure who could give them the help they required for recovery, yet they did not look upon him as infallible, nor did they think of him as a threatening person. These individuals sometimes had complaints about doctors but they were, on the whole, able to accept them as human beings, many of whom they liked and others whom they felt free to dislike. Statements such as, "I liked all but one doctor but I figured you couldn't like everybody in a place like that," were common.

Four patients expressed resentment against dependency on medical authority. All of these had strong feeling about the necessity for "taking orders" from the medical staff and indicated their feelings in such statements as, "I just can't be ruled."

The remaining group of four, showed a tendency toward over-dependence on medical authority. All four of these patients gave definite evidence of enjoying their dependent state and of accepting doctors as benevolent, omniscient father-figures. Perhaps the most striking descriptive statement elicited from a patient in this category was, "I figure the doctor knows best. If the doctor told me to do some thing, I did it. You could always depend on them to pull you through!"

In this chapter, an effort has been made to set forth clearly, the problems of the selected group of patients from the time of diagnosis, through their period of hospitalization. It has been evident that the patients have had strong feeling and many difficulties in relation to this phase of their illness and that they have responded in many different ways to the stresses of hospitalization and illness according to their individual personalities and life experience.

This completes material pertaining to the hospitalization period. The problems and feelings surrounding discharge from hospital and the post-discharge period will be dealt with in Chapter V.

CHAPTER V

PERSONAL ADJUSTMENT OF MARRIED PATIENTS DURING THE POST-DISCHARGE PERIOD

The preceding chapter has been confined to a discussion of the emotional adjustment during hospitalization, of the 23 married patients studied. While it is apparent from the material presented in Chapter IV that serious problems are experienced by the patient while he is in hospital, it is also important to recognize that discharge from hospital brings with it fears and misgivings of considerable intensity. The areas in which re-adjustment must be made are outlined by Wittkower who says, "If recovery of patients following discharge is to continue, they have to re-adapt themselves (a) to being healthy (b) to life in a healthy environment and (c) to resumption of work."[1]

In contemplating the problem of helping patients adjust to the demands of a normal environment, it is necessary to realize that these are individuals who, over a long period of time, have lived in the sheltered protection of a hospital. The return to a family, hardened to the demands of normal home life, in which the status of the newly-discharged patient may have shifted during his period of

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1. E. D. Wittkower, M.D. "Psychological Aspects of After-care", Paper presented before the Regional Conference on Chest Disease, Montreal, March 7, 1952.

semi-isolation, may have many traumatic aspects. Venturing into the struggle of social life within the community and into the economic world, will call forth any doubts the individual has about himself with reference to his adequacy as a social being and a wage-earner.

Data in this chapter will be organized under the following headings: 1) Attitude to Leaving Hospital, 2) Attitude to Limitations Imposed by Illness Following Discharge, 3) Attitude to Relapse, 4) Post-Discharge Relationship to Patient Group, 5) Post-Discharge Social Adjustment. Material will be presented with illustrative case excerpts as in the foregoing chapter, and particular emphasis will be placed on the feelings of patients about the above aspects of their post-discharge adjustment.

Attitude to Leaving Hospital

The tuberculous patient who has been sheltered, supported and cared for in the hospital setting, is faced with many doubts about himself and his ability to take up the burden of normal life as the time for discharge approaches. Throughout his hospitalization, he has been fed, given treatment, his rest periods have been urged upon him and the efforts of all those around him have been directed toward helping him. The question of approaching discharge, although he may greet

it with outward pleasure, may engender in him many fears as to his possible reception by his family and friends. He may be faced with apprehension about the possibility of relapse when he is away from medical authority. He will perhaps doubt his ability to take up the responsibilities of earning a living.

Some patients will be able to work through their fears and accept discharge in a realistic way. Others may be unable to face their misgivings and may regard separation from hospital care with a great deal of concern. Still a third group may look upon discharge as liberation from a situation which they have never been able to accept and against which they have rebelled.

In the table which follows, "Realistic Acceptance of Discharge" includes those patients who, although they may have had some misgivings about leaving hospital and returning to their normal environment, have nevertheless welcomed discharge and worked through their fears regarding post-hospital adjustment. Under "Apprehension about Discharge" are those who had excessive fears about leaving hospital. "Over-eager for Discharge" covers those who have rebelled against confinement in hospital and are over-anxious to leave.

Table XI

Attitude to Discharge of 23 Married Patients According to Emotional Response.

Attitude to Discharge	Total	Male	Female
Total	23	13	10
Realistic Acceptance of Discharge	11	8	3
Apprehension about Discharge	8	3	5
Over-eager for Discharge	4	2	2

Eleven of the group of 23 married patients accepted discharge in a realistic way. Eight of these were male and three female, and although they may have had some question about leaving hospital care, all were able to accept the return to a normal environment as an important step in their recovery. Examples of a realistic attitude to discharge are the following:

> Case 29. Mrs. D. was a 29 year old woman, who at the time of her discharge, had a five year old daughter. Mrs. D. reported that when she heard she could go home she laughed and cried at the same time. She said, "It was completely unexpected.at the time it came, but I was overjoyed. I could hardly wait to get home and start keeping house again and be with my husband and child!"
>
> Case 39. Mr. R. was a 27 year old man who was separated from his wife shortly after his discharge. He said, "When I got my discharge... I felt quite happy about it. I got a room and a job. I didn't worry about leaving the hospital but I knew I'd

have to take it easy. I was worried when I came out, about not having any money."

Eight patients expressed apprehension about discharge. Five of these were female and three were male. Some of these individuals had doubts regarding leaving medical authority and care, and others were obsessed by fears of relapse or concern about taking up normal responsibilities once more. Two representative cases are cited below:

> Case 11. Mrs. J. was a 43 year old woman with two sons. She mentioned that she felt very lonely at the thought of leaving the hospital and cried about it. She did not want to leave her friends there and said, "They're so happy when someone is well enough to leave! You get so very close to each other!" During an earlier hospitalization for tuberculosis, Mrs. J. began to hemorrage shortly before her proposed discharge.

> Case 15. Mr. A. who was 30 years old, expressed his first feeling about leaving hospital by saying, "I was the happiest man in the world!" He went on to say, however, that he was loath to leave his friends and was afraid even to walk down the street to buy a package of cigarettes. He also said, "I'm afraid to go back to work this time. I haven't much confidence in myself."

Only four patients out of the group of 23 were classified as being over-eager for discharge. Of these, two were male and two female. These patients looked upon the hospital as a prison which was confining them against their will, although some were able to make a relatively good adjustment to hospitalization as a whole. The case excerpt which follows, exemplifies the feelings of this group.

Case 22. Mrs. R. was a 29 year old woman with two small children. Mrs. R. had been resistant to entering hospital and throughout her hospitalization had been rebellious regarding the observance of rules and routines of treatment. The medical staff recommended that she be hospitalized for some further time. However, after a period of nine months, Mrs. R. insisted that she was well enough to leave and her private doctor permitted her to do so.

Attitude to Limitations Imposed by Illness Following Discharge

When the patient has left the hospital and has re-established himself in his normal environment, some of the problems which he has feared, become realities. At first, it is necessary for him to observe many of the rules which were imposed on him while he was in hospital. Later, as time progresses and his condition improves, the restrictions are decreased. However, certain limitations are his for life. The discharged tuberculosis patient, although he is a part of the normal busy world, is never free of these limitations on his pursuits. Although he is expected to take up his responsibilities in his family and community, he must, if he is to remain healthy, observe the health regulations laid down for him by medical authorities.

In table XII the attitude to limitations of the group of 23 married patients is classified under three

headings. Under the first, "Lack of Concern", is included those whose attitude to restrictions was evidenced by their lack of desire to live within the limits laid down for them. These individuals refused to live as though they had been ill with tuberculosis and often expressed doubt that they had ever had the disease. "Acceptance" was used to cover those who were able to take restrictions as necessary to their continued health and carry them out in a reasonable fashion. "Over-concern" refers to patients whose fear over their physical condition led them to excessive observance of restrictions and to pre-occupation with caring for themselves.

Table XII

Attitude to Limitations Imposed by Illness, Following Discharge of 23 Married Patients, According to Degree of Acceptance

Attitude to Limitations	Total	Male	Female
Total	23	13	10
Lack of Concern	2	1	1
Acceptance of Limitations	12	5	7
Over-concern with Limitations	9	7	2

In the group of 23 patients, only two indicated lack of concern with their limitations. One of these was male

and the other female. Both showed a definite tendency to ignore health rules and, in fact, seemed to be sufficiently unconcerned with the possible results of their negligence that they were seriously endangering their health. The following illustration will imply the above statements:

> Case 11. Mrs. J. maintained that she was completely cured. She had had a thoracoplasty and a lobectomy and claimed that these surgical operations had removed the disease and that she could do what she pleased now. She cared for her family and was an immaculate housekeeper who spent a great deal of time working on her house, often doing the scrubbing and heavy washing herself.

Twelve patients, 5 male and 7 females, were able to accept their limitations in a realistic fashion. These individuals recognized the need for limitations but did not place undue emphasis upon them. In some cases, patients were able to fit the restrictions into the habitual pattern of their lives. In others, it was necessary for them to make a greater adjustment and the courses of their lives were considerably changed. The following is an example of this second type of response:

> Case 33. Mrs. G. was a 29 year old woman with a small son. When she was discharged, she was advised to rest the same number of hours as she had while she was in hospital. Mrs. G. gradually took over the care of her own home, as restrictions were removed, and after five months was well enough to bring her son home also. She is still somewhat limited in the amount of activity she is permitted. However, she has accepted these limitations and has planned her life in such a way that she can move at a reduced tempo.

Nine patients showed signs of over-concern with their limitations. Seven of this group were male and only two female. Many of these patients were extremely apprehensive as to the consequences of any unwarranted amount of exercise and hence tended to take unnecessary precautions and to limit themselves more than was necessary. They were, in short, pre-occupied with themselves to an exaggerated degree. Others, in this category seemed over-awed by the dictates of the doctor, and they were inclined to follow his suggestions with an almost religious fervour in what was apparently an effort to gain his approval. The case excerpt which follows is illustrative of this over-concern with limitations:

> Case 2. Mr. R. was a 34 year old married man with three children, who was over-concerned with his symptoms and pre-occupied with his physical health. Mr. R. no longer participated in his former social activities and felt quite restricted in this area. He had formerly done a great deal of work on his home but now makes such statements as, "I can't take it any more!" He worries a great deal about his physical ailments and is perpetually afraid that he will catch a cold. He said, "Look at others and I wish I were healthy like them." When asked if he were concerned about a relapse, he replied, "Absolutely!"

Attitude to Relapse:

One of the strong motivating forces in excessive concern with limitations and symptoms is the gnawing fear of relapse which haunts patients in whom tuberculosis has been apparently arrested. This is an insidious, chronic

disease which may recur at any time. Because it can only be arrested or improved and only in rare cases, cured, discharged patients are rarely free from the fear that it will return with renewed intensity. This feeling is stronger in some individuals than in others, but many patients admit that it is almost perpetually in their consciousness.

No information was available on four patients of the group studied. However, out of a total of 19 patients about whom material was secured, 14 expressed fear of relapse. Nine of these were male and five female. Such comments as, "You know, tuberculosis is always there and worry aggravates it," and "I wondered if I was working too hard and might have to go back to the hospital for a long time," typify this response of fear.

Of the five who expressed no fear of relapse, two were male and three female. One of these patients, a man, had never been able to accept the fact that he had tuberculosis. The others in this group felt that they had been "cured" and would not have a relapse since they did not think of the disease as a chronic one. One patient said, "I'm completely well now," and appeared to believe firmly, as did others in the same category that she would not become ill again.

Post-Discharge Relationship to Social Group:

Wittkower makes the following statement with reference to the effect of hospitalization for tuberculosis on the social relationships of the patient:

> ...admission to a sanatorium means to many patients, recognized clearly only by a few, exclusion if not expulsion from their accustomed and unwilling entrance into another. The ranks of the family have, as it were, closed behind them before they are ready to join the ranks of the many who share their fate.[1]

The patient who has been hospitalized with this disease may have lost his former friends as a result of the ignorance and fear surrounding tuberculosis. On the other hand, the more fortunate patient may have been able to continue some of his former relationships on the same basis as he did before he became ill. However, it seems obvious that long hospitalization and the characteristics of the disease cannot help but change, at least temporarily, the relationship between the patient, his family and friends. Such comments as, "When you're in the hospital, you've got no friends," and "They've all got that fear," are common among those who have found to their dismay that they are no longer accepted on the basis of their own personal worth.

When a patient is at last discharged from hospital, he is faced with the necessity of attempting to re-establish

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1. E. D. Wittkower. A Psychiatrist Looks at Tuberculosis. London, National Association for the Prevention of Tuberculosis, 1949, p. 67.

old social ties or, in some cases he is confronted by the need for adjusting to a social milieu which has changed. Each individual responds differently to this need for re-adjustment. Some patients are unable to face the struggle of making a new circle of friends and return to their hospital acquaintances for friendship and social activities. Others, who are more eager to obliterate the hospital period from their accumulation of experience, turn away from their hospital friends and set about to pick up the threads of their pre-hospital life or to develop new relationships. Still a third group is able to retain the most meaningful of the hospital friendships as well as to develop old and new circles of acquaintance which are not related to the hospital period.

In table XIII "Close Identification" refers to those patients who turn almost exclusively to the patient group for post-discharge relationships. "Partial Identification" includes those who have retained some hospital friends but have also broadened their interests to include others. "Complete Withdrawal" covers the remainder who no longer relate to the patient group in any way.

Table XIII

Degree of Identification with Patient Group During the Post-Discharge Period of 23 Married Patients.

Degree of Identification	Total	Male	Female
Total	23	13	10
Close Identification	4	1	3
Partial Identification	11	6	5
Complete Withdrawal	8	6	2

Only four patients of the group of 23 found it necessary to turn completely to the patient group for their post-discharge social relationships. Of the three, one was male and two female. The three women were individuals whose hospitalizations had been relatively long. Two had been somewhat reluctant to leave hospital and following discharge they retained hospital friendships almost exclusively. The third, who was mentally ill, had only one friend, a woman, who had been in hospital with her. The male, on the other hand, had had a relatively short period of hospitalization, but, like the females, had been ambivalent about leaving the shelter and support of hospital care, and he had

considerable difficulty in taking up his family responsibilities once more.

Eleven patients, six males and five females, reported that they had retained some of their closer hospital friendships, but they had also gone on to continue pre-hospital social relationships and to develop new ones. One of the men contacted his hospital friends only when he returned for clinical examinations. Four others in this category contacted them often, by telephone or letter and the remaining six visited hospital acquaintances at frequent intervals. All of these eleven patients seemed equally as much attached to friends who were in no way related to the hospital group, as they were to those made during their hospitalization.

Eight patients, or 47 percent of the total group have not maintained any connection with the patient group. Six of these were male and two female. Two of the males have withdrawn into themselves and do not have any friends either within the patient group or among their outside acquaintances. Both tend to sit alone at home and bemoan their state. The other four males have completely severed ties with the hospital and appear to desire to obliterate the experience from their memories. They have, however, established outside social relationships. The two females seem pre-occupied with family responsibilities and relationships and have continued no outside friendships beside these.

Effect of Illness on Social and Recreational Activities

Since tuberculosis is a chronic, relapsing disease, imposing many limitations on those who have suffered from it, it is obvious that in many cases social activities will be somewhat restricted following discharge from hospital. To those whose recreational and social life has always been quiet and slow in tempo, these limitations will not be burdensome, and little change will be necessary. However, the patient who previously has been active in sports may become frustrated and embittered about health rules which prevent him from pursuing his former interests and about a disease which has made it impossible for him even to enjoy a relatively inactive game like golf. It is equally upsetting to an individual who has previously had a full social schedule to discover that only a minimum of activity is now open to him.

Table XIV which follows, indicates the degree of change in the social activities of patients in the group studied. The heading "Active Social Life" is used to include all those whose social activities, prior to illness, were centered on parties, dancing, drinking, and which frequently involved late hours. "Sports and Recreation" refers to patients whose leisure time was centered primarily upon active sports and club activities before their hospital-

ization. Individuals whose former leisure time activities were relatively inactive, have been placed under "Sedentary Pursuits". This would include card games, movies and visiting with friends or relatives.

The difference in patients' post-discharge pursuits, in relation to their former activities, has been graded in terms of complete change, some modification, and no change. Included under "Complete Change" were those who had made the transformation from a previously active, social life to a relatively restricted, quiet one. "Some modification" was used to refer to those who had made a partial change in their former mode of life. "No change" is self-explanatory.

Table XIV

Post Discharge Adjustment of 18 Married Patients to Social and Recreational Activities According to the Degree of Change

Type of Activity	Total	Complete Change	Some Modification	No Change
Total	18	3	4	11
Active Social Life	4	1	3	-
Sports and Recreation	3	2	1	-
Sedentary Pursuits	11	-	-	11

Since no information was available on five patients, this table has included data pertaining to only 18 out of the 23 married patients. Four of this group had, prior to hospitalization, had an active social life, One of these, a male, had completely changed his social activities. His feelings regarding his present mode of life are outlined below:

> Case 39. Mr. R. was a young man of 27 years who obtained a separation from his wife shortly after his discharge from hospital, 15 months prior to the interview. His comment was, "You see you can't live the same sort of life you lived before, not the night life. I used to get out quite a bit before to night clubs sometimes - but I don't do that now. I used to be a heavy drinker, too, but I find I can't do that now. When you come out of hospital and don't have the money, you haven't got your friends either. Now I go to a show once in a while and I have a little car. I fool around with that and that's about all. I go to bed early two or three times a week, about 8 o'clock, and read and listen to the radio. I couldn't have done that before. I was more nervous."

The three others who had previously been very active socially made a partial change in their activities. The illustration below is typical of this group:

> Case 28. Mrs. B. was a 23 year old woman who had been very active socially prior to her illness. Following her discharge 16 months prior to the interview she began resuming her former activities in a limited way and now goes to dances occasionally and is beginning to attend parties in the homes of her friends. She has, however, begun several sedentary activities since her illness and now enjoys knitting and crocheting in some of her leisure time.

Three patients, had prior to their hospitalization, been active in sports and recreational pursuits. Two of

these made a complete change in their leisure-time activities after discharge. The case excerpt, which follows, is a particularly good example of changes made:

> Case 8. Mr. R. was a 27 year old married man, discharged 11 months who had previously been a professional hockey player and spent most of his free time in other sports. This patient was rather preoccupied with his physical symptoms and, for a time, was somewhat embittered at his fate since tuberculosis had robbed him of his occupation as well as his leisure-time activity. Mr. R. now occupies himself in sedentary pursuits including an occasional movie. He expressed a wish to play golf but was very doubtful as to whether he would ever feel safe in beginning any active games or sports.

One patient who was formerly active in sports made some modification in his activities. His comment was, "I can't take a chance on swimming now, or skating or playing too hard games. I see a show once a week. This patient has, however, kept up some of the less strenuous of his previous activities.

By far the largest group of all were those who had previously occupied their free time in sedentary pursuits, and who continued in the same interests following discharge. In all, 11 patients, or approximately 61 percent of the total number, fell into this category. The limitations imposed by illness made little difference in the social life of these patients since it was necessary for them to make very little change. The illustration below is typical of the group:

Case 12. Mr. E. was a married man of 34 years who had two young sons. He had been discharged 17 months previous to the interview. He stated that he had always led a quiet life and had rarely stayed out late at night. He said that the limitations imposed by his illness were not burdensome since they impinged very little on his customary way of life. Since discharge, Mr. E. has attended an occasional barn dance or card party at his church and has served on some committees there. Aside from this, he spends a great deal of his time in leather tooling and woodwork and sees an occasional movie with his wife.

This completes the analysis of the available material with regard to the emotional adjustment of patients during the post-discharge period. This chapter has described the attitudes and adjustment of patients to discharge from hospital, limitations imposed by illness, relapse, relationship to patient group and social activities. Causative factors have not been included since the primary aim was to describe behaviour, adjustment, and attitudes. Adjustment in the familial, economic and vocational areas will be discussed in subsequent sections of this thesis.

Findings

An analysis of the psychological adjustment of 23 married tuberculous patients to their illness, hospitalization, and some aspects of their post-discharge period revealed the following findings.

Most of the patients in the married group reacted to their diagnosis with severe distress or disbelief. Only

three patients were slightly concerned. About one-quarter of the patients were markedly fearful or resisted the need for hospitalization. Most of these patients seemed apprehensive about the hospital itself and a few had fears regarding separation from their families. The majority of the married patients accepted realistically the need to be hospitalized and felt this was the quickest way to be cured.

One-third of the married patients showed severe concern about their illness during their hospital stay. Four other patients apparently lacked concern but it was evident that they were using defense mechanisms to cover up anxiety.

About one-half of the 23 patients seemed to have problems in relation to the treatment procedures and medical authority. These patients were either excessively fearful or resentful of treatment. In many instances, patients were too conscientious and this seemed to portray over-anxiety or over-dependence.

Upon examination of the patients' feelings about leaving the hospital, problems were evident among half of the patients. The majority who showed problems in this area were fearful they would have a relapse when they left medical authority, or they were concerned about resuming normal responsibilities. Several patients seemed over eager to be

discharged and it was felt that they felt that they had difficulties in accepting authority and regimentation. The limitations which were imposed by the illness in the post-discharge period presented difficulties to some of the 23 patients in the married group. Only two of the patients showed a tendency to ignore restrictions. However, as many as nine individuals seemed excessively pre-occupied with themselves and exhibited a hypochondriacal state on account of the illness. The majority of patients stated they were fearful of a relapse.

The married patients on the whole tended to draw away from the patient group and resumed relations with their former social group once they were discharged. Only four patients identified closely with their hospital friends. In a great majority of cases, although some kept in touch with the patient group, the married individuals had their main interest in their family life and former circle of friends. They were not very much affected in this area.

In the analysis of social and recreational activities, information was available on only 18 of the 23 married patients. For the majority of these patients, the illness had no effect on their social and recreational life. For the most part they had pursued sedentary interests before their illness and it was not necessary for them to change their accustomed activities. However, those patients

who had been active in sports or who had enjoyed going out a great deal had to change or modify their interests.

It has been apparent that the tuberculous patient, regardless of the attitude he displays, requires assistance in working through and in accepting the many problems involved in his illness, from the time of diagnosis until he has been re-assimilated into the community. Although patients, in many cases, were able to accept realistically their disease in its various stages of progress, this was not an indication that they did not require help. Instead, it emphasized the strength of the individual in being able to adjust to adverse circumstances in a healthy manner, a process which could have been less painful had help been available.

PART III

IMPACT OF HOSPITALIZATION UPON THE ECONOMIC STATUS OF PATIENTS AND THEIR FAMILIES

CHAPTER VI

IMPACT OF HOSPITALIZATION UPON THE ECONOMIC STATUS OF PATIENTS AND THEIR FAMILIES.

"Economic problems are indigenous to the problem of tuberculosis."[1] This seems to be the general concensus of opinion as gleaned from the literature on the subject. Another writer states the following about the financial aspect of tuberculosis:

> The long continued period of medical care almost invariably involved in tuberculosis tends to drain accumulated savings from most patients and families; only a very few can stand the full cost of all the ramifications of tuberculosis from their savings or the earnings of the rest of the family."[2]

The extent and seriousness of the financial problem varies from patient to patient, depending upon the stage of his illness, the wage-earning role he has played in his family, the maturity and adaptability of the wife and mother, and the patient's own capacity to accept realistically the changes brought about by his illness. Other factors also play an important part in determining the scope of the economic problem. Some employers make financial provision for enforced absence from work for reasons such as hospitalization for tuberculosis. When such is the case, the burden is much

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1. U. S. Public Health Service, Medical Social Service in Tuberculosis Control, 1946 (Miscellaneous Publication 37). p. 15

2. Pauline Miller, Medical Social Service in a Tuberculosis Sanatorium, Federal Security Agency. Public Health Service, Division of Chronic Disease and Tuberculosis, 1951, p. 32.

lighter than when the family income ceases when the individual is no longer able to work. The economic status of the patient is also an indication of the size and meaning of the problem in the financial area, although, as Pauline Miller has said[1] only a very few can withstand the drain of prolonged treatment.

It can therefore be seen that authorities are in general agreement that tuberculosis is a disease that gives rise to problems in the economic area, because of the enforced absence from work, and the long-term aspect of the treatment. Because of the prevalence of the economic impact, and the importance of making adjustments in order that the patient's family may carry on while he is undergoing the necessary treatment, a section in this study has been devoted to an examination of the economic area in relation to the 43 patients interviewed.

This part of the study has attempted to show the effect of hospitalization for tuberculosis upon the economic status of patients and their families, the problems in the financial area they have faced because of their illness, and the ways in which they have solved, or been unable to solve these problems.

Although the actual cost of hospitalization and treatment is borne by the Provincial Government, the financial

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1. Ibid p. 32

problem which the patient faces, particularly if he is the breadwinner of a family, is a very great one. If his illness means the cessation of the family income for an indefinite period, adjustments must be made by the patient and his family to secure some means of maintaining the family while the patient is availing himself of the treatment prescribed for the arresting of his disease. The family in which an earning member is stricken, even though he is not the breadwinner, also faces a serious situation if his income has been relied upon to assist in the maintenance of the family to any extent. The single person who lives outside a family group is also confronted with the question of how he is going to manage without an income during the long period of hospitalization and after care. Cost of placement of a large family, necessitated by the illness of the mother, is often a serious drain on marginal incomes, even though the illness has no effect on the size or constancy of the income.

These problems, and others, have been studied in relation to the sample group of 43 patients, the adjustments they have been able to effect, and the meaning of these adjustments to the patient and the family as an interacting whole. All the patients in the sample group had been discharged with medical approval, indicating that they had all been able in

some way to make the financial arrangements necessary to enable them to undergo treatment for the prescribed period. Although a more accurate economic picture could probably have been obtained if patients who left hospital against medical approval could have been included, it is believed that a study of a group who have been able to complete treatment, and the adjustments they have made, is significant. It is felt to be indicative of the type of problem encountered by tuberculous patients in general, and illustrative of the changes made necessary by the disease, as well as the feelings engendered by the changes.

The first chapter of this part deals with the impact of hospitalization upon the economic status of the 43 patients studied. This included a study of the number of cases in which there has been a financial impact, and the nature of that impact. For this purpose, the sample group fell into four categories: the family breadwinner, the single earning member of a family group, the single earning person who lives alone outside a family group and the housewife. The incidence and nature of the impact has been explored with reference to these four groups. The chapter also includes a study of the adjustments made by patients and their families to the economic impact. This, too, has been dealt with in relation

to the four groups mentioned above. The spending money of the patient while in hospital, which often constitutes a problem, has been dealt with as a general question in this chapter, and the sources of this money have been explored. Housing, and the bearing it has upon the patient's condition for recovery also came within the scope of this chapter, and has been dealt with to the extent of the available material.

The second chapter of this part is an exploration of the attitudes of patients and their families toward their lowered economic status. This includes a study of patients' attitudes toward his financial status during the hospital period, toward his present financial status, and toward the help he received from his family and other sources. It contains an examination of the community resources used, and their adequacy. The effect of the economic impact upon family relationships has also been considered, as well as changes in financial dominance and the effect of these changes upon the patient and other members of his family.

Frequency of Occurrence and Nature of the Impact

It has already been mentioned that only a very few patients are able to withstand the financial strain of protracted hospitalization and after care. It is to be expect-

ed that the group under study follows this same general pattern. From an analysis of the data collected, it has been found that an impact in the financial area is common to the majority of the patients. Among the groups into which the 43 patients have been divided, the breadwinners have been found to have the highest percentage of patients who felt a definite economic strain, occasioned by illness. Their problems are discussed in the following section.

Economic Impact upon the Breadwinning Group:

It was found that there was not one patient of the breadwinning group who had not been affected in some way in the financial area by the onset of tuberculosis and subsequent hospitalization. This group consisted of 14 married men with families to support, and one woman,who, previous to illness, had been the sole support of her family. The degree to which these patients and their families were affected varied from patient to patient. The situations ranged from one, where the wife had always worked, and whose income was sufficient to support herself and bring needed things to her husband while he was in the hospital to one where the wife had to go to work during her husband's illness although at the time she had several small children. At present the former patient is working for a slightly higher

wage than formerly, and, with the addition of his wife's income, he is able to manage on the same level as before his illness. Yet even this couple felt the impact as they were new Canadians who were trying to establish themselves in Canada on the same plane as that to which they had been accustomed in Europe. The patient's hospitalization had temporarily set them back financially. At the opposite extreme from this family, the latter family suffered a serious financial impact as the result of the illness. The wife had to go to work and it was also necessary to apply to a welfare agency for supplementation to her income. The patient is working at present, but at a much smaller wage than formerly which is due to his illness, and his wife is still obliged to work. The remaining patients in this group range between these two situations in the degree of seriousness of the economic problems which hospitalization for tuberculosis posed for them. The following table shows the total income for this group of breadwinners before, during and after illness with a view to illustrating the effect of tuberculosis upon the income of these 15 patients.

Table XV

Distribution of Total Income Per Month From all Sources, Before, During and After Illness for the Group of 15 Breadwinners.

	Distribution of Breadwinners		
Monthly Income	Before Illness	During Illness	After Illness
Total	15	15	15
Less than $99	-	7	1
100 to 124	1(a	1	2(b
125 to 149	-	2	-
150 to 174	6	3	1
175 to 199	1	2	2
200 to 224	-	-	3
225 to 249	2	-	-
250 to 274	2	-	2
275 to 299	-	-	1
300 to 324	1	-	-
325 to 349	1	-	2
Over 350	1	-	1

a) This was a 1943 income.

b) Both patients have been unable to find employment.

This table shows the total income of the patient and his family prior to illness. It indicates the sharp

drop in income level during the hospitalization period. Before illness, there were seven families with an income of $225.00 or more per month, while during hospitalization there was no family with an income of $225.00 or more. Another significant factor which this table shows, is the fact that previous to illness, there was no family with an income of less than $99.00 per month, and only one, a 1943 figure, between $100.00 and $149.00 per month. During hospitalization ten of the 15 families had an income of less than $150.00, seven of which received less than $99.00.

The post-illness period shows a gradual return to the pre-illness status. There are six families in the over $225.00 per month group, and the number with an income of less than $99.00 has been reduced to one. In the two families shown as having an income of between $100.00 and $124.00 per month, the patients have been unable to find employment. While this table is significant, in that it shows that there seems to be a general return of this group to the same or better status than before, it must be taken into consideration that the cost of living has changed since many of them became ill. This would indicate that while the actual income may have increased, the economic status of the patient may be the same or even lower.

While this table has shown the change in actual income caused by illness, the following table summarizes the changes

in income level.

Table XVI

Effects of Hospitalization on Income of 15 Breadwinners During and After Hospitalization.

Effect on Total Income	During Hospitalization	After Hospitalization
Income stopped 3 months or more	3	-
Income Markedly Reduced	15	6
Income Remains the Same (a	-	9

a) Includes those whose incomes have followed regular wage increases.

This table shows that the income of the whole group was markedly reduced for the period of hospitalization, and that three of the 15 families had no income at all for a period of three months or more. The following example illustrates a situation where the income ceased for three months or more.

> Case 15. For four months following Mr. A's hospitalization, the family had no income. They had not heard about Needy Mothers' Allowance[1] and hence application for assistance from that source was not received until later. During this period, Mrs. A.

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1. Needy Mother's Allowance is a Provincial Government assistance programme, for families with one or more children where the breadwinner is dead or ill and unable to work. Hereinafter it will be referred to as N.M.A.

was also hospitalized for over a month, and the one child, which the couple had, was cared for by Mr. A's sister, for nothing. What savings they had been able to accumulate were exhausted during this period.

In the post-hospitalization period, nine of the breadwinners' families had an income which was the same, or slightly higher due to regular wage increases, as their pre-illness income. From the table, it can be noted that there are six families whose income is markedly less than was their pre-illness income. Of those six whose income is markedly reduced, two are not as yet physically able to work, two have been unable to find employment due to their illness, and two are only able to do part time work due to illness, and hence are not able to draw full salaries. The following case example shows a family which is typical of those whose post-hospitalization income is markedly reduced in comparison with their post-illness income, due to the fact that the breadwinner is not yet able to work full time.

Case 5. Previous to his illness, Mr. A. was able to work full time, and make a comfortable living for his family. His eldest daughter supported his family while he was in the hospital, and before he was able to assume part-time employment. At the present time, he is employed as a waiter in a tavern, and is not physically able to work a full day. He found that he was unable to wait on the tables, because of his illness, and had to accept the poorer paying job of working behind the bar. His income is much lower than before his illness.

The following case illustration shows a family in which the breadwinner has been unable to find a job due to

illness, with a resultant reduction in income level in relation to the pre-illness income.

> Case 21. While Mr. F. was in the hospital, his two older children supported Mrs. F. and a younger child. Following Mr. F's discharge the oldest boy left to join the Royal Canadian Mounted Police, and no longer able to contribute. An application was made to N.M.A. for assistance. With the N.M.A. grant and the daughter's contribution, the family has been able to manage, Mr. F. is now physically able to do at least part-time work, but he is unable to find anything that is not too strenuous for him. His old job is no longer available, and, although he has looked, he cannot find anything else. As a result, the income of this family is much lower than it was prior to illness. The present income is $100.00 per month as compared with $160.00 per month before the illness.

Economic Impact upon Single Earning Members of a Family Group:

From a study of the 11 patients who were single earning members of a family group, there was only one who did not suffer an economic impact during the period of their hospitalization. This group consisted of eight men, who lived within their family group, but who were not the sole means of support for that family. One was the largest contributor, but as he was single and not the only contributor, he was considered within this category. The group also included three single women who lived within a family constellation. The following table illustrates the total income of these patients, before, during and after hospitalization,

in order to show the effect of illness upon the economic level of this group.

Table XVII

Total Income per Month Before, During and After Illness for 11 Single Earning Members [a] of a Family Group.

Monthly Income	Male			Female		
	Before	During	After	Before	During	After
Total	8	8	8	3	3	3
Less than $99	-	7	2	-	3	3
100 to 124	-	-	-	2	-	-
125 to 149	1	-	1	-	-	-
150 to 174	1	-	-	1	-	-
175 to 199	1	-	1	-	-	-
200 to 224	-	-	1	-	-	-
225 to 249	1	-	1	-	-	-
250 to 274	-	-	-	-	-	-
275 to 299	1	1	1	-	-	-
300 to 324	-	-	-	-	-	-
325 to 349	2	-	-	-	-	-
Over 350	1	-	1	-	-	-

a) One student although a single member of a family group has been omitted because he is not, and never has been, an earning member. He will be dealt with separately.

As can be seen from this table, ten of the eleven earning members of family groups have experienced a large decrease in income during the period of hospitalization. The one exception received his whole income for the duration of his illness. For the eight men in this group, the post-hospital income is much the same as the pre-hospital income in the middle income range. There are still two men who receive less than $99.00 per month, one of whom is as yet unable to work. The other patient in this income bracket is working, but at a poorly paying job, and he is still dependent upon his father to a large extent. This was the situation before illness as well, although not as much as is now the case. There has been a change in the upper income range. There were three men, prior to illness, who earned over $325.00 per month. At present there is only one patient who is earning this amount. One of the men who had earned over $325.00 per month is as yet unable to work, while the other one is employed, but is not able to do as much as he had done. The following is an example of one man whose earning power has been markedly reduced as the result of his illness.

> Case 14. Prior to his illness, Mr. A. made $174.00 per month at his regular work. In the evenings he played the piano in an orchestra and was able to add $325.00 to his income each month in this manner. When he became ill, his income ceased entirely, and he was supported by his family. He returned to his

> former position when he was able, and received an increase in salary. He is drawing $212.00 per month from this job, which is more than formerly, but he is not able to continue his playing in the orchestra because it would be too much for him. His income is markedly reduced in relation to his pre-illness status.

There were only three women in this group, and therefore it is difficult to draw any conclusions as to how they compare with the male group in returning to their pre-illness income status. Their incomes were all markedly reduced during illness, and none have regained in the post-illness period, the income they once had. None of the three are working at present, although they are all physically able to do so. This might indicate that women, living within a family constellation, are slower at resuming former earning power than are men in a similar position, but the size of the sample is not large enough to show any conclusive evidence for it. It is however interesting to speculate whether a larger sample group would bear out this trend that is indicated in the group of three women included in this section of the study.

The findings from this table are more valid than for the breadwinning group, as the term of hospitalization for this group was relatively shorter, and they were all first hospitalizations. Therefore the increase in the cost of living, with subsequent wage increases would not have to be considered to such an extent.

The effect of hospitalization upon the income of this group shows differences from the effect upon the breadwinning group. The following table indicates the effect upon the income.

Table XVIII

Effects of Hospitalization upon Income of 11 Earning Members of a Family Group During and After Illness.

Effect upon Income	Male		Female	
Period Relative to Illness	During Illness	After Illness	During Illness	After Illness
Total	8	8	3	3
Income Stopped for Hospitalization Period	5	-	2	3
Income Markedly Reduced	2	3	1	-
Income Remained the Same (a	1	3	-	-
Income Increased with no Relation to Illness	-	2	-	-

a) This includes those whose incomes have followed regular wage increases.

This table shows that of this group of 11 people, there were seven who received no income all the time they were in the hospital. Of these seven, five were men and two were women. As they were all members of a family group,

they were helped by the other members. The adjustments made necessary are dealt with in a later section of this chapter. There were three patients, two men and one woman, who had an income that was markedly reduced while they were in hospital. This income came from the sale of leather work done in the hospital, or from pension and similar funds. It was usually sufficient to provide the spending money necessary for them while they were hospitalized. The patient indicated on the table as having the same income during hospitalization as he had had before his illness received his full income for the whole period of his illness.

In the post-hospitalization period, all the men have regained some income, although three are still receiving incomes that are markedly reduced. Mr. A's situation has already been discussed[1], as an example of a patient who has had a reduction in income due to illness. Mr. G., as shown in the following illustration, is also receiving a much lower income, but due to very different reasons.

> Case 3. Mr. G., prior to his illness had a monthly income of $342.00. During his hospitalization his income stopped entirely. Upon discharge he applied to the Bureau d'Assistance Sociale aux Familles,[2] from whom he received assistance. He is still receiving $55.00 per month from this agency as he is as yet unable to work. This enables him to live quite comfortably as he lives with his sister, but it is a marked reduction from his pre-illness income

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1. Supra, p.

2. The Bureau d'Assistance Sociale aux Familles, hereinafter referred to as the B.A.S.F., is a private welfare agency in Montreal.

> He has the promise of a job as soon as he is able to work, which will pay him almost as much as he had been getting before, but in the meantime his status is much lower.

There were two men in this group who resumed jobs with incomes that are much higher than their pre-hospitalization incomes. This was in no way connected with their illness, yet this increase was sufficient to warrant a separate category.

There was one schoolboy who, while single and a member of a family group, has been omitted from these tables. He had not had any income prior to his illness, and is hoping to complete his education. His illness affected his family indirectly, in that, if it were not for his illness, he would now be contributing to the total family income, which is very marginal.

Economic Impact upon Single Earning Persons Living Outside a Family Group:

The single earning person who lives alone outside a family group has been considered next. There were seven patients in this category, four of whom were male and three female. It might be expected that this group, with no family to rely upon would find the economic burden extremely difficult. The following table shows the income per month for this group of seven patients, before, during and after their hospitalization.

Table XIX

Total Income per Month; Before, During and After Hospitalization for Seven Single Earning Patients Living outside a Family Group According to Sex

Income Per Month	Male			Female		
	Before	During	After	Before	During	After
Total	4	4	4	3	3	3
Less than $99	-	3	-	-	3	1
100 to 124	-	-	-	-	-	-
125 to 149	1	-	-	-	-	-
150 to 174	1	-	2	2	-	-
175 to 199	-	-	-	1	-	1
200 to 224	-	-	-	-	-	-
225 to 249	1	-	-	-	-	1
250 to 274	-	-	-	-	-	-
275 to 299	-	-	1	-	-	-
300 to 324	-	-	-	-	-	-
325 to 349	-	-	-	-	-	-
Over 350	1	1	1	-	-	-

From this table, it is seen that three of the four men, and all the women have had their incomes affected while they were in the hospital. These six people, all of

whom earned over $125.00 a month prior to illness, had an income of less than $99.00 during their hospitalization. The one man, indicated on the table who had an income of over $350.00 per month throughout his illness, received his full salary for the whole period of his illness. In the post illness period, all the men, and two of the three women have regained their former, or higher status. The one woman who has not, is as yet unable to work because of medical recommendations.

The following table shows the effects of the illness upon the income of this group.

Table XX

Effects of Hospitalization on the Income of Seven Single Earning Patients Living Outside a Family Group According to Sex.

Effect upon Income	Male		Female	
	During	After	During	After
Total	4	4	3	3
Income Stopped for Hospitalization Period	2	-	3	-
Income Markedly Reduced	1	-	-	1
Income remained the Same	1	3	-	1
Income Increased with no Relation to Illness	-	1	-	1

It can be seen from this table that the income of five of the seven people in this group stopped for the whole period of their hospitalization. The patient who had his income markedly reduced was in receipt of a pension from his place of employment. The same patient mentioned above is indicated as having received hissfull income for the duration of his illness.

The table also indicates that six of the seven in the group have been able to regain the same or higher status following hospitalization. One of the main problems of this group seemed to be that of having money to spend while they were in the hospital with no income. This problem is dealt with in a later section of this chapter. Another problem arose upon discharge, as there was no family to support them before they were medically able to resume work.

Economic Impact upon the Housewife Group:

There were nine housewives in the total sample group, and none had had any income prior to illness. Their illness had not meant a reduction in the total family income. But in several cases, the hospitalization of the housewife necessitated the placement of the children, which constituted a heavy family expense when that placement had to be paid for. One family found this extremely difficult. Their

Their situation is illustrated in the following example:

> Case 19. When Mrs. C. was hospitalized, five of her six children had to be placed in homes where board had to be paid for them. Her husband found it very difficult to pay this room and board, as the family had always had financial difficulties, and this was an added burden. With help from the Catholic Welfare Bureau,[1] the family was able to manage.

In general, though, there was little adverse economic effect on the families in which the housewife became ill. The main added expense was in transportation to and from the hospital on visiting days, and the providing of spending money while the wife was in the hospital. This would not total what had previously been required to feed and clothe the patient while living in the home. This group was able to make adjustments which did not require the added expense of employing a housekeeper.

Adjustments made by Patients and Their Families to the Economic Impact Before, During and After Hospitalization

Although there has been an economic impact in nearly every patient's life, with the possible exception of the majority of the housewives, they have all been able to complete the prescribed period of hospitalization and treatment. This indicated that they had all been able to make the adjustments in the financial area which the individ-

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1. The Catholic Welfare Bureau, hereinafter referred to as the C.W.B., is a private welfare agency in Montreal

ual situations demanded. A study of the adjustments made by this group of 43 patients shows the nature of these adjustments, their adequacy, and the changes in the families' way of life in order that the adjustments might be made.

The adjustments made by the group of 15 breadwinners have been considered first as a separate part, as it had been found that they have been affected most strongly by the economic impact. The single patients living at home and those living away from home are considered together in regard to the adjustments which they had to make. The adjustments made by the housewife group are examined lastly.

Adjustments Made by the Breadwinning Group:

It has been shown that the incomes of the breadwinning group felt the economic impact more strongly than any other group. This group also illustrated the multiplicity of adjustments necessary for a family to maintain itself when the chief source of maintenance has been removed. The following table shows the sources of total income for this group of 15 breadwinners before, during and after hospitalization in an attempt to indicate the nature of these adjustments.

Table XXI

Sources of Total Income, Before, During and After Hospitalization of 15 Breadwinners.

Sources of Income	Before	During	After
Patient's Employment	15	-	10
Family Income Spouse	2	5	4
Children	-	4	3
Other Relatives	-	2	-
Boarders and Roomers	1	1	2
Savings	-	2	-
Community Resources Public Assistance	-	2	3
Relief	-	5	2

This table indicates that the income received for the maintenance of the families of the 15 breadwinners during the period of their hospitalization came largely from two sources. The wives and children of the patients assumed the wage-earning roles in nine of the 15 families, whereas before illness, only two wives worked and contributed to the support of the family. The next most frequent source of income was from community resources. There were seven families who received supplementation to their income from public assitance or from private welfare agencies.

Other types of adjustments were made by a few. Some had to rely upon other relatives for assistance, while others had to draw upon their savings. One family had roomers and boarders to help augment the family income during the patient's hospitalization.

Following the hospitalization, a resumption of wage-earning responsibilities by the patient is seen. Of the 15 people who had been the chief source of income prior to illness, ten have become employed in the post-hospitalization period. There has been a decline in the multiplicity of income sources, but the number of income sources has not returned to the pre-illness level. There are seven families who are still relying to a certain extent upon income from other members of the family, and five families are still in receipt of community assistance. These two main sources of hospitalization income have each been reduced slightly in frequency of use. One family began to take in boarders in the post-hospitalization period to augment its income.

The following example will serve to illustrate the way in which a family survived the economic impact by using myriad adjustments.

> Case 7. Mr. P., aged 54, was the only source of income for his family which consisted of himself, his wife and five children, aged 15, 14, 11, 9 and 6. He was hospitalized for ten months, and was unable to do any work for four months following discharge. This was a total of 14 months with no

income from the breadwinner. At the time of hospitalization the only known income was $35.00 a month from the Family Allowance. Mrs. P. applied to the C.W.B. who paid the rent and light, and gave a small amount per week toward the food which amounted to about $135.00 per month. This was not adequate and Mrs. P. found work as a charwoman, at which she earned about $30.00 a month. The daughters also earned a little money as baby-sitters. This gave the family a total income for the 14 months during which Mr. P. was unable to work, of about $200.00 per month. The family income previous to illness had been $352.00 per month. From the time Mr. P. began to work until the time of the interview, a space of seven months, he has only been able to do part time work. This necessitated that Mrs. P. continue her work at which she now earns $29.00 per week. Their present income is $352.00 per month.

This family made use of a private welfare agency to help maintain itself, and in addition the patient's wife had to assume wage-earning responsibilities. The example that follows illustrates a situation where community resources are used as the major source of income.

Case 24. Previous to illness, Mrs. A., aged 29, had been the only means of support for herself and her six year old daughter. She had also supplied her husband, a patient in the sanatorium for three years, with the spending money he required. She had a total monthly income of $240.00, which was obtained from her employment and from roomers. When she became ill, and had to be hospitalized, she had to place her daughter with relatives, where she did not have to pay board. She had no income for the period of her hospitalization which was eight months. Her relatives had to supply both the patient and her husband with spending money. Upon discharge, Mrs. A. applied to the E. AS.F., through whom she received Q.P.C.A.[1] for herself and her daughter. She was also in receipt of M.M.A. She once again took in roomers, and her total income was increased to $196.00 per month. She is as yet unable to work.

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1. Q.P.C.A. stands for the Quebec Public Charities Act, which is the act of the Provincial Government referring to public relief. It is administered through private welfare agencies.

In this situation, two community resources were used and boarders were taken in to augment the income. From these two illustrations it can be seen that more than one change was necessary to adjust to the financial circumstances in which these families found themselves when the breadwinner became ill with tuberculosis.

Adjustments made by Single Earning Patients:

For the purpose of determining the nature of the adjustments, the single earning patients, both those living within a family group and those living alone outside a family constellation, have been considered together. It would seem reasonable that there would be a difference in the adjustments made, as between these two groups, and the table to show the total source of income bears out this fact.

Table XXII

Source of Total Income, Before, During and After Hospitalization for 18 Single Earning Patients[a] According to their Living Within or Outside a Family Group.

Source of Income	Patients Within a Family Group			Patients Outside a Family Group		
	Before	During	After	Before	During	After
Patients' Employment	11	1	7	7	2	6
Family Income Parents	-	7	3	-	2	-
Siblings	-	4	2	-	-	-
Other Relatives	-	-	-	-	2	-
Savings	-	-	-	-	5	-
Community Resources Public Assistance						
Relief	-	-	1	-	-	1

a) One patient, though single has been omitted, as he had been a student prior to illness and has never worked.

The 18 patients in this group all had their own employment as the only source of income prior to illness. From the table it can be seen that during the hospitalization period, the family was the only source of income for the single patients who lived within a family group. No other source was used, with the exception of one man who received his full pay from his place of employment for the duration

of his illness. In contrast to this, there were only two single patients living outside a family group who received help from this source. They, for the most part relied upon their savings, and, to a smaller extent, upon relatives other than those in their immediate family.

Following hospitalization, at the time of the interview, 13 of the 18 patients were once again receiving income from their own employment. Broken down into the two groups, this represented seven out of the 11 patients within a family group, and six of the seven who lived alone. Five of those living with their families are still receiving help from this source, One patient in each group is receiving assistance from a community resource.

The following case illustration is quite typical of the adjustment made by the group who had their family to support them while they were ill.

> Case 9. Mr. R., aged 20, had supported himself prior to illness, on his monthly income of $183.00. During his hospitalization, when he was without income, his family would bring him food and pocket money. Following discharge, and before going back to work, he lived at home and was supported by his family. Mr. R. is at present employed, and earning $175.00 a month. He is no longer financially dependent upon his parents.

The example that follows is not typical of this group, but is a situation that one family had to face when the patient was hospitalized. It indicated the adjustments sometimes necessary when a single family member becomes ill.

Case 31. Mr. W., aged 28, had an income of $238.00 per month before he became ill. He was the main source of income for the family which consisted of the patient, his mother, one brother and one sister. His siblings contributed something toward the maintenance of the family, but Mr. W. was the largest contributor. While Mr. W. was ill, his mother had to find work, while his brother and sister continued to contribute. The patient received financial help from these three sources while he was unable to work. Mr. W. is at present employed, and earning a markedly higher wage than he had before. He is once again the major source of income for his mother and his brother, who has also become ill. His present income is about $600.00 per month.

The following case example is fairly indicative of the way in which the single patients, who lived alone, managed in the financial area during the course of their illness.

Case 36. Miss N., aged 39, had lived alone, with an income of $173.00 per month previous to her illness. Her income ceased when she was no longer able to work, and she lived entirely from her savings while she was in the hospital and for the period following hospitalization when she was unable to work. She began to work shortly before it was medically recommended because her savings had become depleted.

Once again the student has been omitted here, although he was a single member of a family group, on the basis that he is not and never has been a wage-earner. He was supported by his family throughout, and although it represented a difficult situation, as the family was in very strained financial circumstances, there were no major adjustments made, other than careful planning.

Adjustments Occasioned by the Illness of the Housewives:

The illness of the nine housewives in the study, did not, by and large, necessitate many financial adjustments.

There were two patients whose families experienced difficulties. One was the situation mentioned earlier[1], where the six children had to be placed. The financial problems that resulted were serious, and application was made to a welfare agency for assistance. This family, however, had always had financial difficulty. The illness put added strains upon it, for the period when the patient was hospitalized. When she was able to return to her home, the children came back, yet the financial situation has continued to be strained. Another housewife experienced financial difficulty during the period of her hospitalization, which was due to marital troubles with her husband. She was without the necessary spending money on many occasions, but neither the financial difficulty, nor the reason for it, the marital problem, was due to the illness of the patient.

In the families of the other seven patients in the housewife group, there were no adjustments made. The income of the breadwinner in all cases continued as before, and no difficulties were encountered in providing for the patient while she was in the hospital.

Adjustments were made in all situations that required adjustment in the financial area, in order that the patient might be hospitalized and treated, and the people dependent or partially dependent upon him might be maintained. The

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1. Supra, p.146

meaning of these adjustments to the patient and his family and their adequacy will be discussed in the following chapter.

The Problem of Spending Money in the Hospital

While the hospital maintains the patient, provides him with food and medical care, he has other requirements that are not provided by the hospital. He needs pyjamas, bedroom slippers, money for cigarettes, cosmetics, shaving materials and the other sundries that come outside the scope of maintenance as provided by the sanatorium. The need for the money to provide these articles has more significance to the patient than is evident at the first glance. It is true that these articles are necessary for the comfort of the patient. They are the same no matter in what way they are provided, and they fulfull the same needs, but, as Pauline Miller said:

> The having and handling of money with which to meet one's own needs is often more important in our social economy than the specified items involved. It is symbolic of adulthood and adequacy. Tuberculosis forces dependence in any case, and the adult who has no money in hand and no immediate prospect of earning any feels himself more helpless, less vitally a part of the world he lives in, more shut off from normal channels of everyday living.[1]

It is true that about the only opportunity which the patient has to spend money is through mail orders and the sanatorium canteens, yet the needs just mentioned exist even

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1. Pauline Miller, Medical Social Service in a Tuberculosis Sanatorium, Federal Security Agency, Public Health Service, Division of Chronic Disease and Tuberculosis, 1951, p.32.

under these limiting conditions. If the patient has no savings from which to draw to secure these needs, or no family to supply him with funds, he is in need of an allowance. This would give him the symbol of adulthood and adequacy that is needed, and would relate him again to the outside world that he had to leave. Pauline Miller again said:

> Without financial support, the stresses of the outside situation and the insecurity and sense of helplessness within the sanatorium rob the patient of needed rest. His energies are dissipated in efforts to overcome conditions that he cannot, in any case, bring under control as long as he is ill. To have the means to meet his illness with dignity and to maintain his status as a member of a family and community may in the individual case prove as important in the management of a man's disease as the exquisite precision of the surgeon working directly on his lung tissue.[1]

With this view of the importance of the securing of spending money for the patient while he is in the hospital, an exploration of the sample group of 43 patients included in this study, has shown how great the problem was for them, and the ways in which they solved it.

All of the patients studied had some means of obtaining money with which to buy the necessities while in hospital. There were none for whom special arrangements had to be made. The following table shows the sources of the patients' spending money while in hospital.

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1. Ibid, p. 32

Table XXIII

Sources of Spending Money during Hospitalization for the Group of 43 Patients, According to Sex.

Source	Total	Male	Female
Total	43	27	16
Parents	10	7	3
Spouse	15	6	9
Children	4	4	-
Other Relatives	5	3	2
Savings	7	5	2
Community Resources	2	2	-

The single earning members of a family group did not, on the whole, experience too much difficulty, and no severe strains were put upon their families. This group included the larger percentage of those who are shown on the table as having received their spending money from their parents. In several instances there were some deprivations because of the loss of the patient's income, but the adjustments were made fairly easily, and spending money was not a great problem. The family which had the most difficulty because of the loss of earning power by a single member has been described before.[1] Mrs. W. supplied her son with spending money only with difficulty. Yet she was able, with the help of her other two

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1. Supra, p. 154

children, to make the changes necessary to supply her son with the money he needed.

The experience of the single patients living outside a family group was different. They are shown on the table as having relied on their savings largely for the source of their spending money. They had some help from relatives out of town, also. Their greatest worry was what they would do if their savings became depleted before their discharge.

The breadwinners, as a group, are those indicated in the table as having received their spending money from their wives or children. This was the group that found the financial strain of tuberculosis the most difficult. Because the breadwinning group were so seriously affected in the financial area, it followed that it was very difficult for the families to supply the needed spending money. The following example illustrates one of the more difficult situations.

> Case 7. Mrs. P. found it extremely difficult to supply Mr. P. with spending money while he was in hospital. Her income was barely enough to maintain her children and herself. Assistance from the C.W.B. was obtained, and she was able to supply her husband with some money, but it meant depriving the family of some of their needs.

The housewives were all supplied with their spending money by their husbands, and are thus indicated on the table. The housewife group experienced the least difficulty with this

problem, and with one exception, were provided with spending money with no added strain in the economic area. This was due to the fact that their requirements were not as great in the hospital as they had been in the home, prior to illness, and there had been no decrease in the family income as the result of their illness. The one exception was the case illustration cited previously,[1] where five of the family's six children had to be placed where board had to be paid for them from the marginal income which the husband made. This family were able to manage because of the help they received from a welfare agency.

The materials collected in the interviews were not detailed or extensive enough to permit a more complete study of this area. The available materials do indicate further problems and a more careful survey of this aspect of financial adjustment might show that spending money is the source of more financial strain than it is possible to indicate here.

Housing

Housing falls within the scope of this section, largely because of the close connection it has with the standard of living of a patient and his economic status. With the lowering of the income level which has been shown in the above sections, particularly during the hospitalization period, it might be

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1. Supra, p.

assumed that housing would be affected by this change in the econonic level. It might necessitate a move to inferior housing where there are lower rents, or it might mean a deterioration in the original housing because of the financial inability to expend funds to keep up the home as it falls into disrepair. This latter was difficult to indicate in this study as very little was known of the homes prior to illness, and the data obtained did not give a clear picture of the relationship of present housing to previous housing. A few of the patients did mention this as one of their major problems, and because of this the problems of housing will be included to the extent of the material available.

When this study was embarked upon, it was hoped that it would be possible to find some information on the bearing that housing has upon the patient's conditions for recovery. The data collected had in no way given any real indication of the answer to this question, but what has been found will be presented.

Changes in Housing:

From a study of the 43 patients interviewed, it was found that 34 were in the same housing as they had been previous to illness. The other nine patients had changed the location of their dwelling. Of these nine moves, two represented a change to inferior housing, and seven a change to improved housing. The reasons for these changes are illustrated in the following table.

Table XXIV

Reasons for the Change in Housing for the Nine Patients Who Made Such a Change According to the Status of Housing and the Change Involved.

Reasons for Change	Total	Housing Improved	Housing Inferior
Total	9	7	2
Housing Changed to Accomodate Roomers	2	1	1
Housing shared to Save Money	1	1	-
Housing Changed for Other Reasons	6	5	1

This table indicates that six of the nine changes were for reasons other than those caused by illness. Three were the direct result of illness. The following example is an illustration of the change to improved housing in order to save money.

> Case 15. When Mr. A. was hospitalized, his wife was obliged to give up their living quarters and move in with Mr. A's parents, as there was not sufficient money to maintain a separate home. The patient, his wife and young son are still with his parents, as Mr. A., although employed, is not earning as much as formerly. The present housing is an improvement upon their former accomodations, but it is not satisfactory to the patient and his family as there is some friction between the two families. The present arrangements will be continued for a while longer, as it represents an economic saving.

The case illustration, which follows, shows the change to inferior housing caused by the necessity of accomodating roomers as a means of increasing the family income.

Case 31. Prior to Mr. W's illness, he and his family lived in a very comfortable house. Due to financial strain, caused by the illness of the patient who was the main breadwinner of the family, this house had to be sold. A rooming house was purchased in order that there might be some income from rentals. This has meant that the patient and the family are living in three basement rooms of this house, which are not comfortable or good for the family's health or morale. They have remained only for economic reasons, and plan to move as soon as it is feasible.

The next example shows the other move that was necessitated by illness. It was a young couple who improved their housing in order that they might accomodate roomers.

Case 40. When Mr. C. was discharged from the hospital, his wife moved to the apartment in which they are now living. It is larger and more comfortable than their previous quarters, and is an improvement. This move was made to accomodate roomers, in order that the family income might be increased. This plan has not worked too well, as Mr. C. is unemployed at present, and the income from the roomers is not sufficient to offset the higher cost of the improved housing. A move to more inexpensive quarters is under consideration.

It is not possible to ascertain from the available data how many of the patients, who did not change the locale of their housing, experienced a deterioration in their original dwelling due to a financial inability to replace and repair over the period of lowered income. One patient, though, did mention this as a special problem.

Case 2. While Mr. R. was in the hospital, his wife received assistance from W.M.A. and from a welfare agency, which was sufficient to cover current expenses, but it was not enough, in the words of the patient, "to replace things as they wore out around the house." He is now working at a higher salary than before, but the advantage has been offset to a large extent because a lot has had, again in the words of the patient, "to go in for back stuff."

This family found that, while they could manage from day to day, it was impossible to maintain the home on the same level during the period when the income had been markedly reduced, as had been possible on their pre-illness income. Since they found this to be the case, it is quite possible that other families have experienced a similar deterioration in their housing, although the locale of the housing had not actually changed. As has been mentioned, there is not sufficient material to investigate this area further.

It was hoped that the data obtained might furnish some information regarding the relationship between housing and the patient's conditions for recovery. However, it has not been possible to obtain any information to substantiate the premise that there might be such a relationship. Many of the patients live in what might be termed "poor" housing conditions. This involves overcrowding, lack of fresh air and sunshine, unsatisfactory sleeping arrangements, and a neighbourhood that is not conducive to rest. Yet there is no indication that the recovery of the patients living under these conditions is in any way slower than for those patients who live in what might be termed better surroundings. Moreover, the members of the sample group have been out of the hospital for varying periods of time, and for many, the length of time

since discharge is not sufficient to give any evidence of a relationship between their housing and the rapidity and completeness of their recovery.

None of the information gathered in relation to the problem of housing is extensive or conclusive enough to offer any real significance. For the group as a whole, it would seem that deterioration in housing has not been a serious problem for these families. A very small percentage of the patients in the sample group have experienced problems in this area, yet they consider them to be a minor part of the more important financial problem.

This chapter has presented the financial problems which the sample group of 43 patients have experienced as a result of their illness and the way in which they met these problems. The following chapter attempts to show the attitudes of the patients toward these problems and the adjustments and changes which they necessitated.

CHAPTER VII

ATTITUDES OF PATIENTS AND THEIR FAMILIES TOWARD THE EFFECT OF TUBERCULOSIS ON THEIR ECONOMIC STATUS.

The preceding chapter has attempted to show the prevalence of economic problems as the result of tuberculosis, and the nature of those problems in relation to the sample group of patients. Although something was said about the adjustments this group made to the impact of this disease in the financial area, there has been no mention made of the attitudes of these patients towards the financial changes and adjustments occasioned by illness. The economic insecurity of the patient with tuberculosis intensifies any existing emotional problems of anxiety over illness, fears for the future, and the sense of personal inadequacy and insecurity. It is hoped that this chapter will furnish some information regarding the meaning to the patient of the change in economic status, whether it is permanent or temporary. This, and a consideration of the community resources that have been used by the patients and their families, and the adequacy of these resources, has been dealt with in the first section of this chapter. The effect that the changes in economic status have had upon relationships within the family has been considered next, followed by a discussion of financial dominance within the family, and the changes in financial dominance as a result of illness.

Attitudes of the Patients Towards the Effect of Illness upon their Financial Status.

It is difficult for a person to relinquish financial independence, when he has been accustomed to it. Yet the majority of tuberculosis patients must lose their financial independence while they are undergoing treatment. The way in which they react depends upon the financial position of the patient, his personality, and the role he has played in the maintenance of a family. The more economically secure a person is, the less his concern will be. The person who has a good reserve for emergencies will have fewer worries in the financial area. Yet tuberculosis is a disease that requires a relatively long period of absence from remunerative employment, and very few people have reserves that will carry them through the whole period. The person who has been the breadwinner of a family will have greater concern about the loss of his earning power than will the single person who is largely responsible for his own maintenance only. The man who is no longer able to support his wife and children may feel very insecure and inadequate. This insecurity may be intensified by the fact that his family is having a difficult time in making the adjustments necessary for them to manage while the patient is absent. However, the way in which these factors affect the patient's reaction is dependent also upon the patient's

personality. The tuberculous patient is usually an anxious person, because his security about his health has collapsed. Because of this anxiety, he is prone to worry about any matter which is of importance to him and which he sees being affected by his illness. Dr. Littkower feels that resentment is another cause of financial concern. He says; "while it is true that inadequate financial support causes resentment, it is equally true that resentment (of the illness) is often unduly fixed on the financial situation."[1]

While it was difficult to ascertain the cause of the financial concern from the data collected in the space of one interview, many of the patients spoke freely about their attitudes toward their changed status and toward the help they received, both from their family and from community resources. It is with this aspect of the patient's adjustment that this section deals, with a discussion of the causes wherever such are apparent.

The Patient's Attitude Toward his Economic Status During Hospitalization.

While the patient is in the sanatorium, he is surrounded by people who are in the same position as he. It might

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1. Eric Littkower, A Psychiatrist Looks at Tuberculosis, London, The National Association for the Prevention of Tuberculosis, 1949. p. 63.

seem that his feelings of concern and inadequacy would not be as great when he is in the hospital as when he is in his own home. The patients were interviewed at least two months and often much longer following discharge and therefore it was difficult to be sure that they were still able to separate the attitudes they had while in the hospital from those which they had acquired since discharge. It is almost impossible to judge, because of this fact, whether their concern was greater during the hospitalization period or during the period after they had returned to their homes. It is likely that individual differences in the situation of patients would influence their reactions in this regard. Practically all of the sample group have expressed their feelings about the financial area, and what they have said will be presented.

The breadwinning group were particularly vocal regarding the financial difficulties they encountered as the result of their illness. Most of them related it specifically to their present status, but many could go further back and discuss it in relation to the way they felt while they were in the hospital. Three of the four men whose children supported the family while they were unable to do so evidenced the strongest feelings toward their changed status. These three felt they had lost much of their status, both in the financial

area and as the head of the household. They worried while they were in the hospital, and felt that it was not fair that their illness should necessitate that their children support the family whose support was rightfully the responsibility of the head of the family. They all felt that the money the children earned belonged to them, with the exception of what was paid in the way of room and board. They felt inadequate and as though they had failed an obligation. The following case illustration indicates one patient's attitude toward his family's reluctance to assume the breadwinning responsibilities:

> Case 5. When Mr. E. became ill, there were two daughters living at home who were working. Two other children were in school. For the first part of the hospitalization period, both the earning daughters contributed equally to the support of the family. Shortly after, one of them married, and so was no longer able to contribute. The burden fell on the one daughter that remained, and the patient felt very badly that such had to be the case. This was heightened by the fact that he also felt that she did it reluctantly. In one way he felt that it was natural for her to want to have her money largely for herself, yet he was hurt that she did not give it more willingly. Her attitude struck him at a point where he was most vulnerable. It made him feel his own inability to be out and earning money and it made him feel inadequate in an area in which it was very important for him to be adequate. He also felt that his wife was in a difficult position, because she had to defend him and try to build him up in the eyes of his daughter. This situation continued from from the hospitalization period until Mr. E. began to work. Then as he was unable to earn enough to completely support his family, his daughter still had to contribute. The situation grew somewhat worse as time progressed.

This situation is illustrative of the attitudes of the other patients in a similar position. It also points up the fact that it is difficult to separate the hospitalization period from the post-hospital. One of the situations continued to grow worse as the patient went into the after-care period at his home. It might be indicative of the fact that the patient felt more bitter and inadequate about his inability to earn a living and support his family when he was at home and could see his family's reluctance to assume the wage earning responsibilities.

There was a fourth man whose children supported the family during his hospitalization. His attitudes are very different from those of the other three men in this group. His situation is outlined in the following illustration:

> Case 20. Mr. S's three children supported the family while Mr. S. was in the hospital. The family was very closely knit and there was evident affection one member for the other. Mr. S. seemed to expect that his children would be willing to contribute when he was not able to, and they were quite willing to do so. Mr. S. was not made to feel inadequate, because of his family's desire to help during this period, and because of his own personality which helped him to view the situation realistically.

None of the six men whose wives worked during their hospitalization expressed such strong attitudes as did the men whose children had assumed similar responsibilities. Of the six wives who worked, since two had been employed prior to illness, this did not represent a change. They

were childless couples and the salaries which the wives earned were sufficient to keep themselves and supply the patient with spending money. The other four men did not have very much to say in regard to the hospitalization period. Their focus was largely on the post-hospital situation and the present, which will be dealt with later. This might bear out the assumption mentioned earlier, which Dr. Wittkower stated, that "the tuberculous patient feels his inability to earn a living much more strongly at home than at a sanatorium where, in a community of fellow-sufferers, everybody is in the same position."[1]

The other five patients in the group of 15 bread-winners also focused largely upon the present situation. The majority of these had relied upon community resources for assistance during the hospitalization period, and did not express their feelings toward their status while in the sanatorium.

The single earning patients who lived within a family group did not express their attitudes toward their hospital status, but like the other groups focused upon the post-hospital situation. The single earning patients who lived outside a family group had a little more to say about their hospital status. The patients who had only their savings to

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[1] Ibid, P. 64

rely upon worried that they might become exhausted before they would be able to go back to work. The following example shows the situation of a woman who had only her savings to rely upon during the hospitalization period:

> Case 4. Miss J. had no family in Montreal upon whom to rely when she became ill. In her own words, she said, "I had to draw on my savings. Just as I would start to save there would be one swoop and then another. I had to borrow on my life insurance, too. One of my friends paid it for me while I was in bed. My family would send me small amounts of money but often I would not let them send it. Being away from home I found it difficult as I had no family here to supply me with things that others had."

This shows the feeling that the patient had about being without a family to supply the things that she needed while she was in the hospital and which other patients with families nearby did have.

By and large, it was difficult to ascertain what the patient's attitudes were toward their hospital status. It was not possible to discover whether this is because it was almost impossible for them to separate them from their present attitudes, or because it bears out Dr. Wittkower's belief that the patient feels his inability to earn much more when he has returned to his home. The following section is concerned with the patient's attitudes toward his present status.

The Patient's Attitude Toward his Present Status

When considering the patients' attitudes toward their

present status, it must be remembered that all the patients in the sample group are not at the same stage. Some have begun to work and have been able to resume their life much as it had been before. Others are still not able to work, and so would have different attitudes toward their present status. With this in mind, an examination of the attitudes of the patients follows.

Of the 15 breadwinners interviewed, eight felt that they had been fortunate, and that the illness had not affected them too much financially. It is significant to note that seven of these eight have returned to jobs at which they are receiving wages which are comparable to, or superior to, those which they had received prior to illness. The eighth is about to work into a new business venture and is very hopeful about the success of it. The following case illustrates the attitudes of one patient toward his present status:

> Case 12. Mr. E., when interviewed, had just begun to work full-time, although he had been drawing his full salary for several months for part-time work. His salary was the same as his pre-illness salary. During his illness, his wife had worked part-time now and then, whenever some extra money was needed. They felt they had been extremely fortunate during this period since, with the supplementation which came from Mrs. E's earnings, it was not necessary for them to go into debt, nor for them to change materially their former standard of living. Mr. E. said of the financial situation, "We figure we've been pretty lucky." Both feel particularly pleased that it was never necessary for Mrs. E. to leave the two children.

The other patients in this group felt much the same way toward their present status. They acknowledged that there had been inconveniences, and that their illness had put them back temporarily. By and large, though, they felt they had been much more fortunate than many others they knew and were glad they had not been affected to a greater extent in the financial area.

Of the remaining seven patients in the breadwinning group, there were six who felt very strongly about the effects of the illness on their financial status. Of these six patients, four were unemployed, and two were working only part-time due to their illness. They were all bitter about the change in their status, although some feel much more strongly about it than others. The following illustration indicates the attitudes of a man who has been unable to work since 1943, and whose children has been supporting the family:

> Case 10. Mr. F. has been unable to work since 1943, when he first became ill. For the first years of his illness, his family was in receipt of N.L.A. When his children became of working age, they assumed wage-earning responsibilities. Mr. F. feels badly that they have had to give their earnings to keep his family. He said, "The kids need to work for themselves, not for me." One son got married a few months prior to the interview, and one daughter was to be married a few months after. These two are no longer able to contribute, and Mr. F. feels that this is as it should be. He is only sorry that they could not have all that they had been obliged to give to the support of the family over the years. He feels sorry that he has been the cause of their having to give up so much of what he feels should be theirs. He expressed

feelings of inadequacy, yet he had not lost his perspective and could look at the situation realistically.

Another illustration points up the attitudes of a man who has had to rely on his wife to support him.

Case 40. Mr. C. was unemployed at the time of the interview. He had been working since his discharge from the hospital, but had had to leave his job. The only income the family had was from Mrs. C's wages and from roomers. The patient's comments regarding the situation were, "The wife has to work and look after me. She has to buy my tobacco. I should even cut that out. It makes a person obstreperous. It gets on my nerves. I'm not working and I haven't got a cent but I don't want to go to work under $30.00 a week. I've lost courage in myself." Mr. C. feels that his illness has ruined his life, yet the interviewer questioned whether the illness was as much to blame as the patient felt, or whether it was as much the result of the type of person the patient was.

This situation shows a man who feels inadequate and insecure, because he is not able to support himself. It might also be indicative of a situation where the personality of the patient has played a larger part than the actual circumstances which were the result of illness. The interviewer felt quite strongly that Mr. C. was a person who would feel that things and people were against him no matter what the circumstances.

The men who were included in the breadwinning group all felt inadequate and insecure. They focused all their disappointments upon the financial area, and could scarcely talk of anything else. It was felt that many were not facing

the situation realistically, and that all their hostility and bitterness for all reasons were being related to the economic area. It was an area where they could lay the blame upon outside sources, such as community welfare agencies, which had been unable to help them because of eligibility regulations. Bitterness toward the inability of these agencies to help was common to this group, and will be dealt with in a later section. It was evident, though, that this group had problems other than in the financial area, and that these other problems, mainly in the area of family relationships, seemed to have an influence upon the way in which the patient reacted to the financial impact. The two factors were in almost every case existent together. A continuation of the study of this supposition was not possible because of limited material, but further study might bring evidence to view.

The one woman in this group of breadwinners exhibited a very apathetic attitude toward the whole financial picture. She had experienced a change in status, but did not seem to have very strong feelings one way or the other. Her husband has been in the sanatorium for several years and she seemed to have lost interest in all things, including the subject of finance. She did admit that it was more difficult to manage than before, but that it was not too bad. She was the only patient interviewed who was definitely apathetic about this subject which most of the patients found so important.

Of the 11 single earning patients interviewed, eight expressed no feeling about having accepted help from their families during the period of their illness. They all felt at times that they might be a drag on their families, but seemed to expect that their families should do as they did. They missed having their own spending money before they were able to return to work. Of these eight, four had returned to their employment at the time of the interview, while four, including the three girls in this group, had not returned at that time. The following example is fairly indicative of this group, and their attitudes toward their financial dependency upon their families during their illness:

> Case 6. Mr. W. received some money during hospitalization from a pension scheme, which was sufficient to keep him in spending money. Following discharge, he was sent home for ten months, during which time his parents supported him, before he started to work. The patient's father earned a salary which was ample to support his son, and he did not feel that he was a strain on his family. He felt every once in a while that he was a burden upon his family, but that attitude did not last very long as he was not made to feel at all uncomfortable. He also missed having his own spending money. He got whatever he wished from his parents, but he did not feel that he was demanding and in his own words said, "I didn't expect to blow the town."

This group of patients who did not seem to mind their enforced financial dependency very much is in contrast to the three single patients who felt quite strongly about it. In one situation, the financial strain was serious, as the patient was the main wage-earner of the family. In the other two, the

patients' families were very willing to support them, and while it might have been an added strain, they made the patient feel very welcome to the help which they gave. The patients both found, though, that their financial dependency was very difficult for them to accept. They felt they were a burden upon the family, and were anxious to resume their financial independence. The following example illustrates one of these situations:

> Case 17. Mr. W. is a single man, living with his married sister and her family. He had always been dependent upon them with the exception of the financial area where he had always paid his way in a co-operating household. His illness made him financially dependent as well during hospitalization and following discharge before he was able to work. He found that it was very difficult for him to accept the fact that he was no longer financially independent, and had to rely upon his sister's family. This attitude began to fade as he became able to contribute once more.

By and large, the single earning group who lived within a family constellation did not have very strong attitudes towards the adjustments that had to be made in the financial area. These adjustments consisted mainly of assistance from their families, and with the few exceptions, noted above, they were able to accept this dependence realistically.

The single patients who lived alone have not experienced a change in status, with one exception. Six of the seven patients in this group have returned to jobs where their income is the same or higher than it had been prior to illness. Their only

comment regarding their attitudes toward the effect of the illness upon the economic area is that it did put them back temporarily, and several just about exhausted their savings. Yet they felt that they had been fortunate and were quite happy about their present situation. The one patient in this group who has had a great change in status, is a girl who is not as yet able to work. Her situation is given in the following case illustration:

> Case 37. Miss D. prior to illness had been employed, with quite a good salary, and was living at home as her parents were alive then. Her parents both died while she was in the hospital, and when she was discharged she went to live with an aunt. It was not possible for her to remain there, and she moved to a single room, which she rented with assistance from the Family Welfare Association.[1] She eats her meals at her aunt's, and receives money from F.W.A. for food also. She is slightly bitter about her present small income. She feels that she is imposing upon her aunt, because the amount of money which she is able to give her aunt does not nearly cover what she receives from her. She also resents the fact that the amount of money which she has is not sufficient to buy clothing, and that she also has to have help from her aunt to buy cigarettes.

The Patients' Attitudes Towards Help Received

There were two main sources of the assistance which the patients in this sample group received. These sources were the families of the patients and the various community resources which were available to them. Attitudes of the

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1. The Family Welfare Association, hereinafter referred to as the F.W.A., is a private welfare agency in Montreal.

patients who received help from their families will be discussed first, followed by a discussion of their attitudes toward receiving help from community resources. The adequacy of these resources will also be considered.

Of the 33 patients who had been employed prior to illness, 20 received assistance during the period of their immediate family. Their attitudes have already been largely discussed as coming within the scope of the section on the attitudes of the patients toward their hospital status. Nevertheless, little has been said regarding their attitudes toward receiving this help when they returned to their homes, and before they were able to return to work. Following the same pattern as during hospitalization, the married men found it more difficult to accept help from their children than they did from their wives. The men who felt badly during hospitalization felt much worse when they returned home and their children had to continue to support them. Several of the men found it more difficult to accept the fact that they received all their maintenance from their wives, following discharge, than they had while they were in the hospital It seemed to bear out Dr. Wittkower's statement that married supporters at home were more concerned about financial matters than when they were in the hospital where everyone was in the same position.

The attitudes of the single patients living within a family group toward the help they received from their families has already been discussed also. By and large, they have not felt very strongly about accepting such help, and seem to have accepted it as a matter of course.

From the material gathered, it did not seem that help received from the family caused many feelings of guilt and inadequacy except in the case of the married breadwinners who had to accept help from their children. The majority were comfortable in accepting help from their families.

Of those same 34 patients who had been employed prior to illness, nine received assistance from some community resource, or resources. There were six applications for public assistance, and 12 for assistance from private agencies, three of which were refused. These nine families were in receipt of assistance from the resources where application had been made and accepted. Of these nine patients, seven were of the breadwinning group, one was a single patient living within a family constellation, and one was a single person, living alone.

Needy Mother's Assistance was the most used single resource, and was being received by four families. In no case was assistance from this source sufficient to maintain the family, and income from other sources had to be obtained.

The case illustration which follows is indicative od the attitudes of another family who received help from public assistance and from a private agency.

> Case 2. When Mr. R. was hospitalized his wife applied to a private agency and to M.M.A. from whom she received assistance until Mr. R. was able to resume work. This couple felt that while it was sufficient to maintain them during this period, there was not enough to replace things as they fell into disrepair. They were also resentful of the fact that their three children had to be deprived of things because their income was not sufficient to supply them with many of the things that they needed. They felt that the economic area was one of the main problems when the wage earner had to be hospitalized for tuberculosis.

There were seven patients receiving assistance from private agencies, or from Q.P.C.A. through private agencies. The following example illustrates the attitudes of one family toward the help they received from a public assistance programme which was administered through a private welfare agency.

> Case 7. Mr. P. aged 54, had five children, with ages ranging from 6 to 17. He had never been able to accumulate savings, and when he was hospitalized application was made to a private agency, who agreed to pay the rent, the light, and a small amount per week for food. With the Family Allowance added to this, it was still not sufficient to maintain the family. Both the patient and his wife felt that they had had a very difficult time financially. The children had been continually deprived of material things, and the parents had been in a state of perpetual anxiety. Mrs. P. had had to go to work to supplement the income, and had to hide this fact from the welfare agency. The main object of this family's bitterness was "the city", who made the eligibility investigations when the welfare agency applied for Q.P.C.A. The investigator continually returned to go

> over the same gruelling investigation again and again though none of the facts had changed. They spoke of the worker from the welfare agency as having been very nice and very kind, but said that the head of the agency was a "hard man" who would give on no issue. At present the patient is working part-time, Mrs. P. still works and they are no longer in receipt of assistance. They both feel independent as they are no longer responsible to anyone for the way in which they spend their money, and they no longer have to conceal the fact that Mrs. P. works.

The general concensus of opinion, as gleaned from the two examples given above and the other situations in the group, was that the income obtained from community resources was not sufficient to maintain a family on the level, or even close to it, which they had enjoyed prior to illness. On many occasions, in order that a family receive enough to manage, some source of income had to be concealed from a public or private agency, which the patients did not like to do.

The three patients who had made application to private welfare agencies, and whose applications had been refused were quite bitter about it. They felt that to be eligible a person would have to be completely destitute. The following case example shows the attitudes of one family toward their refusal of assistance by a welfare agency:

> Case 40. Mr. and Mrs. C. had no children. When Mr. C. was hospitalized, Mrs. C. continued to work as she always had, and that was the only income which the family had for this period. Following Mr. C's discharge, they took in roomers to augment the income. Yet even with this the income was not what

> this family considered adequate. They applied to a welfare agency, and were not found eligible for assistance. They were bitter about it and expressed it in the following terms. "I went to the agency after I came out of the Grace Dart, but they wouldn't help me because we had this place here and we were paying too much money and had a phone. We'd have to have nothing to get help from them - no furniture, no work, nothing." The interviewer felt, though, that they had no understanding of eligibility rules, and were the type of couple who would expect rules and regulations to be waived for them. It is therefore difficult to assess their resentment in terms of it being justified.

The following example is of a man who has been unable to work since 1943. After his last hospitalization he applied to a private welfare agency for assistance, where his application was refused:

> Case 10. Mr. F. applied to a welfare agency following his last discharge from the hospital. He claimed that assistance was promised to him, and that nothing ever happened. He felt, in his words, "very let down." His two sons were contributing to the support of the family, and the application was probably refused on the basis that their income was considered adequate according to agency standards. The patient was not bitter because he had been refused, but because he had understood that his application would be accepted, and then he was later refused. He could not understand what had happened, and apparently no one had explained it to him so that he could understand.

The community resources of which the sample group availed themselves were considered to be of great help, but they were not extensive enough to satisfy them. They all felt that it was enough to subsist upon, but not enough to maintain them even near to the standard to which they had been accustomed. It was also true, although there were only three

situations from which to generalize, that those who had been refused assistance, focused most of their resentment of the whole illness upon the agency which had refused them.

Effect of the Economic Impact upon Family Relationships

With the assumption of wage-earning responsibilities by the patient's wife or children, it might be assumed that the patient would subsequently lose in status as a result, and the very nature of the relationships within the family would be changed. Yet in only three of the cases has there been such an impact upon family relationships as the result of the economic impact. In two of these the result has been detrimental to both the patient and his family, and has destroyed the previously quite harmonious atmosphere. The third situation has been faced realistically by both the patient and his family, and although the relationships have changed, the new pattern is acceptable to all, and no unhappiness has resulted. The following example shows a situation where family relationships have been undermined as the result of the impact in the financial area:

> Case 15. When Mr. A. was discharged from the hospital, he, his wife and young son went to live with his parents, in order to save money. During his illness, his wife assumed all responsibilities, and does not want to relinquish them now. Mr. A. would like to assert himself, but he has never been a person who asserted himself to a great extent, and now he feels

that since he has not been able to look after his family in the financial area, he has no right to take a more aggressive stand. He is very unhappy as a result.

This case is illustrative of a situation where there was a change in relationship due to the wife assuming the responsibilities that had once been shared. The following situation shows a change in family relationships due to a child assuming wage-earning responsibilities:

Case 5: Mr. E's daughter had supported his family while he was in the hospital, and up until the time he was able to return to work. Mr. E. felt that she gave the money reluctantly, and he was bitter that she did not give it more willingly. He did say that it was difficult to expect a girl to give so much of her hard-earned money to keep her family when there was a breadwinner, yet it made him unhappy that she should be as unwilling as she was. This situation has harmed the relationship between the patient and his daughter, as he is very disappointed in her reaction.

The third situation in which the impact in the economic area has had an effect upon family relationships is described in the following illustration. It is indicative of the way in which family relationships may be changed with no resultant resentment.

Case 10. While Mr. F. was ill, his children took over the financial responsibilities of the family. In this way, Mr. F. no longer holds the place with them that he once did. This is natural as they have grown up in the interim, yet he feels that he does not hold the place he would hold, had he not been ill. Even though the patient has lost some of his status as the result of the financial impact, the relationships are good because Mr. F recognizes what has happened as inevitable and he does not try

> to resume the relationship as it was prior to illness. They are a very happy family, and the patient is secure and content in the over-all pattern of family relationships.

In conclusion, it might be said that there seemed to be a very small percentage of the families in which a change in family relationships occurred as the result of the financial impact. Of the 26 patients who lived within a family group, only three experienced a change in relationships. These changes all occurred in the families of married men, two of which might be considered to be a change to poorer relationships, while the other one was just a realistic adjustment in relation to the changed circumstances.

Financial Dominance

The question of financial dominance has been discussed indirectly already, in relation to attitudes toward change in status, and the effect of the financial impact upon family relationships. This section has been included, however, to give a picture of the patients who had been financially dominant before illness, and the position which they held before going back to work, as well as their present status in the area of financial dominance. The group under discussion has been limited to those who had been the financially dominant member of the family prior to illness, and hence includes the group of 15 breadwinners, and the one single

man who was the main source of income for his family. This constitutes a group of 16 patients, 15 of whom are men.

A serious problem may arise if the patient sees another member of his family take over his traditional role of breadwinner. As Dr. Littkover says, "(It) may lower his prestige in the family circle and, as seen from his angle, may underline his humiliating position."[1] The following table illustrates the financially dominant member of the family before illness, and after hospitalization, both before and following resumption of work.

Table XXV

Financially Dominant Member of the Families of 16 Breadwinners, Before and Following Resumption of Work.

Financially Dominant Member of the Family	Before Illness	Post Hospitalization	
		Prior to Work	Following Work
Total	16	16	12(a
Patient	16	1	8
Spouse	-	10	3
Children	-	4	1
Parents	-	1	-

a) Four patients have as yet been unable to return to work.

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1. Eric Littkower, A Psychiatrist Looks at Tuberculosis, London, The National Association for the Prevention of Tuberculosis, 1949. p. 65.

This table shows that only one patient was financially dominant before returning to work, and that was the one female whose husband was in the sanatorium during and following her hospitalization. In ten of the 16 situations, the wife became the financially dominant member, while in four the children assumed wage-earning responsibilities, and thus became financially dominant. Following work, one-half of the wage-earners had resumed their dominant position, while four, although working, had not been able to regain this position from their wives and children. Four of the group of 16 had not resumed work at the time of the interview.

The effects of this change in dominance, where such has taken place, has been largely discussed, before, and examples given in case illustrations.[1] It will suffice to say here that, by and large, the patient has not been happy in relinquishing his dominance in the financial area, yet in several instances has been able to make the necessary adjustments.

Findings

From the material presented in the last two chapters, it can be seen that the financial area is one which poses a problem for the majority of patients who have been hospitalized

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1. Supra, p.186 and p.197

for tuberculosis. It is a problem which may confront any person, regardless of his personality or maturity. His use of available treatment to maximum advantage is dependent upon the adjustments he is able to make to his satisfaction in this area. An examination of the 43 patients in the sample group has provided some interesting findings in relation to the financial problem and its effect upon the patients and his family.

Four-fifths of the patients in the group experienced problems in the financial area. Only the families of the housewives were exempt from the stresses and strains imposed by illness in this area. It was evident that some patients were more affected than others. By and large, the bread-winning group faced the most difficult situation. The next most difficult situation was that of the wage-earning group who lived outside a family constellation. The nature of these problems varied slightly from patient to patient, but they centered largely around concern for the maintenance of their family while they were unable to be gainfully employed. The single wage-earning patients who lived within a family group did not have as much worry as the breadwinning group, yet it also constituted a part of their problem.

The adjustments made by the patients who had a financial problem were many. The largest source of income for the

period when the patients were unable to work was from other members of the family. The wives of many patients began to work, while in other situations the children assumed wage-earning responsibilities. Some of the patients relied upon their siblings to provide for them during and following their hospitalization. Another source of income which was frequently used was assistance from such public and private community resources as were available to them. Meanwhile, it was noted that the money which they received from these resources was not adequate to support the families without some other financial adjustments and these were often disruptive of normal family living. This group did not give evidence that "spending money" for the period of their hospitalization was a great problem, but a more careful study of this area might prove that it did constitute a more serious problem than was apparent here. This might be particularly true of the wage-earning patients who lived outside a family constellation.

Nothing very significant was found in regard to the question of housing and its relation to the patient's conditions for recovery. Although one-fifth of the patients or their families had moved during the period of illness, in only three cases was this due to the illness itself. From the data collected it was impossible to assess the relationship of the type of housing to the rapidity and completeness of the recovery.

All the patients, who had been employed prior to illness, felt that the economic area presented one of the greatest problems when they became ill. The patients who had no dependents felt that they were more fortunate than those with a family dependent upon them, yet all disliked the fact that they were no longer financially independent. They did not seem to mind their financial status while in the hospital as much as they did after their discharge and before they were able to work. A few of the patients found that the change in financial dominance which occurred while they were unable to earn an income, had created a change in family relationships, which continued even after the patient was once again gainfully employed.

If it had been possible to interview a larger number of patients, or if more integration among the areas of this study had been feasible, more significant findings would have been possible. Further study of the economic area, and its impact in the lives of patients, would furnish much more information about the services and facilities which are needed to make tuberculosis less disruptive of normal family living. It would help to point up means to lessen the burden and the anxiety of the patient when all his energy and concentration should be directed to his recovery.

PART IV

ADAPTIVE PROCESSES IN THE FAMILIES OF TUBERCULOUS PATIENTS

CHAPTER VIII

CHANGES IN FAMILY STRUCTURE BROUGHT ABOUT BY THE HOSPITALIZATION OF THE PATIENT

The present-day treatment of illness has moved away from the almost complete absorption with the defective organ which had characterized it for so many years to include other facets of the patient's life. Although there had always been advanced thinkers in the field of medicine who had recognized the importance of the patient's total life situation in its bearing on his illness, nevertheless, it was established practice to concentrate on the diseased organ. It had come to be regarded as an entity existing independently of the patient, who was reduced to "a heart", "a pair of lungs", "a gastric ulcer". That he was also an individual subject to hopes and fears, frustrations and achievements, marital conflict, parental domination, employment difficulties, seemed extraneous to the course of his illness and rehabilitation.

Gradually, however, this limited concept was replaced by one more comprehensive which recognized that the separation of the organ from the person and the person from the organ was an artificial dichotomy. The patient was more than "a structural defect in some vital organ".[1] As Hatfield says,

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1. Henry L. Richardson, Patients have Families, (New York, 1945), Intro., p.xiv.

"A patient cannot be divided into parts. He must be looked upon as a whole human being"[1] and, with this in sight, the "profession of medicine progressed from the diseased organ to the total personality of the patient".[2]

The inevitable next step soon followed - the recognition that the patient did not exist in a vacuum but rather as "a unit in a family",[3] and treatment and rehabilitation, as an integral part of the treatment programme, had to reckon with this facet of his life. This broadened concept of illness, treatment and rehabilitation is most relevant, of course, in cases of prolonged and serious illness and in this category tuberculosis, because of its peculiar characteristics, has a rather unique place.

> With tuberculosis the social factors likely to be present are indicated by the very nature of the disease itself; the duration, the uncertainty of cure, the kind and degree of incapacitation (economic, professional, social, and recreational, etc.), the separation from the family group, the public health aspect of infection, the stigma and fear of the disease. Tuberculosis hits at the roots of family life, it undermines economic independence and hope for the future.[4]

"Tuberculosis hits at the roots of family life." Usually it involves a lengthy period of hospitalization with

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1. M. E. Hatfield, Handbook on Tuberculosis, (Provincial Board of Health of British Columbia, 1944), p.49

2. Richardson, op. cit., p. xviii.

3. Hatfield, op. cit., p. 50

4. Ibid, p. 90.

accompanying separation from home and family. For the patient who may subscribe to the superstitions and fallacies which surround tuberculosis, his infection may often represent stigma and consequent loss of status, and these feelings may be accentuated by the segregation imposed by public health laws for the protection of his family and the community. "He is not only himself threatened but is also a threat to his family,[1] and at a time when he most needs their affection and support he has to be removed from their midst. Under such circumstances it is easy to conceive of the whole structure of his life being threatened.

> As a member of the family group he will have to consider how his family will react to his breakdown and what it entails for them in the way of economic hardships and separation..... He may be assailed by doubts about his family; will they stand by him? can he trust them?..... The patient will expect the same quality of help from his family as he has received in previous situations. However, his emotional need requiring greater proof of affection, he may often feel that he is receiving less from them.[2]

The feeling of rejection referred to above may have no basis in fact or, again, it may be quite objective. The family may attach blame to the patient because of his mode of life; if he is the breadwinner they may feel that he has

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1. Alfred O. Ludwig, Extracts from Public Health Reports, Vol.63, No. 27, July 2, 1948, "Emotional Factors in Tuberculosis."

2. Edith G. Seltzer, The Personal Problems of the Patient as a Factor in the Treatment of Tuberculosis. Presented at the Health Section, New York State Conference on Social Work, (New York City, Nov. 18, 1943), p. 3.

let them down by undermining the domestic economy and lowering their standard of living. They may fear infection themselves. On the other hand, they may be over-solicitous for the patient and he, in turn, may enjoy reverting to the role of dependent. Inevitably, the long separation inherent in treatment of the illness will alter the "balance of power" existing in family life. The father's role, for instance, may be assumed by an elder son or the mother may have to turn breadwinner, and these changes in culturally conditioned roles will likely give rise to feelings of loss of status on the patient's return to normal life.

In addition to changes in role and status, the hospitalization of the patient often brings about changes or modifications in the physical structure of the family or the members may even be scattered. This type of change, too, can create tensions and feelings of inadequacy which militate against the patient's fullest return to health and eventual rehabilitation.

This part of the study will concern itself with these two aspects of the patient's illness and hospitalization, namely, their effect on the structure of the family and the changes in status which they create for him. This chapter will deal with the first part and consider such changes and modifications in family structure and the ways and means

devised by the families of the patient group to cope with their several situations. The next chapter will be concerned with the changes in status.

As the nature of the structural change will probably be determined by the role of the patient in the family, the group will be considered in two categories: married patients and single patients. These two groups would seem to represent different types of problems and, certainly, within the single category there would not be the possible complicating factor of care of children. In the married group, if the mother is removed from the home what structural adaptations will be forced upon the family? Will there be older children to care for the home so that the family may remain together as a unit? If there are younger children can help be procured to look after them in their homes or will some form of placement be necessary? When the father is the patient, who becomes the breadwinner and what effect does this have upon structure? The single patient will not be faced with difficulties such as these unless possibly he is the sole support of his family who may have to resort to measures in supporting themselves which will affect structure.

These structural changes will also be considered in relation to time as the hospitalization period will bring one form of adaptation while the post-discharge period may see this reversed and the original structure restored. On the other

hand, further adaptations may become necessary.

Changes in Family Structure of Married Patients During Hospitalization.

Separation is inherent in the treatment of tuberculosis. Consideration has already been given to the meaning of its diagnosis for the patient for, although much of the ignorance and superstition surrounding the illness has been dissipated by educational programmes and a more enlightened public outlook, these still persist to some extent, and they add to the burden of the patient who accepts such fallacies. Then, as a climax, separation from his home and family is thrust upon him for "the nature of the disease makes segregation desirable both to prevent spread of infection and also to provide more adequate rest and specialized treatment."[1] The patient at the point of admission to hospital, however, is unlikely to be receptive to this logical course of action. Rather, he may be overwhelmed by the thought that he is a menace to the health and safety of his family, and torture himself with feelings of self-blame and loss of status. Then, to undermine him still further and, rather paradoxically, this separation from his family comes at a time when he most needs their presence and support. Frances Upham says:

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1. Ludwig, op. cit., p. 183

> The recommendation for sanatorium care has the same meaning as separation and loss in childhood ..... Psychologically, going to a sanatorium means that one is pushed out of the home..... because of personal undesirability.[1]

But the process sometimes does not stop here. Inevitably the patient is separated from his home and family, thus altering its structure, but often the remaining structure has to undergo further modification or it may even disintegrate entirely. The various adaptations which families are forced to accept when the structure undergoes change will mean different things to different patients and may be particularly extensive and traumatic for the married patient. If the mother in the family is ill, the care of home and children may be threatened while, if the father is the patient, great financial strain may be imposed on the family. The father may have to place his children or get outside help to care for them in their own home. They may move in with relatives. He may manage to remain with them or they may be separated. Whatever the disposition it will likely be a source of worry to the mother. Are her children receiving adequate physical care? Are they becoming too much attached to some other person? Will it be possible for them all to be together again when she is discharged? These and many other questions will plague her. When the father is out of the house it would seem more likely

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1. Frances Upham, A Dynamic Approach to Illness, A Social Work Guide. Family Service Association of America, (New York, 1949), p. 112.

that the remaining members could stay together, but what if the mother is forced to work? What happens to her children then? What are the father's feelings and worries about his family group?

The data showed that the twenty-three married patients[1] within the sample group of forty-three saw their family structure modified during their hospitalization in the following ways:

Table XXVI

Distribution of Structural Change in Families of 23 Married Patients during Their Period of Hospitalization

Structural Change in the Family	Total	Male	Female
	23	13	10
No Change	12	9	3
Children Placed Outside Home	3	1	2
Family living with Relatives	6	1	5
Relatives Living with Family	1	1	-
Roomers in Home	1	1	-

As the table shows, 70 percent of the families of male patients retained their original structure and were able to

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1. One of this group was a widower.

remain in their own homes. In the female group, however, this applied to only 30 percent of the cases. In other words, in this sample group the hospitalization of the husband and father had a far less disrupting effect on the structure of the family than did the illness and hospitalization of the mother. Superficially this would seem to be a logical development, the sex of the patient being the decisive factor, as presumably, with the mother still functioning in the home, there would be a far greater likelihood of the family's remaining together as a unit. Examination of the cases did not, however, conclusively support such a contention for, of the nine families of male patients who were enabled to remain in their own homes and retain their pre-hospitalization structure, two were childless couples and the wives continued to support themselves by continuing the employment in which they had already been engaged, and a third was a widower whose children had been living in a foster home since the death of their mother. His illness in no way affected this arrangement and they continued on in the foster home. In the remaining six families there were children, but in over two-thirds of these cases they were working and keeping their homes together by financial contributions. In the other cases the children were too young to work but, with the help of financial assistance, they were able to remain in the home with their mothers. This was, of course,

a desirable situation but imposed terrific strain with, as one patient expressed it, he and his wife living in a "state of perpetual anxiety."

In the families of female patients this retention of structure was complicated by the age level of the children. In the families of male patients, as already observed, a number of children were working and in a position to keep their home together, but the children of female patients, with one exception, were too young to be employed. To remain in their own home, therefore, the father would have required the services of a housekeeper or some other female help. Although there was not the same financial urgency in this group as the illness of the mother in no way affected the earning capacity of the father, nevertheless, it did impose extra financial strains, and the employment of household help over the period of time required for the treatment of tuberculosis was too costly. To solve their difficulties, therefore, five families or 50 percent of the total moved into the homes of relatives. In the one instance, where the daughter in the family was working, she did relinquish her job to care for her father and an eight year old brother.

Separation of Children from Remaining Parent:

In spite of the high incidence of change in the familial structure of female patients, symbolized for the most part by

an exodus from their homes, the actual separation of children from their remaining parent, in the case of both male and female patients, occurred in only four instances, three of which are categorized in the table as "Children Placed Outside Home." The fourth is included in the female section of "Family Living with Relatives" and was a rather unusual case for, at the time of the mother's hospitalization, the child's father had already been in the Grace Dart Hospital for over a year, and she and her mother had been sharing an apartment with her mother's two sisters. When it became necessary for the mother to enter hospital the child, who was six years old, went to live with her paternal grandmother as her aunts, who were working, were unable to look after her. At the time of her mother's discharge her father was still in hospital. Although the mother's hospitalization did mean that the child was deprived of the care of both parents she was, nevertheless, not in unfamiliar surroundings nor was she with strangers. This, however, was the case with the other three child placements. In one instance the two children were placed in an orphanage when the mother went to hospital; in another the children were sent to a foster home, again when the mother was the patient; and in the third, where the father was ill, the child, only seven months old, was sent to the United States to be cared for by his maternal grandparents. The following were the circumstances:

> Case 8. Mr. R., a Canadian by birth, had spent considerable time in the United States and married an American wife. He had planned to become an American citizen but during their wedding trip to Canada an x-ray revealed some trouble with his lungs and he was refused re-entry into the United States. Two years later, when their son was seven months old, Mr. R. had to be hospitalized, to the great distress of his wife who was forced to send the baby to relatives in the United States so that she might return to work. Both parents were greatly concerned about this separation from their young and only child, although the father felt that, worrying as it was, this arrangement was preferable to placement in a foster home which he regarded as a "terrible experience."

This was the only instance in which the illness of the father necessitated placement of the child away from his home and mother. All three placements, however, were of great concern to one or both parents. The circumstances of the orphanage placement and the mother's reaction to it were as follows:

> Case 11. When Mrs. J. became ill the care of her two boys caused her great concern and anxiety as neither she nor her husband had relatives in Canada -- they had come from Ireland. The decision to place them in an orphanage was small consolation to her as she considered this a measure to be adopted only when both parents were dead. The arrangement was probably doubly hard for her as the interview suggested that she was experiencing a great deail of guilt around her illness in that she had persisted in working against her husband's wishes and when she fell ill he immediately attributed it to the extra burden she had carried.

It is interesting to speculate on this particular placement as, on the surface at least, it would have seemed possible to have them remain in their home with their father. The family was less hard pressed financially than many of the others,

and the husband did not relinquish their apartment throughout his wife's illness. He himself lived there, although he took his meals outside, and to have kept the boys with him would not have seemed unreasonable. Another father had kept his son with him although he was less favourably situated than this particular family. Relationships in his home, however, were far from harmonious and the separation of the sons from their father may have been indicative of the lack of unity and integration in other areas.

The foster home placement of her children was also very disturbing for another mother who had undergone a similar experience before her illness when her defective child had had to be placed in the same way. This case will be discussed at greater length in the next chapter.[1]

Family Living with Relatives:

This group, with one exception, was composed of the families of female patients, consisting for the most part of quite young children. In the exceptional case the wife of the male patient was herself in poor health and unable to cope with employment so that she and their two year old son moved into the home of her husband's mother and step-father. This proved to be a most unhappy arrangement -- from the husband's point of view, at any rate -- and is discussed more fully in the next chapter.[2] The remaining families of female patients were able, for the most part, to be together as a unit. In

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1. Infra, pp.228 and 236

2. Infra, pp.221 and 236

one instance, however, the family was too big for such an arrangement and had to be divided between the patient's sister and two of her sisters-in-law. Their father, however, kept in constant touch with all six children by regular visits. In another family the father, his two year old son and four months old daughter shared the home of his wife's mother but her solicitude was so overwhelming that in order to have greater independence, he moved with the baby to the home of his own mother, leaving his small son with his maternal grandmother. In order to have most of his time during the day with his children, this father found another job which gave him this opportunity.

Relatives Living with Family:

Only one family fell within this category, that of a male patient, and here his wife's mother and sister moved into his home to be with her and their two young sons. It seemed an amicable arrangement and continued after the husband's discharge. Also, the sister's financial contributions helped with the family budget.

Changes in Family Structure of Single Patients During Hospitalization

As already observed, the hospitalization of the single patient would, in the normal course of events, probably have few repercussions on family structure. His illness might be expected to be a more personal experience. For instance, if

he is a younger person he may just have begun to separate himself from his family and to acquire his own independent identity. He may have been on the road to financial independence, and under such circumstances his illness would spell interruption and possible regression of his development and independence. If he were without family or separate from them his illness would in no way affect the familial structure. In such a situation it would be an even more strictly personal experience.

Examination of the data showed that for the twenty[1] single patients within the sample group of forty-three in only one instance did the patient's illness and hospitalization affect the family structure. In six cases the patient's family was either dead or he was living independently of them. The following table shows this group as opposed to that in which the patient was living at home with his family:

Table XXVII

Family Grouping of 20 Single Patients Prior to Their Hospitalization

Family Grouping of Single Patients	Total	Male	Female
	20	14	6
Living with Family	14	10	4
Living Independently of Family	6	4	2

1. Included in this group are three male patients, two of whom were legally separated from their wives and the other divorced.

Included in the group of six were the two patients already referred to who were separated from their wives. They had set up their own establishments and were carrying on independently of them. With one exception the parents of all six patients were dead although there were near relatives -- sisters or brothers or, in one instance, two nieces -- to give the patients moral support. Because of their independence, however, their illness, in so far as family structure was concerned, affected no one.

In the remaining group of fourteen patients who were living in their own homes there were only two instances in which their parents were not living but in each case the patient had found a father or mother substitute. The parents of one, a female patient, had died when she was quite young but her brother who was twelve years older had assumed the parental role as well as financial responsibility for his sister's illness. The other, a male patient, lived in the home of his sister and brother-in-law and was treated almost as their son. Included in this group, too, is the divorced patient who returned to his father's home following his divorce. The one case in which the patient's illness precipitated change in family structure is described below:

> Case 27. Mr. J., a young man of 26, was the sole support of his mother. His father had died twenty years before and as soon as Mr. J. had been old enough to work he had assumed

> responsibility for his mother. They had managed to get a home together with modern conveniences but when he became ill and was hospitalized she was left alone. To ease this situation she had taken a young couple into the home for company.

Not only were changes in structure negligible for this group of single patients but also, unlike the married group, it experienced little financial urgency, except in two or three cases where the family was counting on their contributions towards the family upkeep.

Post-Hospital Structure for the Patient Group

The post-hospital period saw many of the changes in structure precipitated by the illness and hospitalization of the patient either eliminated or modified. In some instances the original structure was restored, and in others further modifications were introduced. The bulk of the changes which had occurred in the female group and those in which the total family was disbanded and the members stayed with relatives were reversed with the restoration of all five patients to their families. The male group, however, which had undergone such slight change saw most of these changes continue after discharge and new ones take shape. The following table indicates the post-hospital structure for both the married and single group:

Table XXVIII

Changes in Family Structure for the Group of 43 Patients After Their Hospitalization

Changes in Family Structure After Hospitalization of Patients	Total	Married			Single		
		Total	Male	Female	Total	Male	Female
	43	23	13	10	20	14	6
No change	27	14	8	6	13	9	4
Change in Structure	16	9	5	4	7	5	2

In other words, in 27 cases or almost 63 percent, the post-hospital group had either undergone no change in structure or the original structure had been restored, while changes had occurred in 37 percent of the group. Again, the incidence of change was higher for the married group although appreciably less so than during the period of hospitalization, it being represented by 39 percent for the married group and 35 percent for the single group.

Changes in Family Structure of Single Patients After Their Hospitalization:

The one change which was undergone by this group during the hospitalization period and directly attributable to the patient's illness, continued after his discharge, while several others had occurred. None of them, however, had been precipitated by the patients' illness although in two instances they did

affect his status in the home. In each case these changes were brought about by the death of the father which occurred during the patients' hospitalization. In one instance it meant increased status for the son who now became head of the home and the breadwinner, whilst for the other it represented considerable anxiety as he was still unable to work and was now forced to depend on his sister. Family ties were strong and there was no evidence to show that she resented this, but the patient, himself, seemed to feel it more difficult to accept this role in relationship to his sister. Another patient moved away from his home to another city, where he had found employment, but again the interview did not suggest that this change was in any way relevant to his illness.

A drastic change occurred for one female patient with the death of both her parents while she was in hospital, but as this will be dealt with more fully in the next chapter[1] in relation to her status it will not be discussed here. This was the only change for the group of single female patients.

Changes in Family Structure of Married Patients After Their Hospitalization:

As already observed, most of the changes which had occurred in the families of the married, male patient group continued. The young child sent to the United States to his maternal grandparents had not returned home; the patient, whose

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1. Infra, p.231

wife and child had gone to live with his mother and step-father, joined them there as he was still unable to maintain a home for them, and the mother-in-law and sister-in-law of a third patient continued to make their home with him and his wife. When the patient was discharged whose wife had taken roomers into their home, they no longer kept them on but, at the time of the interview, their first child was only three weeks old. They had not been allowed to take him home, however, and he was then being cared for by the E.C.G. Clinic. This was also the case for the female patient whose two children had been placed in a foster-home. Since discharge she had given birth to another child but it had been removed from her immediately, and it was also placed in the E.C.G. Clinic. This was of great concern to her and, as already stated, is being discussed at greater length in the next chapter. Another female patient had given birth to twin daughters during her hospitalization and they, too, had been placed at the above clinic and later in a foster home. They had returned home, however, after their mother's discharge.

One very happy change occurred with the re-marriage of the widower who was then in a position to have his children back home with him. At the time of the interview relationships within this whole family were most happy and positive. The husband of one of the female patients who had been married only

a short time before her hospitalization had arranged for his parents to come from Europe shortly before his wife's discharge. He had thought that they would be company for her during his working hours and also that his mother would be able to help in the care of the house. Yet another type of structural change, arising directly out of the patient's illness, is described below:

> Case 13. Mrs. C., a married woman of 44 years, had had several hospitalizations for tuberculosis. During her stay at the Grace Dart Hospital her 22 year old daughter had give up her job to care for her father and 8 year old brother. Later, after her mother's discharge, the daughter married, but, in order to continue caring for her mother, she and her husband moved in with her family. At the time of the interview the family, which now included the daughter's new baby, were still living together so that Mrs. C. might still have the advantage of her daughter's attention.

Minor changes took place within this group, such as the marriage of brothers and sisters, but they in no way affected the patients concerned nor were they precipitated by their illness.

With changes in structure having been discussed in this chapter, the succeeding one will, as already indicated, consider another type of change, namely, that of status, experienced by a number of patients as a result of their illness.

CHAPTER IX

CHANGES IN EMOTIONAL PATTERNS WITHIN THE FAMILY

We have seen that tuberculosis because of its usually long-term treatment can drastically alter family structure. It takes a member of the family out of his home at least for months and often imposes changes and modifications on the group remaining at home. These changes were usually precipitated by financial pressure and the need for care and supervision of the young children involved. Sometimes the return of the patient reversed these changes although in other instances they were maintained. Such changes in structure, however, were often not the only ones brought about by the illness, for the patient frequently returned home to be confronted with a change in status. Carol Cooley says:

> In every family, each member has a certain niche or place for himself. When illness comes, there is a shifting which may be unconscious but is very real.[1]

For instance, a father may return from the hospital to find that his son or some other family member has taken over the role of breadwinner and his place of authority, and is now considered the head of the family. If the mother has been the patient it may well be that some one else has usurped her place in their affections and that they have grown away

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1. Carol H. Cooley, Social Aspects of Illness (Philadelphia and London, 1951), p. 59.

from her or, if there are quite young children, that they have even forgotten her. For many wives the all-pervading dread will be that of their husbands' losing interest in them and seeking companionship and love elsewhere. For the single patient there will be other fears and difficulties. A move towards independence may be halted and dependency again enforced or his withdrawal from the family financial scene may impose added responsibilities on the siblings in the family.

As already indicated, this chapter will consider any such changes in status which occurred as a result of the patient's illness and separation from his home and family and also their effect on the emotional patterns of the married group. When the patient's role has been assumed by some other family member during his illness he may find it difficult to slip back into it or his health may not permit that he do so. This may apply to the breadwinner in the family and also to the mother whose children have been cared for by another woman. What are their feelings on returning home and coming face to face with such changes? Tensions may have been created, both during the course of the illness and afterwards, and the patient may come to feel that he is of little account. Will this loss of status impair the marriage itself or will it remain fundamentally sound in spite of tensions and conflicts? What has happened for the single patient? Will he be able to assume

an independent role or will be forced to dependency within the family? The emotional repercussions generated will have a direct bearing on his recovery and rehabilitation. Carol Cooley describes it thus:

> It is not necessary to reiterate how much the family's feelings and actions affect the response of any of its members to a situation. In the period of readjustment after illness, they can either make it possible for the patient to regain the feeling that his place in the world is secure or they can keep him from ever attaining it.[1]

The group will again be considered in the two categories of married and single patients although the time element within this chapter will be confined to the post-hospital period for, although any changes in status would be operating during the period of hospitalization, they impinged directly on the patient only after his discharge and return home.

Examination of the data revealed the following situation with respect to changes in status of the patient group:

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1. Ibid, p. 51.

Table XXIX

Changes in Status of 43 Tuberculous Patients Discharged from the Grace Dart Hospital

Patients' Status in the Family	Total	Married Patients			Single Patients		
		Total	Male	Female	Total	Male	Female
	43	23	13	10	20	14	6
Status Unchanged	20	8	4	4	12	8	4
Status Increased	5	4	2	2	1	1	-
Status Diminished	18	11	7	4	7	5	2

As the table demonstrates, approximately one-half of the married patients found that their illness had created loss of status for them in some area or other of their life. In the single group this was true for approximately one-third of the patients. In this group, too, there was little difference between male and female patients whereas, in the married group, the male patients were more adversely affected than the female. Five patients of the total group emerged with increased status, and in the third category of "Status Unchanged" there were twenty patients, almost three-quarters of whom were single.

Changes in Status for Married Group

Frances Upham says that "separation alters all personal relationships but the loss is greater and is usually more keenly felt if the patient is married."[1] Certainly, for most of the

1. Upham, op.cit., p. 112

married patients unfavourable changes in status occurred in areas related to their married state and these changes were accompanied in most instances by a wide range of emotional reactions including feelings of rejection, resentment, dependency and friction. These did not always imply a poor marital relationship, but often the long period of hospitalization had resulted in frayed nerves for the married partner remaining in the home and subjected the relationship to tensions of one kind or another. In families with young children where the husband had been the patient there had in some cases been deprivation for the children because of the "extras" required by the patient and other expenses related to his illness. Even when he had again assumed his role of breadwinner the financial strain often continued. Household articles, such as clothes and bed-linen, needed replacing, repairs would be in order around the home, and a long "catching-up" period would set in. This type of situation did nothing to enhance status or give the patient a feeling of adequacy even when the marital partner was understanding and tolerant. When resentment flared, however, tension and strife developed which added to the strain of day to day living.

Frequently differences arose around the patient's attitude to his illness and handicap and that of his family. Where financial assistance had had to be sought bitter feelings carried

over from the experience, and these gave the patient a sense of failure in that he had precipitated such a situation.

Illustrative of many of such repercussions was the case of Mr. R.

> Case 2. Mr. and Mrs. R., a young couple in their thirties with three children, have had a good marriage but since Mr. R.'s discharge from hospital the relationship has been subjected to pressures and tensions arising out of his illness. Mrs. R. had found the children extremely hard to discipline during her husband's hospitalization and also complained that they had had to be denied things to meet the extra expense of the illness. She did not mind for herself but was most resentful because of their children. She felt, too, that her husband was too absorbed in his symptoms, and fearful of relapse while he, on the other hand, claimed that she was unrealistic. The interview suggested that he had lost status in the family although their relationship was still basically sound. Prior to his illness Mr. R., too, had been in the habit of helping his wife around the house but he now found this too strenuous in addition to his normal work. His claim that it took his presence back in the home to enforce discipline for the children seemed to be in the nature of compensation for his other inadequacies.

Another patient evinced no feeling of inadequacy or loss of status because of his wife's supporting him but was most bitter and resentful over the placement of their first and only child. As a parent he felt he was a failure, commenting, "It's just as if I didn't have a baby. Why, he doesn't even know his own parents!" There were several instances of this "alienation of affection" in the case of parents of both sexes who expressed keen regret especially if their children had been

quite young, that they had missed out on a phase of their own development which could never be relived. One father said that his hardest job on coming out of hospital had been his efforts in rehabilitating himself with his young son. This particular case points up loss of status all along the line -- with his wife, with his child and in the economic area as head of the household.

> Case 15. Mr. A. and his wife are a young couple just past thirty with one child. When Mr. A. went to hospital his wife and son were compelled to move to the home of his mother and step-father because of financial reasons. Prior to hospitalization he said that they had been happy but after his discharge the marriage seemed to disintegrate. Mr. A. found that his wife no longer gave him the attention he craved and that she was less affectionate. His son had moved away from him and grew closed to his grandfather who was spoiling the boy and yet the father was afraid to intervene in case his relationship with his son should deteriorate still further. As he had not found employment they were forced to remain in his mother's home where his role was a subordinate one. He complained, too, that his wife had become more independent during his illness and was now loath to revert to her former status in relationship to him.

It is difficult to assess the objectivity of Mr. A's claim that his wife was less attentive and affectionate than formerly, but that he would require such support and attention is borne out by current thinking. Frances Upham says in speaking of the impact of illness on the relationship of married patients;

> ".....The emotional balance of the marriage is changed. The patient becomes more dependent upon the well partner for support and affection. The helplessness

> and the threat to sexuality inherent in the illness make the patient especially vulnerable to the fear of losing the partner's love."[1]

Edith Seltzer says further:

> "The patient will expect the same quality of help from his family as he has received in previous situations. However, his emotional need requiring greater proof of affection, he may often feel that he is receiving less from them."[2]

Mr. A. who experienced loss of status on several points, also considered that his marriage had deteriorated. He had also given evidence of feelings of great rejection and inadequacy and of the need for special consideration and affection.

There were other instances where patients had experienced loss of status where their children were concerned. One mother whose two boys had been placed in an orphanage during her hospitalization complained that the older one was no longer close to her and was indifferent to her welfare in that he neglected to do chores around the house of which he was capable. This same mother had feelings of inferiority about her illness, and also because she had had an unfortunate experience while in hospital. One day when her husband had taken her driving she had asked to stop and talk to her children who were playing in the orphanage garden but he had refused, saying that she might infect them. Since that time she had feared to come too close to them. Edith Seltzer describes this reaction as follows:

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1. Ibid, op. cit., p. 112
2. Seltzer, op. cit., p. 3.

> "By the very nature of the illness, the tuberculosis patient is doomed to a certain amount of rejection by his family and friends.....(A) source of anxiety which may condition the family's attitude toward the patient comes from the new and specific threat in their lives.....They now find themselves in a state of constant fear of contacting a dread disease. They wonder who will get it next."[1]

Another mother, whose twins had been born during her hospitalization, felt that they belonged to the foster mother rather than to her. "I don't feel that they're my children", she said. "I've missed caring for them when they were babies." In yet another instance a mother was terribly upset by her child's relationship with her sister who cared for the child during the mother's illness. In any crisis which arose and for the meeting of little, every day needs the child turned to the aunt for fulfilment. Carol Cooley has described this type of situation very clearly:

> "When the patient is a mother, the problem of care of the home and children must be met. Even if she is well adjusted, the fear hangs over her that her children will become attached to someone else and that young ones will forget her."[2]

For the older, married, male patient the biggest threat to status seemed to lie in the area where our culture expects him to be dominant, that is, in the role of breadwinner and head of the family. Where the patient fell into this category most families suffered little deprivation or financial stress

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1. Ibid, p.3
2. Cooley, op.cit., p.231

as older children were in a position to assume financial responsibility for the family. In this category, too, the relationship between husband and wife was seldom affected but the patient returned home to find himself in a new relationship to other members of his family. His children might still hold him dear, but he was no longer consulted about family affairs and decisions as before his illness.

> "Occasionally, a member of the family other than the patient finds that his position in the group now commands more respect with the shifting of status. For instance, an eldest son may assume the responsibility of support when the father becomes ill, and he may find that he is considered the head of the family. In some households this could lead to serious feelings of rivalry between father and son."[1]

A situation almost identical with this did arise for one patient in which his daughter assumed the dominant role in the family. He was also heavily indebted to her financially, and their relationship had seriously deteriorated because of her resentment at shouldering extra responsibilities. Her attitude was very distressing for her father who felt that his prestige had suffered a serious blow. He was also bitterly hurt at her grudging acceptance of responsibility. In another case the outcome was more fortunate. The sons had taken over the father's role but still regarded him with affection and were solicitous for his welfare. Nevertheless, although he

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1. Ibid, p. 59

was appreciative of the development he looked longingly to the period when he had been the head of his household.

The four married, female patients whose status within their families had decreased following their illness were in a position analagous to that of the married, male patients. That is to say, the areas in which they suffered this loss were those in which our culture expects them to be dominant, namely, in the role of wife, mother and house-wife. The average age within this group was lower than that applying in the married, male group, being 33 years for the female patient and 42 years for the male group. The children of the former group, too, were considerably younger than those of the male patient and consequently more emotionally dependent on their mothers. For them it was a disturbing experience to have their children form close ties and attachments to other figures during their illness. This was a threat to their adequacy as a mother, but even more undermining for status and self-esteem was the loss of their husband's love and loyalty, a development which struck at the very roots of the marriage.

In only one case did the patient admit that her husband was associating with another woman, but for the others it was something of a nameless fear which found expression in the words of one patient who was probably unaware of their implication. She had been describing the support and affection of her family

throughout her illness and commented that, as for her husband, he had been "absolutely wonderful and never strayed." Another's reaction was, "My husband was wonderful when I was away and never forgot to see me and this is everything when you have to be shut in."

Significant, too, was the emphasis placed by this group of patients on the regularity of their husbands' visits while they were in hospital, and this form of interest and consideration on the part of the husband did seem an augury of the future status of the wife in the home and the tone of the marriage. One patient was rather proud of the fact that on several occasions her husband had managed to "sneak in" to see her in addition to the regular visiting periods. On the other hand, half of this group whose marital status had declined during hospitalization spoke rather sadly of the nature of their husbands' visits or lack of visits. One woman said that her husband visited only to urge her to get permission to return home periodically so that she might exercise some care of the home, and he was completely indifferent to her state of health; another man visited most reluctantly as he feared infection.

Such comments, too, as "I never had any decent pyjamas" and "Everybody else on the ward had food brought them but me" were indicative of the diminished status with which these women were faced when they returned home. The husband's participation in household tasks following his wife's discharge seemed also

to be a criterion of her status in the home and the quality of the marital relationship. Representative of many of these reactions was the case of Mrs. J.:

> Case 1. Mrs. J., age 34, had been married for thirteen years and there were three children of the marriage, one of whom, a mental defective, had been placed in a foster home prior to her illness. Care of this child over a period of time had imposed considerable strain on the marriage which, during the wife's hospitalization, quickly deteriorated. Her husband appeared quite disinterested in her health in her health and rehabilitation and about a year after her discharge her fourth child was born. Shortly after the beginning of her pregnancy the discovery that her husband had formed a relationship with another woman caused her great anguish and at the time of the interview she was under considerable mental strain and her general health was rather precarious. The new baby she had seen only for five minutes before it had been placed in the D.C.G. Clinic and the other children were still in foster homes because of the unsuitability of the home. The husband laid the responsibility for finding better quarters on her shoulders as, during her time in hospital, he had expected her to come home periodically to attend to his needs and keep the house together. The calibre of this marriage had been poor before illness but it later deteriorated still more as did the wife's status, both as a mother and a wife.

In the small percentage of patients whose status had been heightened by illness, family ties had originally been quite strong, and illness and separation from the family circle had merely served to enhance their position within the group. One family, for instance, was described as being "all for one and one for all" and the patient, the father in this instance, declared that the return to his family and their renewed appreciation and enjoyment of each other had almost made the

illness worthwhile. This man, contrary to the findings already stated for his group, was an older man with grown children. Another patient, a young married woman, was made to feel most secure and cherished by the attitude and attentions of her husband but, again, the ties here had been well-knit.

Changes in Status for Single Group

As already noted, just a little over a third of the group of single, male patients suffered loss of status as a result of their illness, and for the female group just one third of the number was so affected. A factor contributing to these proportions could, for the male group, be the number of patients on their own without family ties or living independently of their families who, after discharge, found it possible to slip back into their former niche with little or no change in their routine or standing. The five patients who saw their status suffer were older men within this group, and they felt their loss most keenly in the financial area. Mr. G. is typical of this section of the single, male group.

> Case 3. Mr. G., a man of 34, was a member of a family between whose members close ties existed. At the time of his hospitalization he made his home with his father and a younger sister, and helped towards the upkeep of the family. During Mr. G's hospitalization his father died, and upon discharge the patient returned home to his sister. At the time of the interview his doctor had not permitted him to return to work, and he was feeling his depend-

> ency keenly although his sister, he claimed, was understanding and helpful. Nevertheless, his inability to contribute financially towards the home made him feel that he had lost status. The interview suggested that he might have felt differently had his father been living.

A striking feature of a section of this group of single, male patients was to be found in the nature of the mother-son relationship. For over a third of this group the patients' age range extended from 18 to 26 and, in each case, the mother was extremely over-protective of her son. Had there been rebellion against this pattern and resentment on the part of the patient he might have considered his status in the home to have been impaired. One patient did comment that his mother wished to treat him like a baby, but there was no evidence to show that this was frustrating or irksome for him. The other members of this younger section within the single, male group faced similar treatment, but they neither verbalized nor hinted at dissatisfaction. Typical of such situations were the comments, "My mother kept me out of work for a year, and she sees that I eat well and get to bed early"; "My mother always sees that I have enough clothes on;" and, "My mother said I didn't have to work as long as I got better." Even in the case of the patient whose family consisted of his mother and himself, and who was unquestionably the dominant figure in their relationship, the mother became quite vigilant and protective of his health, seeing that he did not do too much.

In the single, female group, consisting of six patients, two suffered loss of status. For one patient this occurred, as in the single, male group, within the financial area. For the other patient, her life was drastically altered.

> Case 37. Miss D., age 23, had been a patient at the sanatorium for a year and a half. A few months after her admission her mother died suddenly, and approximately the same period before her discharge saw her father's death also. As her only brother and the only other remaining member of the family had also married during her hospitalization, the patient's home was completely broken. To complicate matters still further, her health did not permit an immediate return to work, and, as a consequence, she was forced to seek financial help from a welfare agency. True, she did spend most of her days at her aunt's home nearby, but she missed her parents and the security of her own home. Her brother she described as a "very indifferent person" and, as he lived outside the city, there was little communication between them. Her aunt, who had been unable to have her with her completely because of lack of room, was "fairly good" but Miss D. sometimes felt that she was "imposing" on her, and that her aunt was "over critical". She said, "It's not like home". The patient expressed bitterness over her changed financial status, and it was obvious that, in spite of her protestations, the total upheaval within her way of life had rendered her status vulnerable and, in many ways, inferior to that which she had enjoyed prior to her illness.

The pattern of dependency noted for the single, male group was also in evidence for the single female patients although, in this group, it was less pronounced and not as definitely focused. One patient, for instance, kept returning home between jobs. The interviewer commented that "although the whole family group seems somewhat isolated and unable to communicate thoughts or feelings to each other yet the patient seems very much dependent on her family." The diagnosis was further expanded

by the following observation: "Interviewer had the feeling that each family member was rather "a being unto himself' and yet it also seemed that the patient's inability to hold down a job and her constant returns to her family were worthy of consideration."

In only one instance within this total single group did the patient find that his status had increased. The father of one male patient died during his hospitalization, and upon his return to work, he became head of the home and the breadwinner for the family. This brought him increased prestige and status. At the same time, too, his illness made him closed to his family in that his limitations compelled him to use his leisure in greater rest and relaxation than formerly, and in this way he really became an integral part of the family group.

Present Emotional Patterns of Married Group

The preceding discussion has shown that the long separation of the patient from his family and the economic pressures and deprivations inherent in the treatment of tuberculosis have a direct effect on the status of the patient within his family group and that in this area the incidence of change was higher for married patients than for single. The question also arises as to the effect of tuberculosis on the marriage itself. In some cases it was inevitable that

that the status of the patient would undergo change, eg., the father in the home whose role of breadwinner had been assumed by an older child or children or the parent who returned from hospital to find himself supplanted in his child's affections, but such changes need not necessarily alter the fundamental quality of the marriage itself. Frictions and tension might arise which would detract from the harmony of the home and certainly would not be in the best interests of the patient's health and yet there could remain a deep,underlying affection of the marital partners for each other. The following table demonstrates the changes which occurred in the group of twenty-three married patients as a result of their illness:

Table XXX

Changes in Marital Relationship of Twenty-Three Married tuberculous Patients.

	Total	Male	Female
Marital Relationships	23	13	10
Relationship Unchanged	16	11	5
Relationship Strengthened	5	1	4
Relationship Impaired	2	1	1

The table shows that eleven of the thirteen male, married patients and five of the ten female, married patients saw no basic change in their marriage as a result of their illness. This does not mean that in every case the marriage was a happy or successful one, but merely that for this group of patients their marriage had neither improved nor deteriorated. Three of the marriages had been indifferent ones before the patient's illness and in neither case did their calibre improve. Four female patients and one male patient fell within the "relationship strengthened" category, and one of each sex emerged with their marital relationship impaired.

The interviews showed that the strengthening of the marital bond for the four female patients had been achieved in two instances by an increased maturity on the part of the wife as a result of her illness. A third patient felt that her husband's sacrifice in engaging in work that was distasteful to him in order to have more time to spend with their children had "endeared him to me more and more"; and, in the fourth instance, the wife's illness and hospitalization had merely served to draw herself and her husband together in mutually increasing appreciation and affection. The marriage of one of the patients, whose illness had helped her towards greater maturity, had not been too satisfying prior to her illness, and it is described below:

Case 32. Mrs. L., age 31, had married her husband, a Canadian, in Scotland during the war, and four years later she had come to Canada with their young son to join him. He had returned home the previous year. The patient had been unhappy and lonely for her home and family in Scotland, and, as a consequence, she had made her husband "miserable". She felt that her mother-in-law had not accepted her, and, as she and her husband had been forced to live with her, the situation had been strained and unhappy. Mrs. L. described her feelings in this way: "I was so home-sick I guess I was unconscious half the time." Sometime after her mother-in-law's death Mrs. L. was hospitalized, and this experience, she said, taught her that "when you're in hospital you find you're home-sick for only one place -- the place you've been living, and not Scotland." She could even speak tolerantly of her mother-in-law by commenting that she probably had not been well when she had been so disagreeable. There was a new harmony in her relationship with her husband, and, together with their young son, they were living happily as a family.

The one male patient whose marriage, after his illness, fell within the "relationship strengthened" category was a man of 52. His three children were adult and working so that there had been no financial worries or deprivation during his illness. They had accepted this responsibility cheerfully, and the patient returned home to feel that his marriage had acquired increased worth. Indeed, family relationships in general became even closer than they had before the patient's illness and separation from home. The interviewer observed that the great and obvious affection between members of the family was striking and could be described as "one for all, and all for one."

In the "relationship impaired" category there was one

patient of each sex, and each has been considered before when loss of status was being discussed. Mr. A.[1] claimed that before his illness and his wife's and child's removal to the home of his mother and step-father his marriage had been happy. Upon discharge, however, he found that his wife had acquired a new independence which she did not wish to relinquish, and she no longer had the same affection for him. He was unable, too, to maintain a home of their own for his wife and son, and he felt that, in addition to the loss of status which he had suffered, his marriage itself had deteriorated as a result of his illness.

Mrs. J.,[2] in addition to seeing her separation from her children continue after her discharge, had had a further separation forced upon her when her baby, born less than a year after her return home, was placed in the E.C.G. Clinic. This was a great source of worry to her and gave her a sense of failure as a mother. Then she discovered that her husband was associating with another woman, and it seemed to her that her very marriage was disintegrating. This marriage, it should be explained, had not been on a very sound basis even before the patient became ill.

In general, then, the marital relationship of married, female patients had been modified for exactly half their number whereas, in the married, male group, only approximately

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1. Supra, p. 222

2. Supra, p. 228

one sixth had been thus affected. For the female group, however, four of the five changes had been in the direction of a happier and more mature married life, so that illness and hospitalization had helped these patients towards a more positive relationship.

Findings

The premise that tuberculosis, in addition to separating the patient from his family, often further modified the remaining familial structure, has been borne out by an examination of the forty-three cases considered in this study. Such structural changes, however, as were occasioned directly by the illness of the patient, were confined almost entirely to the married group and, within this category, the incidence of change was much higher for the families of female patients. Where there were children in the families of the married group, the sex of the parent would seem to be the determining factor in this situation, but the data did not bear this out conclusively as the children of female patients were much younger than those of the male patients. Many of the children of the latter group had been working, and they helped to keep the home together in the father's absence. Had they, too, been younger it might have been impossible for the mothers to keep them together and preserve the family structure intact.

In spite of this high incidence of change in families of female patients which, in most cases took the form of the father and the children moving into the home of relatives, it was noted that in only two instances were the fathers separated from their children. In each of these two families the relationships had not been at all sound so that placement of the children could almost represent dissolution of the marriage.

In the group of twenty single patients the family structure was altered in only one instance, that is, as a direct result of the patient's illness. Of this group approximately one-third were either without families or else living independently of them, and the hospitalization of the remainder in no way affected the structure of the family.

In two cases the illness of the parent prevented the entry into the home of the new-born child, and the T.C.G. Clinic cared for it temporarily. This would seem to be one of the more dramatic changes in structure brought about by tuberculosis, namely, the separation of the mother from her new-born child.

It was also assumed that, in addition to changes in structure, tuberculosis created changes in status for the patients concerned. In the case of married patients it seemed probable that in some instances the marriage itself

might undergo modification in view of the prolonged separation of the marital partners.

Analysis of the data showed that twelve of the twenty-seven male patients, or approximately 45 percent, suffered loss of status. For the female group six of the total number of sixteen, or approximately thirty-seven percent were similarly affected.

The incidence of change was higher in the married group than in the unmarried. Seven of the thirteen married, male patients, or over fifty percent, experienced loss of status, and four of the ten married, female patients, or forty percent, suffered in the same way. In the single group only five of the fourteen male patients, or approximately one-third, saw their status adversely affected. For the single, female patients this was the case for two out of six or exactly one-third of the number. Only a small number emerged with increased status, namely, four of the married group and one of the single group.

In the married group the changes were appropriate to to the patient's familial role. The father, for instance, experienced loss of status as head of the family and breadwinner, and this was particularly true for the older patient whose earning children in some instances had taken over the financial upkeep of the home. The mother in the family was more affected in relationship to her children and also with respect to her

husband's affections. In only one instance did the wife find that her husband had been consorting with another woman during her hospitalization, but many of the patients expressed a fear of this development.

In the single group loss of status was experienced for the male patient as a result of financial dependency. In this group a striking feature was the dependence of its younger members upon their families. The younger male patients were attached to their mothers in a quite dependent fashion.

For the married patients illness made little difference to the quality of their marriage, at least in the male group where, for eleven of the total number of thirteen, the relationship was unchanged. Four of the ten married, female patients found that their illness and hospitalization had improved the calibre of their marriage.

The loss of status suffered by patients in many cases created tensions and in some instances they invaded the marital relationship itself although they did not necessarily undermine the marriage.

In considering these two types of changes which the illness of this group of patients created for them one significant factor emerged, namely, that some of the less favourable aspects of the changes might have been averted, or at least modified, if there had been some referral to a Social Service Department. Especially was this true for some of the changes

in status which occurred. Changes in structure might have been inevitable, but many of the painful repercussions experienced by patients as a result of loss of status could have been avoided with the help of interpretation of the meaning of the illness to both the patient and the family. The education of the family of the tuberculous patient is of the greatest importance and cannot be accomplished in the span of one or two brief interviews. A social service worker, however, as an integral part of the hospital staff could help the family and the patient with many of the misconceptions and anxieties which are almost inevitable in relation to a disease with the characteristics of tuberculosis. Any such preparation of both the family and the patient for his eventual discharge would probably be one of the biggest steps towards his fullest rehabilitation.

CHAPTER X

GENERAL CONCLUSIONS AND RECOMMENDATIONS

This study was originally undertaken by five student social workers with the purpose of examining the various factors that influence the rehabilitation process of patients who have been hospitalized for tuberculosis. It was based on an analysis of 43 tuberculous patients who were discharged from the Grace Dart Hospital over an 18 month period. Orientation to the subject was done by the group. Preparation of an interview schedule and preliminary analysis was also a group effort. The interviewing was carried out by each individual student assuming one-fifth of the responsibility and the collected data were made available to each of the five students. Various aspects of the rehabilitation process were considered and four major areas were covered, namely the psychological, economic, vocational and family adaptive processes. It is unfortunate that it has not been possible to include within the scope of this thesis the study of the adjustments of the 43 patients within the vocational area as was originally planned. It has already been indicated in chapter 1 that this study will be completed as a separate project.[1] In order to facilitate the study of the psychological adjustment to the illness, the sample cases were divided

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1. Supra, p. 6.

The time limit for the completion of this single study expired in August, 1955. The analysis of the vocational aspects of rehabilitation is therefore not available.

into married and single patients and each of these marital status groups was analyzed by one student, since the material for the whole sample was too broad for one person to cover alone.

While the initial planning was carried out by the research investigators working together as a group, and the individual interviews were pooled for use by all the students, no attempt was made to integrate the various parts of the study. The segmentation of material proved to be a limitation in that it created gaps and overlapping in the presentation of the material. A more significant study might have been possible had there been some attempt at integration. The study had a further limitation in that the breadth of material to be covered in one interview necessitated a somewhat superficial coverage of some aspects of the topics studied. Nor was it possible to interview relatives separately, so that in a number of cases one or more members of the family were seen during the process of the interview with the patient. This procedure may have inhibited both the patient and the relatives who were present, from expressing their feelings freely, particularly in the area of family relationships. On the other hand, in some instances, the information given by members of the family proved to be of value in giving a broader picture of the situation.

While the study attempts to reveal the various problems encountered by the tuberculous patient and his family, no particular effort was made to relate the patient's personality and past experiences to the etiology of the illness itself, or to the specific effects which the illness had upon him.

The sample group of 43 patients may not be considered large enough from which to draw any significant conclusions, but there were characteristics common to the behaviour and attitudes of the patients which indicated a general trend. It has been possible within the framework of the study to reveal meaningful findings in the various areas which were analyzed. The various types of material which were collected, provided for a comprehensive presentation of the problems experienced by tuberculous patients.

The patient group was fairly representative of the population, from an economic, cultural and religious point of view, of the area which the hospital serves. While the French patients who spoke French only were omitted from the sample group, a number of French Canadian patients who could speak English were included with individuals from other cultural groups.

It was recognized that since the Grace Dart Hospital was situated close to the city of Montreal, the impact of

separation from family and friends was probably not as great as that experienced by patients who are hospitalized farther away from their homes.

The Grace Dart Hospital provided a good setting for the project because, although the patients received excellent medical care, there was no social service department or planned rehabilitation programme in the sanatorium. Also, the city of Montreal perhaps was a good locale for the study as the community does not provide any specific programme for the rehabilitation of tuberculous patients. A limited amount of financial aid may be obtained from the province or municipality and some help may be received from a private family agency, but this assistance is not especially geared to the particular needs of the patient who has been hospitalized for tuberculosis.

Conclusions

In reviewing the findings of this study, it may be said that the problems of the tuberculous patients fell into three main types. These were:

(1) those problems which originated within the patient -- his excessive fears of the illness and its treatment, his inability to adjust to the restrictions of hospitalization and the limitations which the illness imposed, and his in-

security in personal relationships which was intensified by the experience of having tuberculosis.

(2) those problems which originated in the economic and vocational sphere and which resulted in dislocations in employment, loss of economic status, and prolonged financial distress.

(3) those problems which originated within the family group resulting in changes within the family structure, altered status of the patient within the family circle, and tension in marital and child-parent relationships.

In surveying the various areas of the patient's adjustment covered by the study, it has been found that the mature and stable individual could withstand more easily the stresses which illness imposed than could the immature individual. Nevertheless the study has demonstrated that tuberculosis and its treatment has far-reaching, permanent and sometimes devastating effects upon the lives of some patients and their families.

In coordinating the findings of each part of the study, it was clear that problems were created for the patient in all aspects of his life situation during the various phases of his illness.

At the time of diagnosis and recommendation for hospitalization, the majority of patients showed marked fear

and anxiety about the illness itself. Many were apprehensive about the need for sanitorium care. Misconceptions about sanitoria, loss of financial security, or separation from the family created problems for some patients who had to face hospitalization. The patients who had been employed prior to illness felt that the economic area presented one of the big problems when they became ill. Particularly the bread-winning group found the financial impact more severe than the others as they worried about the maintenance of their families while they were without income from employment. The married women were concerned about their young children while they were away. For the young single patients, lengthy hospitalization at this period in their lives was particularly overwhelming.

During the period in the hospital, a substantial proportion of the patients had difficulty in accepting treatment procedures and for many individuals there was evidence of strain in adapting to hospital routines. Several persons threatened to leave the hospital at one time or another. Feelings of despair about their physical condition often contributed to a general feeling of malaise in some patients. The group of patients studied here did not receive any skilled help with their emotional problems, but a few derived some relief from discussion of their feelings with the doctors, nurses, members

of their family or other patients.

It was also found that financial problems were a constant source of worry to almost all of the patients. The most serious economic distress was experienced by those families in which the breadwinner was hospitalized. Most of the families experienced a sharp reduction in income. For the families where the wife was hospitalized, added expenses were incurred when the husband and children had to board out of the home. The single wage earners who lived outside a family constellation found the period difficult as they needed spending money while they were in the hospital. For the other patients, money needed for miscellaneous expenses constituted a drain on the financial resources of their families causing some strain in this area. The adjustments made by the sample group of 43 patients were of various kinds, the most frequent being assistance from other members of their families, or assistance from community agencies, bot public and private. Such help either added a heavy financial burden to family members, or in those cases where help was received from community agencies, it was found to be inadequate.

Hospitalization also had a particularly disruptive effect on the families of the married patients. In the case of the married female patients, the children were in many instances placed outside the home while their mother was away. In the case of the married male patients of the sample group under

study, the children proved to be older than those of the female patients and therefore the illness of the patient had less impact upon the family structure. Nevertheless, in some instances, it was necessary for relatives to move in with the family or for the family to move in with relatives.

The married male patients expressed some concern over loss of status in relation to their reduced earning power and the fact that their children, in some cases, had taken over the dominant financial role. Among the married women patients, there was some apprehension over the separation from their children during their early years. Fears over the possible loss of affection of their husbands while they were away was also expressed by this group.

The return to the community was another phase of the illness in which there was evidence, in many instances, of emotional, social and economic stress. There were a few patients who seemed over-anxious to leave the hospital and others who showed little desire to face the outside world. Once discharged, there were those patients who met with some difficulties in adhering to restrictions and limitations imposed by the illness or in returning to their former social circle. A smaller number of married patients ignored restrictions but a larger number in the married group showed hypochondriacal tendencies and preoccupation with self which in some instances created

strains in their marital relationships. It is interesting to note that among the married patients in the sample group, relatively little change had taken place in their social and recreational life as a result of the illness. This was due to the fact that they had led a more settled existence prior to their illness. There were more instances of rejection and ostracism experienced by the single patients and in some cases the illness affected their future plans and hopes for marriage.

From an examination of the economic area it was apparent that the majority of patients who had been wage earners prior to illness experienced continued economic distress in the post-discharge period prior to the resumption of work. In a few situations, problems in the financial area were the cause of changes in family relationships. Changes in financial dominance were common during the course of the illness and where there was a permanent change, further problems arose. The changes in dominance were largely limited to the breadwinning group since its members were the only patients who had been financially dominant prior to illness. Loss of dominance and a concurrent feeling of loss of status caused problems and strains in the area of family relationships. Tensions were created around changes of status but the illness had little effect on the quality of marriage relationship itself. In the group of married female patients, many felt that the illness had strengthened their relationship.

Disruptions in family structure were carried into the post-discharge period when in some cases children continued to be separated from their mother until she was strong enough to look after them.

It was found that housing on the whole was an area that was not very much affected as a result of the illness. Only a small number of the sample group and their families had to move because of the patient's illness and most changes were to better houses than formerly occupied.

Recommendations

It would appear from the findings that some patients did not derive the maximum benefit from their hospitalization, and that after discharge they were not functioning in a manner conducive to an optimum state of health which includes emotional as well as physical well-being. In many instances where patients seemed to be making a satisfactory adjustment on the surface, there was an underlying feeling of concern or anxiety which was covered up by some psychological defense.

Fear and apprehension about the illness, treatment or some of its personal, social and economic effects were manifested in the behaviour and attitude of most of the patients. For each individual the particular experiences encountered during the different phases of the illness had special significance.

It seemed evident that the fact of having tuberculosis created some strains for the patient, whether at the time of diagnosis, during his hospital stay, or when he was discharged into the community again. The majority came through the experience with some measure of adjustment in spite of the numerous social, economic and psychological problems. However, it would seem that the nature of tuberculosis and its treatment is such that every individual requires help in one or more of these areas if he is to achieve a better all round adjustment.

Rehabilitation therefore should be considered as "the restoration of the personality with all its creative power, a state in which the handicapped person has faced all the forces in his environment, physical, economic and social, and made an adjustment to them."[1] If rehabilitation is to be successful in all areas, it requires a comprehensive programme and implies a team work approach which is designed to help the patient with his problems. The methods and services used in rehabilitation are important and vital to the success of any rehabilitation programme. However, the essence of rehabilitation lies in its individualization. In the last analysis it is not the programme which is important, it is the person for whom it is designed. The philosophy underlying this idea is that every human being has the right to achieve his highest measure

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1. Helen Tuck, "The Role of the Social Worker in a Tuberculosis Rehabilitation Programme" unpublished paper delivered at the Canadian Tuberculosis Association Conference, Montreal, June 4, 1953, p.1

of worth both to himself and to the community of which he is a part.

With this basic concept of rehabilitation in mind, the group of students who undertook this study have proposed a number of recommendations which they felt were indicated as a result of their findings. The recommendations will be considered from two points of view; that of the hospital and that of the community.

It was felt that the prime requisite within the hospital was a social service department. This department would be able to free the medical staff of the additional burden which they had undertaken -- that of referrals to community agencies. It would also offer the services of its trained staff in helping the patients adjust to the effects of illness and enforced hospitalization. The utilization of case work skills to help the patient relieve tensions which arise or to give continued support during particularly difficult periods in the hospital or in the post-discharge period may serve to lessen considerably the burden which the tuberculous patient has to bear. The social worker sees the patient as an individual whose behaviour is conditioned by his particular background, personal experiences and environment. A special contribution can be made by the social worker as a member of the professional team by her understanding of the inter-relationship of the persons's medical and emotional

situation with his personal needs and problems. An assessment of the patient's strengths and weaknesses and a sharing of this knowledge with the members of the whole treatment team may serve to make the treatment process more flexible and more adaptive to the patient's needs. The social service department would also provide a means of interpreting the illness and the needs of the patient to his family. As a result, many of the problems which occur in the area of family relationships could be alleviated.

It was not possible to make specific recommendations in the vocational area since this part of the study was not completed. However a vocational training and guidance programme would appear to be essential in any rehabilitation programme. It was also felt that occupational therapy would be of great assistance to the patient in making his hospitalization more pleasant, and in facilitating his utilization of the period to procure the optimum physical, educational and emotional results.

The findings also showed that a few patients had problems which were of such a nature as to indicate the adviseability of psychiatric help. A consultant psychiatrist would offer a valuable service to the patients in the sanitorium.

Within the community, it was felt that the initial lack was in the various clinics where diagnoses were made. No social workers were present to work with the patients from the time

of diagnosis until there was bed space available for them in the hospital. This was found to be a period which afforded the patients a traumatic experience, and was also a time when many adjustments had to be made for the impending hospitalization. The services of a trained social worker would alleviate many of the problems at this point by helping the patient verbalize his feelings about the particular situation confronting him; his bitterness at this interruption in his life, his fears for his family and his distrust of medical treatment. The social worker would also at this time point out the community resources in the form of financial assistance, plans for the care of children, arrangements for the medical examination of the family, and so on, which are appropriate to his particular circumstances.

A social service department attached to the clinics would also be able to follow the patients after their discharge from the hospital, while they are receiving follow-up care from the clinics. In this way the patients would receive help in adjusting to the environment from which they had been absent. It is true that public health nurses undertake some of this type of service, but their training is in the field of medical follow-up, and a much more complete service could be offered if social workers would give the service in the field in which they have been trained.

It was also felt that the community should offer more concrete, financial assistance to tuberculous patients and their families. Although private family agencies, the province and the municipality do offer some financial assistance, it has been found that such assistance is not adequate, and other adjustments often disruptive of the family's normal way of living, are necessitated.

Finally, a programme of interpretation is recommended for the public in general, in order that the public misconceptions surrounding this disease might be eliminated, and the facts presented in their true light. Many patients have been hindered in their return to normal living, in their social and vocational milieux, by the prevalence of ignorance about tuberculosis.

It is the opinion of the students that the implementation of these recommendations would result in a more complete rehabilitation for a greater number of patients than is now possible. The extensive programme proposed here would eliminate much of the anxiety and concern of the patient and his family, and the waste which is inherent in the absence from a normal, meaningful, and productive life.

APPENDIX A

Letter Sent Patient Prior to Interview

Dear

It is some time now since you have been in the Grace Dart Hospital. Although you are seeing the doctors at clinics, the hospital is interested in learning about the progress you are making toward complete recovery and what difficulties you may be having in adjusting to life outside the Hospital.

Medical men in tuberculosis sanatoria and clinics are all concerned about the problems patients face during the convalescent period and are interested in discussing what services should be established in the community to assist discharged patients and their families. A special study to enquire into these problems is being made by the McGill School of Social Work and is being sponsored by the Hospital with the cooperation of the clinics.

As you are in the post-hospital period, information you could give us would be very valuable to those who are making the study and we hope you will give it your full cooperation. We assure you that all such information will be kept strictly confidential.

of the McGill School of Social Work would like to call on you in the near future to talk over your situation with you. She will be calling you on the telephone or sending you a letter within the next few days in order to arrange an appointment.

Both the McGill School of Social Work and I personally, would appreciate your help with this project.

Yours Sincerely

G. R. Howell, M. D.
Medical Director.

APPENDIX E

INTERVIEW SCHEDULE

Source of Information: Who? (Patient, spouse, parents etc.)

Attitude of Informants:

Appearance and Manner of Informants:

A. PATIENT'S ADJUSTMENT TO HIS ILLNESS

1. Attitude to tuberculosis prior to illness,-including patient and family.) Was disease regarded as a social stigma? Was it a disease of "the lower classes," a punishment etc?

2. Reaction to need for hospitalization. eg. separation from family, social group, job as well as emotional reaction including denial, shock etc.

3. Adjustment to hospitalization. Good at first and later.
a) Attitude to doctors and nurses, other patients, food routines, treatment procedures.
b) Use of leisure time. Participation in hospital activities.
c) Attitude to prolonged bedrest and care.
d) Other attitudes, including over-concern with symptoms, boredom, fear of death, behaviour problems, evidence of passive suicidal tendencies.

4. Reaction to leaving hospital. (Acceptance of responsibility, status in family, feelings regarding economic dependency, employment, leaving medical authority, infecting family.

5. Present attitudes to illness including attitude to limitations.

6. Present social and recreational activities--cultural, social, sports, religious, hobbies. Are these individual or group activities? Is patient keeping in touch with hospital acquaintances?

B. ECONOMIC AREA

1. Income-- Total before, during and after illness. Sources of income eg. wife, children, boarders, roomers, investment, roomers, employment, and of whom., Public Assistance.

2. Feelings regarding change in income with relation to what it might have been if patient had not had tuberculosis.

3. Was there any time when income stopped and for how long?

4. Response of patient and family to changed financial status. Who is the financially dominant member?

5. Housing: a) Neighbourhood, number of rooms, apartment or house, condition, sleeping arrangements.
   b) Dwelling changes from pre to post-illness period and reason.
   c) Suitability to patient's condition.

C INTER-FAMILIAL RELATIONS TO PATIENT'S ILLNESS

1. Present marital status.

2. Date of marriage, if married.

3. Structure of family, prior to, during, and post-illness. Give ages and birthdate.

4. Changes in structure of family during or after illness.

5. Emotional Patterns:
   a) Marital history. - Separation, if any, giving reasons for separation and whether it was related to the illness.
   b) Relation of single patients to family
   c) Family problems. (illness, relatives, etc.)
   d) Present patterns.-Nature of present relationships.

6. Feelings of patient regarding family relationships. eg. rejection, loss of status.

7. Family's attitude to patient in hospital and at present.

8. Dominance patterns:- Who has always been the strong person? Effect of illness on this.

9. Indirect effects of illness on family patterns.(eg. fear of marriage, fear of losing partner, fear of having children.)

D. EMPLOYMENT

1. Employment prior to illness.
2. Changes of job for 5 years prior to illness.
3. Educational status plus any additional training in skills.
4. Present employment status according to medical recommendations.
5. Vocational counselling received.
6. Transportation to and from work.
7. How many house of work?
8. Changes in employment status and reasons for this change.
9. Patient's attitude toward telling employers about illness.
10. Experience with attitude of employers.
11. Satisfaction with present employment.

E. OTHER SOURCES OF HELP

1. Help received from such community sources as Casework agencies.

APPENDIX C

Sex and Marital Status of 43 Patients Discharged from the Grace Dart Hospital between the months of May 1951 and November 1952.

Marital Status	Total	Male	Female
	43	27	16
Single	17	11	6
Married	22	12	10
Separated	2	2	0
Divorced	1	1	0
Widowed	0	0	0
Married since Illness	1	1	0

APPENDIX C (continued)

Age and Sex of 43 Patients

Age	Total	Sex	
		Male	Female
	43	27	16
Under 20	1	1	0
20 - 24	7	4	3
25 - 29	10	5	5
30 -34	9	5	4
35 - 39	2	1	1
40 - 44	7	4	3
45 - 49	3	3	0
50 - 54	3	3	0
55 - 59	1	1	0

APPENDIX D

Reasons for Discarding Cases Following Perusal of Medical Charts.

Reasons for Discarding Cases	Number of Cases Discarded.
Total Cases Discarded	36
Over age	3
Out of town	7
Transferred to other hospitals	18
Left without medical approval	8

Number of cases retained after reading medical charts - 73.

Reasons for Not Interviewing Total Selected Group.

Reasons for not Interviewing Cases	Number of Cases Not Interviewed
Total Cases not Interviewed	30
Refused Interview	5
Not Available	12
Lack of Time	13

Total number of patients interviewed - 43.

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