# PSYCHO-SOCIAL ASPECTS OF TUBERCULOSIS

A Study of Cases in a Low Income Group in a Selected Area of Vancouver

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#### ABSTRACT

This study examines the psycho-social aspects of tuberculosis in a low income group in an urban setting. The locale chosen was Social Area Three of the City of Vancouver. Part of this area known as the "Strathcona District" was surveyed in 1947 by a University of British Columbia team, of which the writer was a member, as part of a demonstration slum clearance project.

This group was specially selected to give clearer focus to the important "residual area" problem in tuberculosis control, namely, that large group of the tuberculous in whom the interaction of the emotional aspects of illness and defects in their material environment combine to make them the hard core of the tuberculosis problem and of many other social problems in the community.

A general perspective for the study is drawn from tuberculosis and social work literature from North America, Britain and Scandinavia. The details of the study are based on the case records of seventy-nine people aged eighteen to fifty who were almost one hundred per cent of the diagnosed cases of active tuberculosis in the white races living in Social Area Three of Vancouver in August, 1948. The case list was compiled from the files of the public health nurses of the Metropolitan Health Committee. The Social Service Exchange registrations of patients and their families were followed up and a total of one hundred and eighty seven case records were read. Information from home interviews with selected patients was also utilized.

In terms of social characteristics the sample includes: (a) patients in family settings and, (b) unattached men living alone, who numbered one quarter of the group. The group as a whole were near the border-line income brackets, but might never have become social liabilities but for their tuberculosis. The problems presented by the disease to the patient as an individual, to his family and to the community are then discussed. The importance of the personality of the patient as a factor in illness is stressed, and the role of the medical social worker in diagnosis and treatment is outlined. Illustrative case material is utilized.

The study indicates that the three most important factors determining the successful management of tuberculosis are: (a) the existence of facilities for finding, treating and rehabilitating cases, (b) adequate ancillary social services for the treatment of the social aspects of the disease, (c) the degree of cooperation of the patient and his family in the treatment plan, which cooperation is largely determined by their degree of emotional maturity. The problem of patient non-cooperation is found to stem mainly from lack of sufficient services to meet primary human needs. Because of this lack the life experiences of most people in the group in their formative years had not been conducive to the development of the requisite emotional maturity for dealing constructively with the problems of chronic illness. There is evidence that the weakness of the rehabilitation services in British Columbia vitiates much of the excellence of other treatment facilities.

The principle conclusion drawn from the evidence is that the prevention and control of tuberculosis are inextricably interwoven with many other social problems, including poverty, bad housing and family insecurity, which must be attacked in their entirety if advances in tuberculosis control are to be continued. Poverty, in particular, shows up its paramount importance in the perpetuation of tuberculosis as a major health and welfare problem. Specific recommendations are made regarding changes in legislation, medical services, medical social work, social assistance, rehabilitation services and voluntary social agencies services. Many of these recommendations would have valid application in the treatment of other chronic illnesses.

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#### CHAPTER 1.

### The Contemporary Tuberculosis Problem

The human race and the bacillus tuberculosis have lived together in conflict since the time of the earliest known civilizations. No other disease has so intrigued mankind, nor continued to baffle men like this one; and it is still the most unpredictable and erratic of all diseases. Tuberculosis has killed more people than all the wars in history. Only in the last few generations has the balance been tilted more favourably on the side of man. The recent war years, however, have shown how quickly ground gained in the struggle can be lost.

There is a widespread tendency today to regard tuberculosis with complacency as a "controlled" disease, the complete eradication of which is within our grasp. It is true that it has yielded pride of place as "Captain 1 of the Men of Death", and is now eighth on the list of "Principle Causes of Death" in most countries of the western world. Increase in life expectancy in these countries has naturally led to a predominance of diseases of the clder age group, such as arteriosclerotic and heart diseases, as overall causes of death. Nevertheless, tuberculosis is the chief cause of death in the fifteen to forty-five age group in these countries, and still the principle cause of death in the world today, taking a toll of five million lives annually.

The ravages of tuberculosis cannot be calculated by consideration of the mortality rate alone. Only against the background of its morbidity

<sup>1.</sup> The original use of this phrase is attributed to John Bunyan.

can the disease be seen in its true perspective. It is estimated that tuber
l culosis disables at least ten times as many people as it kills. - It is this capacity for crippling disablement in the most productive and enjoyable years of life that ranks the disease among the foremost social problems of our day. In British Columbia in 1951, there were 19,000 known cases out of a population of approximately one million. These 19,000 would equal the total population of a fair-sized B. C. city.

Although improvements in living standards and developments in public health measures have undoubtedly contributed to the reduction in tuberculosis mortality rates, the decline had begun at least a quarter of a century before the discovery of the bacillus by Koch in 1884, A.D., and before the initiation of specific public health measures and sanatorium programs anywhere in the world. The decline was also observed in countries which had not begun to carry out vigorous control measures. Authorities are agreed that the decline was not due to any general decrease in the virulence of the bacillus - indeed, bacilli isolated at the beginning of the century are still producing the same sort of disease. Nor is it due to the process of natural selection which, as authorities agree, operates too slowly to account for the phenomenal fall which has occurred. The precise nature of the forces which have been at work is

l. Recent field studies in Massachusetts indicate that there are approximately nine living cases to each death, as postulated by the Framingham Survey in 1917. This evidence is cited by Chadwick, Henry D. and Pope, Alton S. in <u>The Modern Attack on Tuberculosis</u>, The Commonwealth Fund, New York 1942, p. 4

<sup>2.</sup> Frost, W. H. "Age Selection of Mortality from T.B. in Successive Decades". American Journal of Hygiene. Sect. A 30:91-6 Nov. 1939

<sup>3.</sup> Rich, Arnold R. The Pathogenesis of Tuberculosis. Charles C. Thomas, Springfield, Illinois, 1944, page 884.

<sup>4.</sup> Ibid., p. 886.

unknown, so it is impossible to utilize or control them. One theory is that general improvements in living conditions have raised people's resistance to communicable diseases in general, so that the bacillus is now confronted by more resistive host tissue than formerly. Other authorities point out that infectious diseases tend to afflict mankind in cycles which have a span of years, or even centuries; so that it is possible that our present advantage is merely temporary or accidental. Even if this abatement from "natural" causes continues, it is not operating quickly enough to prevent the disease attacking millions of people in our own and future generations.

In an era when chronic diseases have come to the fore as the major cause of social dependency, tuberculosis control programs assume a new importance. They have been in operation longer than similar control measures for other chronic illnesses. They have, therefore, longer experience of the complexities of the economic and social aspects of chronic illness, and the technicalities of community organization and public health administration. They have had an unprecedented opportunity to develop the teamwork approach which is characteristic of modern medical care. The very nature of the disease they have been fighting has led them to focus on the patient as an individual living in a family and a community setting. The lessons they have learned should be applicable in the development of control programs for other chronic illnesses, such as arthritis, heart disease and cancer, with which, apart from communicability, tuberculosis has much in common. In all these diseases, early diagnosis is an important factor in determining the success of medical treatment. All of them involve lengthy hospitalization and rehabilitation, and the protracted economic dependency and prolonged dislocation of personal and family living patterns which make chronic illness such a drain on the resources of the patient, his family, and the community.

In any community, success in tuberculosis control is a good indicator of how successfully a community is tackling its social problems in general. In every country in the world, the tuberculosis mortality rate is the most sensitive barometer of fluctuations in the living standards of the people. It is an accepted maxim that the lower the income, the higher the mortality rate from tuberculosis in any given group. "This inverse relationship between the incidence of tuberculosis on the one hand, and the standard of living on the other, says one life-long student of tuberculosis, is one of the few tangible facts to be found in the whole study of the disease.

It is against the background of these facts that the choice of this topic was made. The study aims at a descriptive evaluation, through illustrative case material, of how a tuberculosis control program which is reputedly one of the best in the world, is actually operating in relation to the people it is most intended to serve - namely, the low income group among whom the disease takes its greatest toll. It is hoped that the study will provide some basis for estimating the effectiveness of current services, and the areas where development and improvement seem to be indicated.

The locale of the study, Social Area Three of the city of Vancouver, Canada, and the criteria for the selection of cases will be described in a later chapter. Before presenting the specific material of the thesis, it is essential to review the principle facts about the disease itself, its epidemiology, and modern methods of diagnosis and treatment.

l. Ustvedt, Hans Jacob, <u>Pulmonary Tuberculosis and its Treatment</u>: John Bale, London, England, 1942, p. 67. This book, published in England during World War Two, was written by a Norwegian doctor and is in general representative of the Scandinavian approach to tuberculosis control.

#### Etiology of the Disease.

Tuberculosis is caused by a minute microbe called the "bacillus tuberculosis". It is an exceedingly hardy germ, protected by a waxy capsule which makes it resistive to drugs, and very difficult for the defences of the human body to destroy. It is extremely resistant to cold, dry heat and disinfectants, but it is destroyed by prolonged exposure to direct sunlight. In moist, damp, dark places, it can remain alive indefinitely, and has been found in the sweepings of dust from the rooms of tuberculous patients as long as three months after the patients have vacated them. Boiling water kills the germ in twenty minutes, however, and a five per cent solution of carbolic acid takes twenty four hours to kill the bacilli in an average sample of sputum.

The germ is a parasite, for though it may remain alive outside the bodies of men and animals for varying periods of time, it cannot multiply except in the suitable soil of the body of its host. The bovine type of tuberculosis germ, though different from the human type, can cause the disease in humans, and reaches them principally through the milk of infected cows. Though it can attack the lungs, it more often attacks the bones and the lymph glands of the neck. This form of the disease is comparatively rare in British Columbia, due to the excellent control of cattle herds and the almost universal pasteurization of milk. This study confines itself to cases of pulmonary tuberculosis, because, although the bacillus can and does attack any organ of the body, it shows a predilection for the lungs. It is the pulmonary form which is most common and which has created the greatest social problems.

# Modes of Infection.

The etiological agent of tuberculosis is the germ itself. There can

<sup>1. &</sup>quot;Prolonged", in this connection, means over twenty-four hours, as it has been proved that the bacilli can survive in sputum lying in the direct rays of the sun for at least twenty-four hours.

be no tuberculosis without the germ. Where then, do the germs come from? great reservoirs of tuberculosis germs are the bodies of the people who have the disease. Germs can leave their bodies in the spray of moisture they emit into the air when they talk, cough, sneeze or laugh, and can be inhaled into the lungs of others by what is called "droplet infection". It is estimated that germs emitted in this way float in the air, alive, for varying periods of time up to several hours or more. Some authorities are of the opinion that this is the most common mode of transmission of infection. The germ-soiled hands of sick patients can contaminate their clothes, personal belongings, dishes and any article which they touch. More intimate contact with others, as for instance kissing, is an obvious mode of transmission. In twenty four hours a sputum positive patient can cough into the air between one and four billion bacilli, not all of which survive, it is true; but a considerable number of them will remain alive indefinitely in closed rooms, in dark damp places, or mixed with the dry dust of the streets, from where they can be carried into people's homes, alive, and deposited on floors and carpets, there to become a source of infection to children and adults alike. It is known, too, that the bacillus can be ingested in food or milk which has been contaminated by people with the disease, or by flies which having ingested tuberculous-positive sputum, then excrete the bacilli.

It is believed that most people - two out of three in Canada - have 2 become infected with tuberculosis germs at some time of their lives. Never-

<sup>1.</sup> Lovell, Robert G. Taking the Cure: The Patient's Approach to Tuberculosis: The MacMillan Co. New York, 1948, p. 53.

<sup>2.</sup> These are the Canadian Tuberculosis Association figures for 1949. There is wide disagreement among authorities both in Canada and elsewhere as to the extent of infection in their adult populations. The only point on which there is agreement is that infection is not ubiquitous as it was a generation ago. No country has figures for their total population, but only for selected groups such as school children, student nurses, where one might expect to find a proportionately high or low rate of infection.

theless, not all infected people develop the disease. Chest X-ray surveys in Canada and elsewhere show that a large number of people have actually had the disease without knowing it. It has healed spontaneously without any outwardly recognizable clinical symptoms; yet the telletale scars on the lungs remain as evidence. When the Canadian armed forces were X-rayed during World War Two, ten out of every thousand showed tuberculosis scars, but only three out of every ten required sanitorium treatment to help heal their lesions. The rest required only periodic re-examinations and moderation in daily living to ensure that their lesions remained stabilized. What then are the factors involved in the transition from infection to disease?

There is uniform agreement among authorities that, in general, the fundamental factor which determines whether or not active disease develops in an infected person is the inherent capacity of the infected body to resist the invasive powers of the bacillus. Other major factors, it is agreed, are the virulence of the particular strain of bacillus, the size and frequency of the dose, and the mechanical factor of the location of the original lesion. As regards the latter, the view is that if the original lesion occurs at a distance from a large blood vessel, it may be walled off and cause no trouble; but if it occurs near one, it may rupture into the blood vessel and cause a rapid spread of the infection. It is this factor which explains the rapid involvement of a whole lobe or sometimes even a whole lung after a

<sup>1.</sup> Variation in virulence of different strains of the same type of bacillus is known to occur. Variations in the same strain can occur depending on such factors as whether or not they have recently left the rich soil of a hospitable human host or have been barely surviving in the dust of the street.

<sup>2.</sup> Animal experiments have proved conclusively that there is a limit to the number of bacilli that even the highest degree of acquired resistance can successfully restrain. See, Rich, op. cit. p. 659

relatively brief period of symptoms as far as the patient is concerned.

As these latter factors are all uncontrollable, most epidemiological study has been directed towards determining, if possible, what factors influence the resistive powers of the individual.

# Factors Influencing the Resistive Powers of an Individual.

This is one of the most controversial areas in the whole field of tuberculosis epidemiology. There is general agreement that all the factors which are now to be discussed are involved to some degree. But there are widely differing, and even contradictory viewpoints as to the comparative weighting to be accorded to each, either in an individual case or in the population at large. Nevertheless, their influence is too well acknowledged to be disregarded in any tuberculosis control program.

Age is undoubtedly a factor, in the sense that people are more vulnerable at certain life-periods than others. In the first few months of life children are especially susceptible, but this susceptibility tends to decrease in early infancy, and incidence is actually lowest in the three to twelve age group. Puberty brings increased susceptibility. In women, the highest incidence occurs in the twenty to twenty-five age group. In men the first peak is reached a decade later than in women, and there has been a growing tendency in B. C. and elsewhere for the incidence curve in males to reach a second and even higher peak in a later decade of life. Middle aged and

Decades: American Journal of Hygiene, Sect. A 30: 91-96, November, 1939.

l. Hatfield, W. H.: <u>Handbook on Tuberculosis</u>, King's Printer, Victoria, B. C., 1944, p. 26.

<sup>2.</sup> One observer, Frost, points out that this should not be interpreted as evidence of a decreased resistance in men in the later years of life, as is sometimes supposed. If the group aged fifty to sixty in 1930 is followed back to birth, they fall within the age group which experienced the highest mortality rate, between twenty and thirty years, and are really residuals of higher rates in earlier life.

W.H. Frost: "Age Selection of Mortality from Tuberculosis in Successive

elderly women, on the other hand seldom develop tuberculosis.

Race is undoubtedly a factor, though its comparative importance is difficult to evaluate. Although Africans, Negroes, Asiatics, American Indians and Eskimos at present show greater susceptibility, this does not necessarily mean that their ultimate capacity to acquire resistance to the bacillus may not prove to be as great, or even greater than the white man's, when they have been exposed to the bacillus for as long a period historically as has the white man, who first brought the germ to their lands. Nor is it possible to estimate how much in these groups their inherent natural capacity to resist the ravages of the disease is being undermined or at least being held in check by the appalling social and economic conditions which are generally found among these people. There is the additional factor of the stresses occasioned by the violent change-over in mores which has accompanied their transition from nomadic life to reservation life and from rural to urban living.

It has not been proved that any particular occupation predisposes a person to tuberculosis, except those involving exposure to silica dust and granite dust. These do not increase the virulence of the bacilli but they provide conditions in the lungs which enable the bacilli to multiply rapidly once they have invaded the body tissues.

Physical overstrain, whether in work or play can be a factor in the development of disease following a primary infection. Fatigue lowers the power of the body's defender cells to fight any bacteria which may gain entrance to the body, including bacillus tuberculosis. Excessive movement and bodily exertion increase both circulation and respiration and these assist in extending

l. There is, however, some evidence to suggest that single, divorced and separated women earning their own living are more susceptible according to an article by Dr. Norman Macdonald: "The Social Aspects of Tuberculosis", in The Almoner, Vol. 2. No. 7. October, 1949; p. 148.

the areas of infection.

Most doctors believe that mental and emotional strain, such as anxiety, and grief can be, and actually are in some cases, important factors influencing the transition from infection to disease. However, as psychiatrists point out, the mere presence of an upsetting event or situation in a patient's life does not necessarily imply that it has pathogenic significance, unless it can be shown that it affected a patient specifically.

Whether or not an external event can be regarded as a precipitating factor does not depend on its dramatic quality, but rather on its specific character. A grain of sand may upset the smooth running of the wheels of a machine if the machine is such as to be upset by grains of sand. Or precipitating events may not be traceable at all, because, in the absence of any specific event in the patients' outer world, conflicts in their inner world may have to come to a climax, and thus the stage may have been set for the onset of a psychosomatic disorder.

The relationship between personality conflicts and pulmonary disease has been the subject of much investigation in recent years. One English observer, Dr. George Day, after many years work in sanitoria which catered to patients of the economic middle class, - ministers, school teachers, and other such professional people - came to the conclusion that:-

"Those who develop the disease in the absence of the classical physical environmental causes, such as poverty, often do so because of some disease in their psychological environment, in their relation to themselves or to the world outside..... In psychological distress, the patient as a whole is ready to be ill, in fact is already ill, and the ubiquitous bacilli, both indogeneous and exogenous are there ready to oblige.... Is it more than just chance that their tissues are so hospitable?"

As a result of some of the investigations in this field, some researchers have concluded that the personalities of tuberculous patients have

<sup>1.</sup> Wittkower, Eric: A Psychiatrist Looks at Tuberculosis, The National Society for the Prevention of Tuberculosis, London, 1949, p. 107

<sup>2.</sup> Pay, George, "Some Observations on the Psychology of the Tuberculous", The Lancet, 16th November, 1946, p. 703

certain features in common, and have begun to talk about "the tuberculous personality". This view has not had general acceptance, however. One of the most thorough investigations of this kind was made by a British psychiatrist. Eric Wittkower, who made an intensive survey of 300 patients, drawn from all social classes, each of whom underwent a psychiatric examination of at least two hours duration, and often with repeated further examinations. His conclusions were that:-

"An inordinate need for affection is an outstanding common feature of the premorbid personality of tuberculous patients. This need for affection may be openly expressed, thinly disguised, well concealed or flatly denied. Coupled with it are conflicts over dependence.... A person's mode of upbringing determines what character defences i.e. what mode of behaviour he adopts. According to their prevailing behaviour pattern, the patients were classified as overtly insecure (sub-groups: over-dependent, leaning, self-assertive) rebellious, self-driving and conflict-harassed types.... In brief, individuals who develop tuberculosis seem to have in comman an inability to deal adequately with their aggressive impulses, and are prone, though for various reasons, and in different ways, to turn against themselves."

As Wittkower goes on to point out, the psychological mechanisms which he has identified represent an attempt to explain the reasons behind the unhealthy mode of life, and the common features in the mental upsets which, as many doctors have observed, often preced the onset of the symptoms of tuberculosis. They in no way invalidate the relevance of other important etiological factors, such as adverse living conditions.

"They do however, help to explain why a person falls ill and why he falls ill when he does, but they fail to explain why he falls ill with pulmonary tuberculosis. In the light of our present knowledge, consideration of this point, though attractive, can only be tentative."

<sup>1.</sup> Wittkower, Eric. op. cit. pp. 136-137

<sup>2.</sup> Ibid. p. 137

With that view, the present writer would concur. None of the other literature which was read seemed to justify any general conclusions in this matter.

Pregnancy though a natural and normal function, was formerly thought to impose sufficient strain on a woman to lower her natural resistance to tuberculosis considerably; and it is observed that many women succumb to tuberculosis during or following a pregnancy. The occurence of pregnancy in a tuberculous woman was in itself once considered sufficient indication for a therapeutic abortion. More recently, on the basis of numerous studies, it has been concluded that it is the strain of nursing the child and attending to household duties in the months following confinement that tend to activate a tubercular lesion. Nowadays, with proper care, including hospitalization three months before confinement and six months after, it has been found possible to carry a tuberculous woman through a pregnancy without reactivation or exacerbation of her disease.

War, which imposes strains of various kinds, invariably causes an ascending tuberculosis rate. It causes more of those infected with the bacillus to develop the disease, and causes a more rapid and progressive course in those who already have active disease. In combatant countries in World War One tuberculosis mortality rates increased between 20%-100%, the increase being proportional to the privations suffered by the particular populations. In Germany the rate fell between 1919 and 1921, but rose almost to war levels again in 1922-3, when food was difficult to obtain, and economic depression was rife.

Traumatic tuberculosis, or tuberculosis following an accident or injury, is often attributed directly to the injury. But to get the disease, the bacillus must become implanted in the body's tissues, and the chances of

<sup>1.</sup> Chadwick and Pope, op. cit. p. 31.

this actually occurring in the course of the injury are exceedingly remote.

Nevertheless, the strain and shock of such an experience might activate an existing lesion.

Personal hygiene and daily mode of life can be an adjunct towards maintaining good health or an invitation to poor health, according to whether one is moderate or immoderate in daily habits of food, sleep, rest, exercise, work and play. The correlation between chronic alcoholism and tuberculosis is largely explainable on this basis. So too, is the striking correlation between mental illness and tuberculosis. The fact that tuberculosis occurs more frequently among this group than in the population at large is an indication of how the neglect of sensible daily living habits, which is often an early symptom of mental illness, has other consequences of serious social significances.

Some of the most controversial discussions among tuberculosis authorities centre around proper evaluation of the role of the hereditary factor in the development of active tuberculosis. Before Koch discovered the bacillus, the hereditary factor was considered the principal one in epidemiology, and the role of the contagious factor tended to be overlooked. Koch's discovery caused the pendulum to swing to the opposite extreme, and until recently, the importance of, and even the existence of the hereditary factor has tended to be ignored. As a result of contemporary studies, it is now known that especially high or low resistance to tuberculosis can be transmitted by heredity. Studies made in U.S.A. indicate that children of tuberculous parents contract tuberculosis twice as frequently as children of non-tuberculous parents, and that the incidence among spouses of tuberculous patients, while higher than in the general population, is not so high as might be expected. Canadian experience can cite the example of those Canadians who endured the privations of the Japanese Prisoner-of War Camps. Some of them showed remarkable resistance

to the bacillus, and did not contract the disease in spite of intimate daily contact with sputum-positive cases under the most adverse living conditions.

The factors involved in the inheritance of resistance are complex, and cannot, in our present degree of knowledge, be explained.

Inherited resistance may be the decisive factor in an individual case, and in certain circumstances, in determining whether an infection results in eventual disease. But it does not thereby follow that it is the chief factor governing incidence of tuberculosis in the population as a whole. If it were, it would radically alter the modern approach to tuberculosis control. Nor is it always the most important factor governing the development of active tuberculosis in an individual case, as some authorities have contended. Some of the most thoughtful students of tuberculosis epidemiology consider that the real problem lies in the accurate weighting of the influence of the hereditary factor, against the influences of all the various environmental factors which might alter the level of both native and acquired resistance, and depress them to the point where they could not withstend the invasive powers of the bacillus.

Importance of Adverse Socio-economic Conditions in Lowering Resistive Powers.

There has already been some discussion regarding the non-medical factors governing human resistance to tuberculosis. Discussion of the most

l. One American researcher, Irwin, found that even after sixty generations of brother-sister matings in animals, marked differences in individual resistance to tuberculosis were still present. Two others, Wright and Lewis, thought that 50% - 60% of the variations in resistance that they observed in their cross-breeds were unexplainable on the basis of heredity, and were due to unknown factors. This and other evidence which he cites, compels Rich to say "We are in no position to state, even approximately, the degree to which heredity may influence the incidence or mortality rate of tuberculosis in man. Any extremist view of this most important question is decidedly unwise, and probably mistaken". Rich, op. cit. p. 136.

important environmental factor has purposely been left to the last. In the writer's opinion it proves conclusively that the importance of the hereditary factor is, for all practical purposes, distinctly subordinate to the very real importance of those environmental factors which can be grouped under the heading of "socio-economic conditions", and which, unlike our hereditary constitutions, we can if we wish, control to our advantage rather than to our disadvantage.

All attempts all over the world to correlate tuberculosis and socioeconomic conditions, show that tuberculosis flourishes in poverty. In all
countries the highest mortality rate is at the lowest economic level, and the
lowest rate at the highest economic level. When a community is divided according to income, there is a noticeable correlation between increasing tuberculosis

l
mortality and decreasing income.

Poverty, as one authority points out, is a complex condition. In addition to inadequate income and the constant strain to trying to make ends meet, poverty usually involves inadequate mutrition and resultant lowered resistance to disease in general, hard work, inadequate medical care, poor housing, and possibly ignorance of good health habits, anxiety, insecurity, frustration, discouragement and apathy. "Poverty, therefore", say two of the leading authorities, "is the predisposing cause of tuberculosis".

<sup>1.</sup> Occupation, used as a guide to income was utilized in the Whitney Survey in U.S.A. in 1934, using material compiled from the U.S.A. census bureau in 1930 to estimate tuberculosis mortality rates in males aged 16-60. It showed that even allowing for the inevitable errors in classification, the mortality rate among unskilled workers was more than twice as high as in skilled workers and foremen, three times as high as in clerks, and six times as high as in professional men.

<sup>2.</sup> Pinner, Max: Pulmonary Tuberculosis in the Adult, Chas. C. Thomas, Springfield, Illinois, 1945. p. 516

<sup>3.</sup> Chadwick and Pope. op. cit. p. 31

Of all the factors associated with poverty, poor nutrition is considered to be the most important in the relation between low standards of living and tuberculosis. It is true that some poor people who develop the disease may be comparatively well-fed, but in dealing with tuberculosis epidemiology it must be remembered that any one factor may be outweighed by a combination of others. The importance of adequate nutrition in resistance to tuberculosis was well illustrated by the experience of neutral countries in World War One. In those affected by the blockade a rise in tuberculosis mortality occurred; in those unaffected or only intermittently affected, tuberculosis mortality declined. Even in combative countries, there was a lower mortality in agricultural countries like Hungary than in highly urbanized countries like Germany. The example of Denmark's experience illustrates most graphically of all the importance of nutrition in tuberculosis control.

During the first three years of the war the Danes exported most of their dairy produce to combatant countries. Though highly profitable commercially, this drained the home market, and the tuberculosis mortality rate rose over twenty-five per cent though living conditions were practically unchanged. In 1917, when German submarines cut Denmark off from her export markets and the Danes had to live on their own produce, in one year, 1918, the tuberculosis mortality rate fell to pre-war level.

Poor housing is universally recognized as an important factor in the spread of tuberculosis, because it usually involves poor sanitation, poor ventilation, inadequate facilities for garbage disposal and overcrowding; all of which tend to increase opportunities for infection and facilitate transmission. English researchers have shown that there is a definite correlation

<sup>1.</sup> Cited by Rich, op. cit. p. 224.

between density of population and tuberculosis, and a significant relationship

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between the number of persons per room and incidence of tuberculosis. In the
slum clearance project at Liverpool, England, it was noted that in the new
housing estates built in the same areas as the old, and rehousing the same families that had previously lived there, the tuberculosis mortality rate fell from
4.00 per thousand to 1.9 per thousand.

# Influence of Total Environment on the Development of Tuberculosis.

This is strikingly illustrated by the findings of a group of South African physicians. In a survey of some 20,000 Bantus in Natal they found that differences in the incidence and type of tuberculosis in these people of uniform racial stock were directly associated with the conditions under which they lived 3 and worked. In those Bantus living on the reserves, the infection rate was between 40% and 50%, and cases of active disease were few; in those living on the Mission Reserves, where living conditions were crowded and there was more contact with the outside world, the incidence of active progressive tuberculosis was three times as high; in those living in the peri-urban areas where there was not only over-crowding in tin shanties, but inadequate nutrition as well, the incidence again rose and the proportion of progressive primary and severe reinfection types of illness was much higher; in the urban areas, where there was gross overcrowding, deficient diet and in addition heavy physical work, the infection rates were 70% - 80%, and the morbidity rates six to eight times

<sup>1.</sup> A Glasgow Survey showed that the infection rate in one and two roomed houses was double that in three and four roomed houses.

<sup>2.</sup> Hatfield, op. cit. p. 30.

<sup>3.</sup> Dormer, B. A., Friedlander, J., and Wiles, J. F. "A South African Team looks at Tuberculosis" in the <u>Proceedings of the Transvaal Mine Medical Officers' Association</u>. Nov. 1943. cited by Chadwick and Pope, op. cit.

p. 34.

as high as among the Bantus on the native reserves. The authors stated "that in this case the conclusion that the determining factors in the development of tuberculosis in an infected population are environmental seems inescapable."

There is enough evidence in the annual statistics of countries of Western civilization to merit the conclusion that adverse socio-economic conditions are of paramount importance in the perpetuation of tuberculosis as a major public welfare problem.

#### The Nature of the Disease.

In order to understand modern treatment of tuberculosis it is necessary to have some understanding of what happens when the germ invades the body tissues. As soon as the bacilli enter the lungs, injury to the tissues begins, or can begin. At once the body's defender cells challenge the invaders.

Depending on the strength of the body's resistive powers, the patient may suffer a mild clinically unrecognizable form of the disease, which nevertheless leaves tell-tale scars visible on the x-ray plate; or a chronic illness of varying length and severity, in which the body eventually overcomes the invader; or the disease may pursue a rapid and irreversible course towards death.

The fierce battle between the body's defender cells and the invading bacilli takes place on the battleground of the lung itself which is injured in the process. The poisons from the bacilli and the dead defender cells are damaging to the lung tissue. This damaged tissue takes on the characteristic nodule-like appearance known to medical men as the "tubercule", from which the disease gets its name. The body forms cobweb-like strands of fibrous scar tissue which it wraps around each tubercule in an effort to wall off the invader and prevent the spread of infection. Sometimes a further degree of healing known as "calcification" takes place in which lime salts are deposited to harden the tubercule further. The healing process is not accomplished either easily

or quickly, and it takes nature many months or even years to make the wall strong enough to hold the invader in check permanently. One of the usual accompaniments of this lenthy process is the "caseation" stage, during which the centre of the tubercule softens and undergoes liquefaction and the bacilli multiply and spread.

This softened material may break into a bronchus, from which it is coughed up from the chest. A cavity is the space left in the lung by this softened tissue which has been coughed out. When a patient is coughing germs from his body in this way he is said to be an "open case". A closed case is one in which germs do not leave the body in this way.

Periods of alternating liquefaction and hardening are characteristic of the disease. Infective material from the first cavity may be aspirated into other bronchial tubes and thus spread patches of infection throughout one or both lungs, perhaps resulting in further cavitation. It is quite possible for a patient to have a considerable degree of healing in some cavities and progressive liquefaction in others. Not until all cavities and lesions are healed is a patient considered well.

## Symptoms.

Early tuberculosis is usually symptomless as far as the patient is concerned. Since the use of the x-ray as a diagnostic tool in tuberculosis, it has been realized that by the time the disease gives rise to clinically recognizable symptoms, it is no longer early. Lesions and even cavities show on the X-ray plate before the patient has begun to feel the lassitude and the vague malaise caused when the poison produced by the bacilli invades the blood stream.

Chronic fatigue is a symptom of numerous illnesses. Many people, recognizing that in our high-pressure way of living it can be due to prolonged

emotional tension, often resort to self-medication with their favorite tonic, or go on a vacation rather than for a medical check-up, when they are troubled by it. Other symptoms such as loss of weight, repeated colds, mild laryngitis, mildly elevated temperatures in the afternoon, upset digestion, constipation, shortness of breath, aenemia, and ammenorrhea in women are not generally considered by the average layman to be the accompaniments of early tuberculosis. Yet medical men are fully aware of how often these symptoms are part of the early presenting picture when the patient later gives his history. These are also conditions which many people do not regard as sufficiently serious to warrant prompt medical attention, and which, it is true, may be entirely unrelated to tuberculosis.

The occurrence of chills, night sweats, a persistent cough with sputum or mild hemorrhage are likely to prove sufficiently disturbing to most people to influence them to consult a doctor. By that time, however, the disease is often quite far advanced. Although the onset is usually slow and insidious, it can begin abruptly with high fever and hemorrhage, although this does not mean that the damage is necessarily greater than when onset is more gradual.

The severity of the disease cannot be judged by the presence or absence of the characteristic cough, nor by whether the cough is productive or unproductive. Productive coughers may be consistently sputum-negative, and conversely, patients producing only small amounts of sputum may be highly sputum-positive. There is usually little or no sputum before the cavitation stage is reached, or if there is it is usually negative for bacilli. Nevertheless, some authorities, including Hatfield, are of the opinion that all patients with sputum should be regarded as infectious.

<sup>1.</sup> Hatfield, op. cit. p. 71.

### Diagnosis.

Diagnosis is not always easy in early tuberculosis, though with modern diagnostic aids, it is easier than it used to be. Many other diseases cast on the X-ray similar shadows to tuberculosis lesions, and a differential diagnosis can only be made through the use of additional examinations and tests such as fluroscopy, skin tests, stomach lavage and sputum tests.

The blood sedimentation rate test, while not specific for tuberculosis, is an important aid in assessing the activity of the disease, once
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diagnosed.

#### Modern Methods of Treatment

The aim of all modern treatment for tuberculosis is to assist the bodily defences to come into play, as fully and effectively as possible in order to overcome the infection. Any inflamed organ needs rest. Therefore the diseased lung must be given as much rest as possible. This is accomplished through general rest of the whole body which includes bed rest plus mental rest in the sense of freedom from anxiety and from the ordinary responsibilities of everyday living. As an additional aid, local rest of the diseased lung is often utilized. This is done through use of one of the modern medical or surgical procedures which will induce partial or complete collapse of the lung, either temporarily or permanently, and thus through shrinkage of the lung area, assist in the closing of cavities. When it is considered that the lungs in the normal activity of breathing move about 25,000 times a day, the value of such artificial forms of rest can be appreciated.

l. There have been recent press reports about the discovery of two new blood tests to detect active tuberculosis by Dr. Gardner Middlebrook of the Rockefeller Medical Institute in New York. These tests are improvements on the former ones he devised for the same purpose. The new tests are said to use two elements in the patient's blood which can be checked against each other to determine activity of the bacillus.

The most commonly used of the temporary forms of collapse is artificial pneumothorax, which is a method of introducing air into the space between the pleura and the chest wall, thus collapsing the lung. Air needs to be replaced at intervals because it is gradually absorbed into the body. Phrenicotomy, which is a severing of the phrenic nerve either completely or partially, causes the diaphragm to rise and compress the lower part of the lungs, and can be used as a temporary or permanent measure.

The most common of the permanent forms of collapse is thoracoplasty, a major surgical procedure, usually done in three or four stages, in which the lung is made to collapse by removal of part of the ribs on the affected side. The removal of a whole lung which is called pneumonectomy; or of part of a lung which is called lobectomy, are permanent and drastic measures which may be resorted to in severe cases. Which of these procedures is indicated in an individual case, and the timing of them so that the patient receives maximum benefit are matters of medical judgement.

Drug therapy is an adjunct to surgical treatment of tuberculosis, though it can be used alone. There has been a great deal of publicity given to the modern wonder drugs, many of which have proved disappointing for use in tuberculosis therapy. The ever-resilient bacillus has, in response to the use of at least one of them, namely streptomycin, developed certain strains that are resistant to the drug, and one strain which is believed to thrive only in the presence of streptomycin. In spite of all the claims being made for the latest developments in this field, Nydrazid, or Rimifon or Marsalid, the most cautious observers believe that no drugs yet discovered, nor any collapse therapy

<sup>1.</sup> See articles "Tuberculosis Milestone", in <u>Life</u> magazine, March 3rd, 1952. p. 20.

has substantially shortened the period of bed rest which is still necessary to enable the body to complete the healing process.

A high standard of nutrition is universally recognized as one of the most potent weapons in assisting the body to overcome the disease.

Climate and altitude, once considered of paramount importance, are not now considered so in modern treatment. No one climate has been proved 1 superior in the treatment of tuberculosis. There is considerable difference of opinion as to the value of fresh-air treatment, as opposed to climate. This is not utilized to any great degree on this continent but is considered very 2 important in Scandinavia and Britain, though not universally so.

Because of the nature of modern treatment measures, it is advisable for all patients to have a period of sanitorium care. The purpose of modern sanitorium care is not merely to isolate an infectious person from the community, but to teach him how to apply the general principles for care of the disease to his own case, how to protect others, and most important of all, to enable him to have medical observation in order to estimate his capacity to cope with his disease and to evaluate which of the modern treatment procedures would be most

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beneficial in his case.

l. It is acknowledged however, that for the minority of patients who suffer from secondary catarrhal bronchitis, or post tuberculosis bronchiectasis with profuse sputum, a warm dry climate can spell the difference between invalidism and almost normal capacity to work. But they must live in a warm dry climate permanently if they are to benefit by it.

<sup>2.</sup> Rich, op. cit. p. 645, thinks that fresh air treatment is not so valueless as many would have us believe. Even the most healthy organism is stimulated and invigorated by continuous living in the open air. It is true that the most important effects may be on the psyche, but as Rich points out, that is important, too.

<sup>3.</sup> Chadwick and Pope, op. cit. p. 121, estimate that 60 to 70% of all patients are potential candidates for some form of collapse therapy. Out of the sample group of 79 patients, only 3 recovered on bed rest alone.

Serial X-rays taken periodically during the treatment process are used to assess changes in the clinical status of the disease. Increase in the size of shadows indicates greater spread of the disease; decrease indicates healing. But the X-ray does not show the degree of encapsulation of the lesions or cavities. Even calcified foci can contain viable bacilli which are a potential source of reactivation of the disease. "Many an unexplained relapse" says one doctor, "is due to incomplete encapsulation which breaks down." For this reason the patient's resumption of normal activity must be carefully graded.

When the X-ray and other tests indicate that the disease is quiescent, the patient is taken off strict bed rest, and allowed "bathroom privileges". Then he is allowed up for one meal, then for two meals, then for all meals. Next, in addition, he is allowed a fifteen minute exercise period once per day. This is increased to thirty minutes, then to one hour, until the patient is taking as much exercise as is medically safe; always with the accompaniment of a mid-day rest. Then he is allowed part-time light work, then full-time light work.

The patient is considered convalescent and his disease is classified "quiescent" when he can undertake full physical exertion without showing any signs of fatigue, maintain a steady and normal temperature, has no cavities, negative sputum, and his lesions are stationary according to X-ray.

When the patient has maintained these gains for three months, during the last two of which he has been taking one hour's walking exercise daily or its equivalent, his disease is classified as "apparently arrested". When he has maintained his gains for six months during the last two of which he has been taking two hour's exercise daily, his disease is classified as "arrested". If he can maintain these gains for a period of two years under ordinary conditions of life, and is proved on examination to have tuberculosis-negative sputum and

negative stomach washings, not only by concentration and microscopic examination, but also by culture or animal inoculation, his disease is classified "apparently 1 cured".

### Importance of the Cooperation of the Patient.

Modern treatment methods in tuberculosis of their very nature require the active participation of the patient in the treatment plan. Though this is true of all illness, it is especially true of tuberculosis. This fact was recognized long before it became the fashion for medical men to shed some of the secrecy surrounding treatment procedures and share more fully with the patient information as to what was being done and why. "No fool" said Osler many years ago, "ever recovered from tuberculosis.... The fate of a person with tuberculosis depends much more on what he has in his head than on what he has in his chest." Most modern tuberculosis control programs endeavor to give the patient the opportunity to assume as much responsibility as possible in the treatment plan for his individual case.

Recognition of the importance of the cooperation and participation of the patient involves much mere than intellectual orientation and education of the patient to the facts regarding the disease. It includes, or should include, recognition of the personality of the patient as an important factor in the management of the disease and even in the prognosis. Some medical men are of the opinion that the personality of the patient is the controlling factor.

<sup>1.</sup> These are the standards set according to the "Diagnostic Standards and Classification of Tuberculosis" published by the National Tuberculosis Association of U.S.A., New York, 1940. p. 21 and 22.

<sup>2.</sup> See Coleman, Jules V., Hurst Allan and Horbein, Ruth, "Psychiatric Contributions to the Care of Tuberculosis Patients", <u>Journal of the American Medical Association</u>, Vol. 135, No. 11, p. 699.

# Importance of the Psychosomatic Approach in Diagnosis and Treatment

The influence of the personality of the patient as a factor in illness has long been recognized by clinicians, but it has been given new importance by the developments in psychosomatic medicine which have taken place in recent years. Psychosomatic medicine is not a new speciality in medicine, but an approach to the whole of medicine, which stresses the inter-relationship of the psyche and the soma, that is, the emotions and the bodily symptoms, in all sick people. This approach to medicine is not new in itself — indeed it is an old as Hippocrates, but in recent years it has been given a scientific validation by the researches and demonstration work which have been done in this field.

As a result of recent studies, it has come to be recognized that in all illness there are three components, first the physical or organic; secondly, the psychological or emotional; and thirdly, the social or environmental. All of these components and their interaction need to be evaluated and taken into consideration, both in diagnosis and treatment.

This concept of illness stresses two important facts about people which have tended to be overlooked in the era of specialization in medicine which has developed in the past generation in response to innumerable discoveries which have made it impossible for one man to master medical science as a whole. These are first, the unity and indivisibility of the human being, and secondly, the fact that illness is an aspect of behaviour. As a result of these realizations the tuberculosis patient has ceased to be regarded as primarily a "pair of diseased lungs", but rather as an individual who is part of a particular family and a particular social environment, and who has his characteristic individualized way of reacting to illness as to other experiences.

In an illness such as tuberculosis it is especially important to know

the nature of the individual personality, because the patient's emotional makeup, the nature of his conflicts, defence mechanisms, areas of satisfactions and frustrations, compensation patterns, and especially the degree of anxiety in his makeup and his ability to adjust, will largely determine how he copes with his part in the management of his disease.

Comprehensive medical care should provide for individualized handling of the patient's case, based on a full understanding of the interaction of the organic disease process, the patient's personality pattern and the particular social environment of which the patient is a part. The advantages of modern medical science are made available to the patient through what has come to be called the "treatment team", of which the patient's own physician is the captain, and the hub around which rotate the services of the other members of the team; murse, dietician, physiotherapist, laboratory technician, X-ray technician, occupational therapist, and medical social worker. The services of these specialists are enlisted by the patient's doctor according to the needs of the patient.

# The Role of the Medical Social Worker in the Treatment Team.

The medical social worker's role on the team developed in response to the need to have a scientific approach to the psychological and social aspects of illness such as had already been developed towards the physical. The medical social worker is professionally trained to assess the role which a emotional and social factors are playing in a patient's illness. She brings

l. It should be noted that the use of the feminine pronoun in reference to the medical social worker is merely for purposes of convenience, in order to differentiate between the worker and the patient and also between the physician and the worker. It is not meant to imply that medical social workers are exclusively feminine, nor that patients and their physicians are exclusively masculine.

her findings to the doctor for correlation with other diagnostic material, and works closely with him in the development of a treatment plan for the solution or alleviation of whatever emotional and social difficulties are affecting the patient's illness. The aim of the medical social worker is to assist the patient to obtain maximum benefit from medical treatment by helping him overcome those personal and social factors which have a bearing on his illness and which are interfering with diagnosis, treatment or recovery. She helps the patient mainly through casework which is her chief professional tool.

Social casework has been defined as:

"an art in which knowledge of the science of human relations and skill in relationship are used to mobilize capacities in the individual and resources in the community, appropriate for better adjustment between the client and all or any part of his total environment".

Casework is the prime activity of the medical social worker. Through the dynamic relationship which is built up between worker and patient during interviews the patient comes to regard the worker as a friendly understanding person who accepts him as he is, who will not censure him, who will respect at all times his right to make his own decisions, with whom he can discuss freely and with full protection of confidentiality, the problems which confront him, from whom he can draw enough support and encouragement to take action to improve his situation in ways he could not do unaided. The patient can, through casework, gain insight into the role which social and emotional factors are playing in his illness, and can be helped to make the

l. Bowers. Swithin, O.M.I., "The Nature and Definition of Social Casework: Part three," in the <u>Journal of Social Casework</u>. Volume 30, No. 10. Dec. 1949. p. 417

maximum effort of which he himself is capable towards the solution or alleviation of his difficulties. He can also be helped to accept and utilize help from available community resources.

The skills and methods of the social work profession are the same in whatever field they are practiced, whether in family welfare, child welfare, recreation, corrections, or medical social work. It is the nature of the field, however, which determines the worker's focus. In a medical setting, the social worker focuses on personal and social problems connected with illness. She gives casework service at the request of the doctor, studies a patient's problems as they appear to him, assesses the meaning they have for him, studies his family background and social circumstances in order to help the doctor discover the reasons behind the patient's behaviour in illness and his response or lack of response to medical treatment. She helps the patient to feel that in spite of busy hospital and clinic routine, his individual needs are understood and are being taken into consideration in treatment. She assesses the role the family is playing in the patient's illness, interprets to them the total situation regarding the patient and their specific part in the treatment plan. She helps them to accept it and carry it out.

She helps other professional personnel caring for the patient to understand him as an individual, and thus assists in the adjusting of the treatment plan to the patient's individual needs. She takes the initiative in mobilizing community resources to meet the patient's needs and helps him and his family to understand and accept these services.

<sup>1.</sup> It is preferable, but not essential, that all referrals for the social worker's service should be made by the patient's doctor. Sometimes, however, it is the nurse, dietician, relative, friend, community agency, or even the patient himself who requests the worker's services. When this happens the medical social worker acquaints patient's doctor with the request and the reasons for it. He makes the decision whether or not he wishes the worker to give service.

If referral to other social agencies is made, she often undertakes in association with them a job of cooperative casework for the benefit
of the patient. She interprets to other agencies the meaning of illness
and hospital experience to the patient, and the social implications of the
medical treatment plan, so that the agency concerned understands the total
situation, and can help further the plan for the patient's medical care.

The medical social worker's job is important and indispensable in illness. Through her contribution the doctor is enabled to understand the patient as a person and so to individualize the treatment plane

#### CHAPTER 2

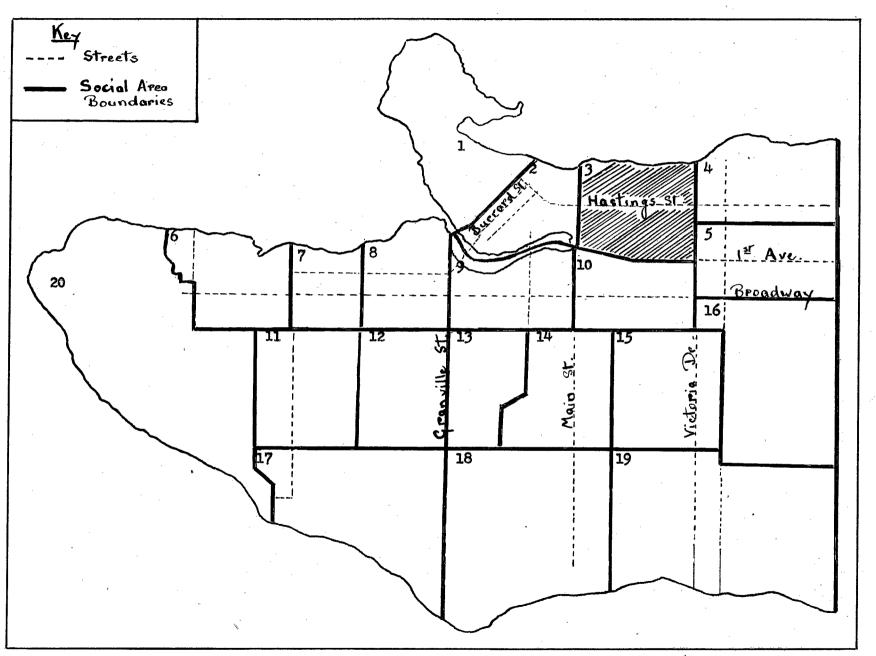
## The Sample Group

The city of Vancouver, on the Pacific Coast of Canada, has grown in little more than half a century from the small lumber settlement of "Gastown" to the third largest city in the country, with a population of approximately 350,000. It is a thriving seaport, the proud possessor of one of the world's finest natural harbours, and occupies a strategic position in commerce between Occident and Orient. The major industries of the Province of British Columbia in which Vancouver is situated, are lumbering, pulp and paper making, fishing, mining, smelting; and most recently, oil.

Such rapid growth was almost inevitably accompanied by undesirable social features which have left their mark on the city as it exists today.

Social Area Three is a "blighted area" type of neighbourhood, unfortunately a common feature of many cities in both the Old World and the New. It is a district which originally possessed, and still retains many desirable features, and which was first settled as a residential section close to the city centre in the early days of the city's history.

In the era of expansion which followed, the district lost its original character. Today it is a confused mixture of dwellings and industrial structures of many varieties. Many of the dwellings in the area are the old-fashioned type of frame house, some still substantial and well kept and housing a single family, but for the most part run-down, dilapidated looking structures, now housing



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several families. There is also a number of roughly constructed wooden dwellings of incredible shapes and sizes which qualify as houses in name only, and would be more appropriately designated as shacks. There are also rows of cabins, originally constructed for the coolie laborers on the railroads, and which were condemned many years ago, but are still inhabited. There is a high percentage of rooming houses, a few of which were originally built as such, but which are mostly inadequately converted structures of various kinds with defective utilities in which there is considerable overcrowding. Thus the area has become one of second hand housing, inhabited principally by people whose income level does not permit them to rent or buy in a more desirable neighbourhood.

The area represents 2.8% of the total area of the city, but about 10% of its built-up area. (See Figure 1, page 32). Most of it is laid out on the gridiron system, but there is a considerable amount of haphazard development, a residue of potentially useful land, and a conspicious lack of parks and open 2 spaces. It is not, however, the area of greatest density, nor does it contain the worst slums, though it faces on a water-front which is one of the most color-ful and exciting in the world, and is within two blocks of the city intersection reputed to be the centre of the drug exchange traffic in the Canadian West. The area has a high percentage of arrests for drunkenness and vagrancy, and a high accident rate. It contains the part of town to which transients naturally gravitate. In it are to be found those establishments to which the underworld

l. Marsh, Leonard C. "Rebuilding a Neighbourhood". Report on a Demonstration Slum Clearance and Urban Rehabilitation Project in a Key Control Area in Vancouver. University of British Columbia, Vancouver, 1950, p. Vii In this Survey of the Strathcona District, covering about 43 blocks in Social Area Three, Dr. Marsh estimates that single houses form three quarters of the dwellings, and that one in four has sub-tenants or boarders.

<sup>2.</sup> Ibid, p. 8. The Strathcona area's population is between 7000 - 7500, and though there are hundreds of single men, it is predominantly (62%) a family area.

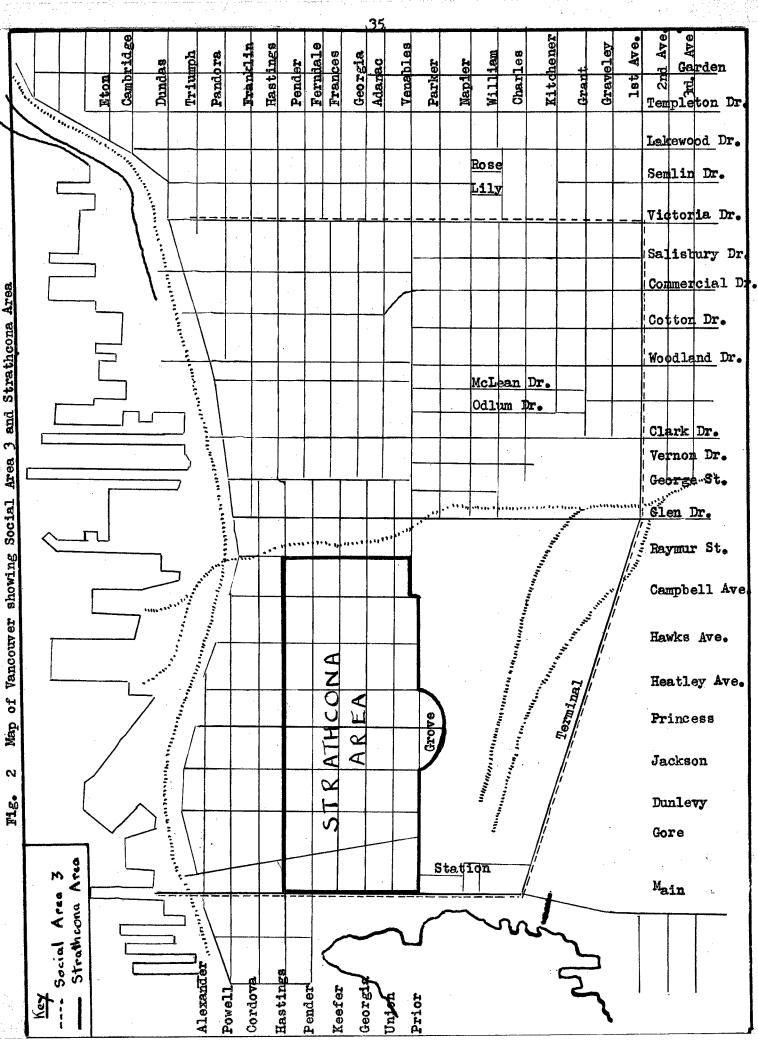
operator can repair when it is expedient to rent a room without being asked inconvenient questions.

The area is a racial melting pot, containing most of the city's Chinese population, and most of the foreign born of European extraction. It is the place where the immigrant can find a cultural or religious organization serving the people from his homeland, and where he can live till he has learned the language, assimilated the customs, and is economically able to move to a better district. Nevertheless, the district has a high percentage of life-long residents, and white people of Anglo-Saxon origin still predominate.

The locality was chosen because it was considered that the case studies of people living in such an area would well illustrate the problem of tuber-culosis as it exists today in many cities of the western world. It is hoped that the study will highlight the ways in which the disease is still a challenging problem; a personal one for the patient and his family, a social one for the community, and a professional one for the doctor, the public health nurse and the social worker; and how it is inextricably interwoven with other social problems.

The area was also chosen with reference to the fact that the writer participated in the housing survey conducted in the area in the summer of 1947 by Dr. Leonard Marsh of the University of British Columbia, in which a concentrated examination was made of the Strathcona Area, a district of about forty blocks within Social Area Three, which is illustrated on the accompanying map. (Figure 2, page 35). The writer thereby gained a first-hand knowledge of the living conditions of the people, and met and talked with many residents of the area, including some of the people whose case histories have been utilized in

<sup>1.</sup> Marsh, op. cit. p. 8. In the Strathcona area 30% of the residents were of British or North American extraction, and practically all of the children Canadian born.



this study.

## Selection of Cases.

A count was made of all the diagnosed cases living in the area in the month of August, 1948. The choice of this particular year was made because of the housing survey of the previous year, to give some perspective to the study, and to lessen the chance of identification of case histories.

The age group eighteen to fifty was chosen as representative of the life-period in which the disease takes its greatest toll and presents the greatest problem.

Chinese and Indian cases living in the area were excluded because it is generally acknowledged that these races have a lower resistance to tuber-culosis, regardless of the level of their environmental hygiene, than have the white races. There were also the added difficulties of language and culture which prevented the obtaining of adequate social case history material for use in this survey.

The actual cases were located by reference to the files of the public health nurses assigned to the area. It was found that the area's boundaries did not coincide with those of the districts assigned to the nurses, but contained parts of the territories assigned to four of them; so an address check was made to ascertain which of the patients on their files were resident in Social Area Three.

The case list thus compiled represents practically one hundred per cent of the diagnosed cases of the white race living in the area. This is because

<sup>1.</sup> According to Marsh, op. cit. p. 8, 28% of the population of the Strathcona area are Chinese.

<sup>2.</sup> Twenty-five per cent of the Indians of Canada live in the Province of British Columbia. The tuberculosis mortality rate among them in 1948 was 480 per 1,000 as compared with 30 per 100,000 other Canadians.

all cases diagnosed through Tuberculosis Control are automatically referred to the district public health nurse for follow-up. All cases diagnosed by private doctors must be reported to Tuberculosis Control, which in turn notifies the public health nurse, who then offers her services to the doctor concerned. Even if the patient elects to attend a private doctor for treatment, most doctors utilize the services of the public health nurse for follow up of the case from the public health aspect.

For public health purposes, tuberculosis cases are divided into two categories, primary and secondary. A primary case is one in which the patient has active tuberculosis, and is, or should be, under regular medical and public health supervision. The public health nurse visits these patients regularly. A secondary case is one in which a patient's tuberculosis is no longer active, and his lesions have become sufficiently stabilized for him to be allowed to undertake full-time light employment. This latter group is not regularly visited by the public health nurse. These patients are contacted by her only if they fail to keep a checkup appointment at Tuberculosis Control.

In the month of August, 1948, there was a total of seventy-nine primary cases and sixty-two secondary cases, plus three unclassified cases, which came within the scope of this study as previously defined. A spot survey of this nature ensured representation of all the different phases of the disease - prehospitalization, hospitalization, convalescence and rehabilitation — and the problems associated with each.

# Research Method

Identifying information regarding both primary and secondary cases was submitted to the Vancouver Social Service Exchange, which supplied a list of the registrations concerning the patients and their immediate families with the various social agencies of the city. The Metropolitan Health Committee

Table 1. Social Service Exchange Registrations regarding patients and their families

Name of Agency	People living in families		People living alone		Total	
Hame of Sector	Prior to		Prior to		10	va.r
	illness			illness	No.	P.C.
1. Metropolitan			Ì	]		
Health Committee		59	·	20	79	100
2. Tuberculosis Control						
Social Service Dept.	1	55		20	75	95
poctat pervice pepus		رر		~	כו	70
3. City Social Service						
Department	17	27	3	18	65	82
	-			]		
4. Children's Aid						
Societies	13	11	1 1	1	25	31
		_ <del></del>	[ _	1		
5. Family Welfare	;			1		1
Bureau	12	2		ļ	14	23
	Ì	• .				
6. Vancouver General	, ,		·			<b>!</b>
Hospital Social	1				· ·	
Service Dept.	5	at.	2	1	8	11
				·	i i	
7. Child Guidance			<b>,</b>	1		' '
Clinic	3	2			5	8
		ev		İ		
8. Child Welfare			l _	1 _	۱ ـ	
Division	2	5	1	1	9	12
						1 ^
9. Family Court		2			2	3
10 Tabu Massaul C	١,,		١			,,
10. John Howard Society	4	ı	3	1	8	11
33 Decidencial Marchal					ļ	
11. Provincial Mental	2	,		1	3	5
Hospital	~	1		· ·	,	"
12. Vancouver Preventori-					1	1
,		3			3	5
um						
13. Victorian Order of						1
Nurses	,	3	}	I	3	5
Total	58	171	10	60	299	
20 002	1 -		<u> </u>	<del>                                     </del>	<del>  -//_</del>	

Source: Public Health Nurses files for all diagnosed white cases of active tuberculosis living in social area three of the City of Vancouver in August, 1948, submitted to the Social Service Exchange for checking of social agency registrations.

registers all diagnosed cases of tuberculosis with the Exchange, and that agency's information regarding patients and their families had already been obtained from the files of the public health nurses.

It was found that seventy-five out of the seventy-nine primary cases were registered with at least one other social agency, in addition to the Metropolitan Health Committee. Ninety-five per cent of the cases in the group were registered with the Social Service Division of Tuberculosis Control. The remaining five per cent were newly diagnosed, so that the full impact of the disease had not yet hit them and their families. All registrations with the Tuberculosis Control Social Service Department, and with the City of Vancouver Social Service Department, the Children's Aid Society, the Catholic Children's Aid Society, and the Family Welfare Bureau were then followed up, and all the case histories pertaining to the sample group were read. This represented a total of 187 case records out of a total of 220 registrations, excluding the registrations of the Metropolitan Health Committee, as illustrated in Table 1 (page 38).

The information was supplemented by discussions with the social workers and public health nurses who knew the patients and their families. Through the assistance of the public health nurses, visits were made to a sampling of patients and families in the group.

Analysis of the secondary group of sixty-two cases revealed that twenty-five of them had been known to at least one other social agency in addition to Metropolitan Health during the course of their illness. Of the remainder, twenty-five proved to be cases whose X-rays showed evidence of a tuber-cular lesion, and were therefore called in to report to Tuberculosis Control; but as within the relatively short period of three to six months their lesions proved to be stabilized, they were allowed to resume their normal routine within this period, though cautioned to observe moderation in living and working habits.

Most of these people had never been aware that they had had a tubercular infection. The rest of the secondary group were twelve healed cases who were neglecting to report for regular checkup.

For purposes of this study, therefore, attention was focussed on the seventy-nine primary cases, regarding whom considerable social data was available, and whose case histories illustrate the crux of the tuberculosis problem. All the tables and charts in the study have been computed on the basis of these seventy-nine cases. In most of the tables, computations are made separately for people in family settings and people living alone. This is because it is considered that the management of the disease presents special problems to both the patient and the community when the tuberculous patient lives alone. Age and Sex Distribution of Cases

The sex distribution of the group was 57% male (45 cases) and 43% female (34 cases). The distribution of cases according to age followed closely the current trend in the tuberculosis morbidity rate for the population as a whole, with a concentration of 61% of the female cases in the 18-25 age group, and 48% of the male cases in the 37-50 age group, as illustrated in the accompanying table. (Table 2)

Table 2 Distribution of tuberculosis cases in the sample group according to age and sex

	Men		Women	
Age Group	No.	P.C.	No.	P.C.
18-25 yrs.	15	33	21	61
26-36 yrs.	8	19	8	23
37-50 yrs.	22	48	5	16
Total	45	100	34	100

## Family Context of Cases

The family status of the patients as illustrated in Table 3 (page 41)

shows that every type of family context was represented in the group. Hence the thesis material is illustrative of the problem of tuberculosis as it affects different family members — husband, wives, parents, single people living within a family group, and people without any family attachments, living alone. It is to be noted that 25% of the total group were unattached people, living alone, and 90% of these were men. This group encounters special problems in relation to tuberculosis which will be discussed later.

Table 3. Family Context of Patients in the Sample Group

Family status	Number of cases	P.C.	Total P.C.
1. Married couples with children			36
(a) Husband tuberculous	9	12	
(b) Wife tuberculous	19	25	
2. Married couples without childre			16
(a) Husband tuberculous	6	7	
(b) Wife tuberculous	7	9	
3. Single people within a family			8
(a) Men	4	5 3	
(b) Women	2	3	
4. Tuberculous "families" i.e.			15
more than one family member		,	ł
with active tuberculosis		:	. ,
(a) Men	8	10	
(b). Women	4	5	N.
5. People living alone			25
(a) Men	18	22	
(b) Women	2	3	
Total	79	100	100

Table 4. Status of Families with Children

	Family Status	No.	P.C.
l.	Normal families (Both parents in the home)	16	48
2.	Broken families (One parent absent) Death Separation Divorce Unmarried mothers	2 6 5 2	52
	Total	31	100

It is significant that over one third of the total cases in the group occurred among married couples with children. Of these 31 families with children, barely half were normal families in the sense that both parents were present in the home. The other half of the group were broken families in which one parent was absent due to death, divorce, separation, or some unusual marital arrangement. (See Table 4, page 41). There were 55 children under the age of sixteen living in these families. Of the total sample group, 15% lived in families where more than one member had active tuberculosis. This group like the group living alone, encounters special difficulties in the management of their tuberculosis, which are discussed in a later chapter.

## Racial Origins of the Sample Group

The racial origins of the group were extremely varied, as Table 5, (page 42) shows. The largest single racial concentration was the Anglo-Saxon, with the Slavonic group a close second; though there was a high subsidiary group of Scandinavians and Finns among the males. Yet twenty per cent of the men and twenty-five per cent of the women were Canadian born, and there were no recent immigrants in the group. All had been in Canada at least eighteen years.

Table 5. Racial Origins of the Sample Group

Racial Origin		Men		Women	
		.No.	P.C.	No.	P.C.
1.	Anglo-Saxon (English and German)	9	20	15	44
2•	Celtic (Irish, Scottish, Welsh)	4	9	0	0
3.	<u>Finnish</u>	7	15	1	3
4.	French-Canadian	3	7	2	6
5.	<u>Latin</u> (French, Italian, Spanish)	5	11	2	6
6.	Scandinavian (Norwegian, Swedish, Danish)	4	9	ı	3
7.	Slay (Russian, Polish, Ukrainian) Czech, Yugo-Slay	13	29	13	38
	Total	45	100	34	100

## Residence and Mobility

It proved impossible to get sufficient information about residence to estimate group mobility, but from the information available, mobility was not as high as might have been expected in such a group. At least sixty per cent of the total group had been resident in Vancouver for five years or more. There seemed to be a very small minority that were highly mobile. Yet even those in seasonal employment tended to room at the same address over a period of years, whenever they were in town. One of the most frequent reasons for change of address was the necessity of obtaining cheaper accommodation when on social assistance.

## Economic Status

The occupations of the people in the sample group were on the whole im the unskilled and semi-skilled classification. (See Table 6 and Table 7, page 44) No less than sixty-two per cent of the men were engaged in heavy manual work; an important factor in rehabilitation planning for this group. About half of the women were housewives, which is also an important factor in rehabilitation planning.

On the whole, apart from the usual seasonal unemployment in logging and allied industries, there was little chronic unemployment in the group until after the onset of tuberculosis. Only 20 out of 79 cases had been in receipt of social assistance prior to the diagnosis of tuberculosis. The agency records showed that the majority of those who had received social assistance prior to diagnosis had done so during depression years. Only a small minority from the group were registered as patients of the Vancouver General Hospital Outpatients' Department which indicates that most of the group either purchased medical care privately or went without it. It was interesting to note that thirty-seven per cent of the cases in the group were registered with child welfare and family

Table 6. Occupations of Male Patients at Diagnosis

	Type of employment		
	`\	No.	P.C.
1.	Heavy Manual Work Logging Labouring Mining Fishing Cement mixing Longshoring	14 5 4 3 1	62
2•	Skilled and Semi-skilled Carpentering Truckdriving Shipwright Seaman Marine engineer Painter	2 1 1 1	18
3∙	Service Occupations  Hospital orderly  Salesman  Barber  Kitchen help	1 1 1	9
4.	University Students	2	4
5•	"Unofficial occupations"  Professional gambler  Bootlegger  Receiver of stolen goods	1 1 1	7
	Total	45	100

Table 7. Occupations of Female Patients at Diagnosis

Type of employment	No.	P.C.
1. Semi-skilled occupations  Labeller  Printing operative  Laundry worker  Telephone operator	1 1 1	12
2. Service occupations Usherette Store clerk Waitress Practical Nurse	1 3 1	21
3. Unskilled occupations Domestic	1 3	9
4. Housewife	17 1	<i>55</i> 3
Total	34	100

welfare agencies before the onset of tuberculosis, which is an indication of the presence of social problems within these families severe enough to require outside help. There were however only sixty Social Service Exchange registrations regarding the total group prior to tuberculosis, an average of less than one registration per case, as against a total of 231 registrations following the onset of tuberculosis, an average of 2.9 registrations per case. The conclusion seems inescapable that problems connected with chronic illness are one of the major reasons why people seek help from social agencies.

Other indications of the economic status of the group are to be found in the fact that ten per cent owned their own homes. It is true that some of the houses were of very inferior quality, yet the aspirations of the home-owning group in terms of good family living and good citizenship cannot be gainsaid. Moreover, twenty-six per cent of the group had either savings or insurance, while a larger majority indicated their appreciation of the value of thrift habits, but had never been able, due to economic stresses, to plan any further ahead than their next pay-day.

#### Housing

The general housing conditions of the group have already been described. The more specific deficiencies of their living accommodation as regards the management of tuberculosis will be discussed in a later chapter.

## Extent of Tuberculosis at Diagnosis

The stage at which tuberculosis is diagnosed is an important factor in determining prognosis. Cases are classified medically as minimal, moderately advanced, and far advanced, according to the extent of lung involvement. Although there is an increasing tendency in British Columbia for cases to be discovered in the minimal stage, in the survey group forty-seven per cent were in the moderately advanced stage at diagnosis, and twenty-three per cent in the far

advanced stage, as Figure 3 (page 47) shows. If the people living alone are considered as a separate group, one half of this group was in the far advanced stage at diagnosis.

There was little difference in the proportion of men and women in the minimal and moderately advanced groups, but there was an overwhelming preponderance of men in the far advanced group.

## Length of Illness and Incapacitation.

On average, as Figure 4, shows, tuberculosis incapacitated patients in the survey group for a period of two to three years. A minority were fortunate enough to overcome their infection and return to normal living within a year. About twenty per cent of the group were incapacitated for five years or more. Though some of them attempted to return to normal living their lesions broke down and a reactiveation of the disease occurred. Estimation of length of illness for purposes of this survey has been computed from length of time between diagnosis and certification "Fit for full-time light work". This certification is the maximum recommendation which the medical profession considers advisable for ex-tuberculous patients.

## Services for Tuberculous Patients in British Columbia

The British Columbia Division of Tuberculosis Control was set up in 1935 by the Provincial Board of Health in order to centralize the work of tuberculosis control throughout the Province. The Central Institute of the Division is in Vancouver. There are no private or municipal tuberculosis clinics in British Columbia, and all institutions treating tuberculosis come under the control of the Division.

This does not mean that the local health authorities are relieved of responsibility for tuberculosis control. They undertake a great deal of survey work and follow-up work under the guidance of the Division. The Division howe

Figure 3 Classification of extent of tuberculosis at diagnosis in the Sample Group

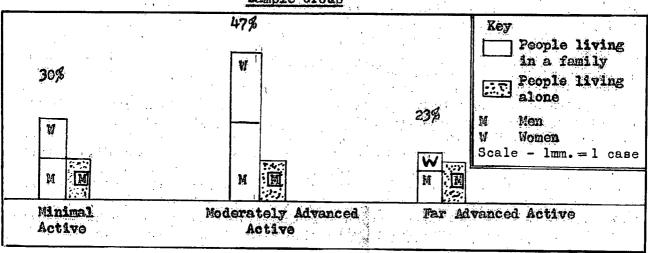
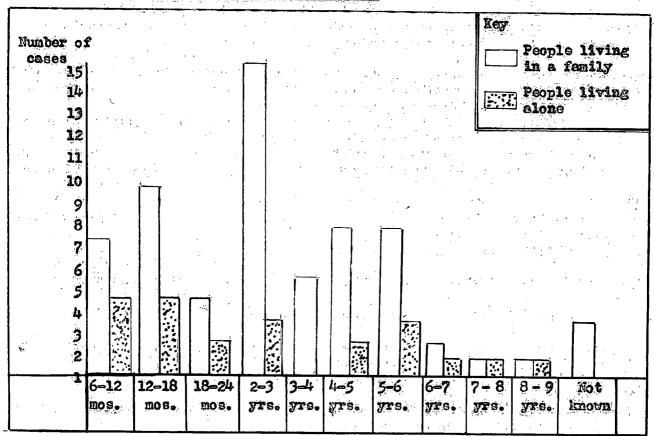


Figure 4 Length of Illness in Sample Group



ever, provides equipment, personnel and facilities which would be too costly for the municipalities to duplicate.

## Hospital Services

1

The Division maintains three hospital units. The Vancouver unit has 232 beds and a complete range of specialist services for treatment of complications ensuing from tuberculosis. It also has the largest outpatient department in the Province. The Tranquille unit has 356 beds and a smaller outpatient department. There is also a unit of 75 beds in Victoria. The Jericho Beach unit in Vancouver cares for chronic fibroids and some convalescents.

St. Joseph's Oriental Hospital is utilized for the treatment of Asiatic and negro patients, though these patients are also admitted to other units, depending on the type of treatment required.

These figures do not include the tuberculosis beds maintained by the Indian Department nor those of the Department of Veteran's Affairs, "Shaughnessy Hospital" in Vancouver.

The Preventorium which has 40 beds, takes children between the ages of two and twelve who have been infected with tuberculosis but not yet developed the frank disease, in order to build up their health and prevent the risk of further infection. It is jointly subsidized by the Province, the City of Vancouver and voluntary organizations.

Adequacy of bed complement for the treatment of tuberculosis is measured against the generally accepted standard: "Bed capacity should equal

<sup>1.</sup> These figures relate to bed capacity in 1948. There has been no significant addition since this survey was undertaken until the opening of the Pearson Unit of 264 beds in May 1952, in Vancouver. Plans are under way to complete this unit and to add further beds at Tranquille, and by 1954 it is hoped that the province will have 1,000 beds for the treatment of tuberculosis. St. Joseph's Oriental Hospital is now no longer used for tuberculous cases.

three times the annual number of deaths". British Columbia's bed capacity at the time of this survey did not quite reach this standard.

## Clinic Services

Diagnostic services in British Columbia are free. The Division maintains stationary diagnostic clinics in Vancouver, Victoria, New Westminster and Kamloops, and stationary survey clinics at Vancouver, Victoria and New Westminster. There are also three mobile survey clinics and five travelling communister. There are forty centres in British Columbia where the patient can get pneumo-thorax. Local doctors have been trained, and equipment provided by the Division. The Province has a good case-finding service as evidenced by the high ratio of known cases to deaths. There are over twenty registered cases per death in British Columbia, while elsewhere the general average is five known cases per death.

## Specialist Services

The Division also maintains in hospitals and clinics specialists such as dieticians, medical social workers and visiting psychiatrists. The Medical Social Service Division gives service to all patients who are referred by their attending doctors, and also carries the family case—work if another social agency is not already active on the case. In the latter event, the medical social worker acts as consultant to the family worker regarding the medical and social aspects of the case, but does not directly visit the family.

## Public Health Nursing Services

The Province has a good public health nursing service which covers eighty per cent of the whole Province. In the Greater Vancouver area these services are provided through the Metropolitan Health Committee. The public health nurse provides follow-up services from the public health point of view.

<sup>1.</sup> Tuberculosis Control statistics for 1948 show that with 780 beds and 286 deaths in the other-than-Indian population (the only figure obtainable) the ratio was approximately 2.8

It is her responsibility to arrange for the carrying out of isolation and precaution techniques in the patient's home; to instruct the patient and his family regarding tuberculosis and general hygiene; to search for and arrange for the examination of contacts; to trace if possible the source of the patient's infection; to provide regular supervision of the family regarding the public health aspects of the disease; to provide a report on a patient's home situation when hospital admission or discharge is recommended, or at any other time when such a report would prove helpful; to know and use all local community health and welfare agencies which can assist the patient and his family; and in general to act as liaison between the patient, his physician, and the services of tuberculosis control.

## Social Services

In the Greater Vancouver area there is a well-developed program of social welfare services, both public and private, available to the tuberculous patient and his family. Of the public welfare programs the most important are those provided by the City Social Service Department.

It was recognized from surveys made by Tuberculosis Control that many patients were requiring re-admission to sanatoria with breakdowns in which inadequate nutrition and unsuitable housing had played a considerable part. In May, 1944, certain changes were made in the social assistance regulations extending to tuberculous patients certain privileges not given to other recipients of social assistance. The most important change was in eligibility requirements. Eligibility was to be based on diagnosis plus willingness to

l. Instruction in the techniques of bedside nursing are given in the Greater Vancouver area by the Victorian Order of Murses, a private and voluntary organization which undertakes this aspect of public health nursing.

accept medical care, and not on destitution. The standard social allowance was to be supplemented in the following ways — first, by a rental allowance which was to be calculated on the basis of the difference between the standard rent allowance paid to social assistance recipients and that currently being paid by the patient's family; secondly, a special dietary and comforts allowance of \$7.50 per month for the patient in addition to the usual food allowance, with a special diet allowance of \$5.00 per month for any member of the family living at home who is infected with tuberculosis as shown by skin or X-ray tests, which allowance is to be continued for six months after last close contact with an infectious patient; thirdly, the patient also to receive comforts allowance of \$3.00 per month while in the sanitorium if he is in receipt of social assistance before admission, or is without funds.

As regards assets, single patients are allowed to have up to \$250.00, and families up to \$500.00 in savings without affecting the allowance given. If the patient has liquid assets in excess of this amount, the allowance payable is to be reduced by 3% in excess of \$500.00, or \$250.00, as applicable. Allowance is also made for instalments on essential furniture and any other necessary payments such as premiums of life insurance policies. Certain allowances for mortgages and taxes might also be met at the discretion of the administrators. A housekeeper might be provided in certain circumstances, but if the man is earning \$125 — \$150 or more, no housekeeping service would be provided.

l. No social assistance allowance is granted to patients who sign themselves out of sanitoria, and no tuberculosis extras are granted unless the patient reports regularly for checkup.

<sup>2.</sup> This has been raised to \$5.00 since the time of the survey. There have also been increases in basic social allowance rates.

<sup>3.</sup> These figures relate to 1948, but there has been little significant increase in this estimate since that time. No exact maximum can be quoted at present but it is true to say that housekeeping service is not provided by the department unless the mother is the patient and there are several children in the family, and other individual circumstances that seem to warrant it.

Patients are also provided with free transportation to and from clinic and hospital, and a free supply of paper handkerchiefs and sputum cups. The services of a nutritionist and budgeting help are also available to patients and their families. The City Social Service Department also provides boarding home care for ambulant convalescent patients but these facilities are limited.

The services of the private social agencies of the community are available to the tuberculous patient and his family on the same basis as to any other citizen. Many of the problems with which the family and child welfare agencies are called on to assist are related to the problem of illness within a family group.

## Rehabilitation Services

Rehabilitation services are a most important part of the tuberculosis control program. Studies made by the Tuberculosis Control Division indicated that many patients between the ages of 20 = 50, because of lack of rehabilitation services, returned to their former employment which was in many cases unsuitable and helped to cause a breakdown. On the other hand many retrainable patients were remaining on social assistance as unemployable. The Vancouver Occupational Industries was founded in 1939 to provide retraining of tuberculous patients and other handicapped people. Vancouver thus became the first city in Canada to have a program for retraining sanatorium patients.

But the project was not successful in actuality. Due in some measure to war economies, an attempt was made to put the sheltered workshops programs on a commercial basis, which in itself made them therapeutically unsound. Also, the initiation of the assembly line method, by which patients made only one part of an article, soon resulted in a loss of interest on the part of the patients. Many of them left sheltered employment and turned to more remunerative work. The project was eventually abandoned.

There are at present facilities for psychological and aptitude tests for patients, and some retraining courses are available. There is also some marketing of articles produced in occupational therapy, some assistance in job placement by the Special Placement Division of the National Employment Service; but there is no adequate retraining and job placement program as such. A great deal of rehabilitation work is currently being done by the British Columbia Tuberculosis Association.

## Voluntary Agencies in Tuberculosis Control

The most important voluntary agency in the field of tuberculosis control is the British Columbia Tuberculosis Society, the Provincial branch of the Canadian Tuberculosis Society. It was founded in 1904 to enlist the services of the ordinary citizen in preventive work, and to cooperate in the treatment of actual cases. Funds are raised principally through the annual Christmas Seal campaign. The Society employs a full-time worker to handle the educational work of the division which includes the publication of an excellent series of pamphlets for patients, their families and the general public. Movies and library facilities are also used in the educational work of the Society. There is a fulletime rehabilitation officer who assists in the retraining and job placement of patients. The Society has also fulfilled two other functions of a voluntary agency in the tuberculosis field, namely, research and demonstration of new activities. It has sponsored the development of survey work through the mobile X-ray vans which it bought and presented to the Tuberculosis Division. In 1949 the Society built and equipped the Christmas Seal Institute at a cost of \$500,000. The Institute provided up-to-date equipment for the more complicated surgical procedures in tuberculosis which had not previously been available in Canada.

British Columbia Tuberculosis Control services compare favorably with

those in the rest of Canada and in many parts of the world.

It is now proposed to examine how these services were utilized by the patients and families in the sample group.

#### CHAPTER 3

# Problems of the Tuberculous Patient as an Individual

Tuberculosis is a chronic reactivating disease requiring protracted treatment. There is no means of foretelling how long it will take for a patient's lesions to become stabilized. Because of this, and its contagiousness, tuberculosis necessitates a more complete dislocation of a patient's living patterns than any other disease. Even if the patient succeeds in arresting the disease, he still has to learn how to live within the life-long limitations it imposes. This usually requires partial or complete revision of his living and working habits.

The cure itself calls for the subjection of the patient to a regime stricter and more all-embracing than that imposed by the sternest military discipline. This must be continued unremittingly for a much longer period of time than in most other illnesses. Even if the patient follows the regime faithfully, there is no guarantee of cure — only the reasonable hope of recovery eventually if he cooperates. There is also no guarantee that recovery will mean that the patient can become completely self-supporting again. This may seem to be a gloomy view of tuberculosis, but it is a factual one; and these implications are sooner or later realized by most patients.

The adjustments that the tuberculous patient must make are complex and leave no area of his life untouched. The personal, family, social, economic and vocational aspects of his life are all involved. What then, are the adjustments which the patient must make if he is to accomplish the cure? What are the problems he must face and overcome both in himself and in his environment? What

seems to be the factors determining success or failure?

Acceptance of the Diagnosis

It may seem self-evident to state that the primary requisite for the successful treatment of tuberculosis is that the patient must accept the diagnosis and face his feelings about it. Yet many patients hinder the successful treatment of their disease for a considerable time, because they do not in the first instance accept the diagnosis. To most patients the diagnosis comes as a shock. Even to those who anticipated the possibility there is still, to most people, some degree of shock in having their fears verified, though to a few, the knowledge comes as a release.

As Table 8 (page 57) shows, sixty-five per cent of the sample group did not suspect that they had tuberculosis. Many of the patients are of the opinion that nothing they have to undergo later compares with the shock of the initial blast of hearing their diagnosis. It has been noted by many observers that, hypochondriacal and anxious individuals apart, patients who are familiar with tuberculosis usually adopt from the start a more courageous attitude than those who know little about it.

"A person who knows what he is up against and what he is in for is at a definite advantage as compared with another who is uncertain about his opponent's strength".

The responses of patients on learning their diagnosis varied widely, from hysterical behavior, to apparent apathy. The feelings which they expressed ran the gamut'from anger, despair, guilt, humiliation, shame, resentment, anxiety, doubt, incredibility, helplessness, and depression, to open belligerency. A small minority rejected the diagnosis completely and maintained this attitude.

l. Wittkower, E., op. cit. p. 21

Table 8. How Cases in the Sample Group Came to be Diagnosed

How Diagnosed	People Living in a Family	People Living Alone		P.C.
1. Following a hemorrhage	5	2	7	10
2. Consulted doctor because of ill health	16	5	21	25
3. Diagnosed by the survey clinic  (a) Mobile survey clinic	38	13	<i>5</i> 1	65
Industrial University General e.g. Department	3 2			
stores	6	2		
(b) Stationary survey clinic  l. Referred for routine X-ray from V.G.HO.P.D. from City Jail from Army Recruiting Centre	1	ĩ		
2. Contacts of known cases reporting for checkup	4			1
3. Healed cases reporting for checkup	i	·		
4. Self referred for checkup	9	3		
5. Reason for referral not stated - apparently self referred	9	7		
6. Tuberculosis accidently discovered when X-rayed for logging injuries	1			,
Total	59	20	79	100

Mrs. G.

Was very angry when given the diagnosis. She ranted and raved as to what she would do to the person who had infected her if she could only get hold of him. She was referring to her husband, an ex-patient, about whose illness she had not known until after their child was born and he requested that the child be given the tuberculin skin test.

Patient was estranged from her husband and living in commonlaw union with another man. Her father told her that her tuberculosis was a retribution for her way of life. Patient denied she had a guilty conscience about it.

Later, when her case proved terminal she described her condition as "a judgment".

Mr. Y.

Said if the guinea pig test was positive it was because the doctor had not scrubbed the germs from other patients off his hands before undertaking Mr. Y's test.

Mr. J.

Said he knew he had tuberculosis, but resented all suggestions that his disease was infectious.

Some patients, while outwardly accepting the diagnosis, seemed impervious to the recommendation that they begin rest treatment right away, to prevent the spread of the disease. This could, however, be due to the fact that many patients when told of their diagnosis hear the dread word "tuberculosis", and suffer a mental blackout. They are unable to absorb anything that the doctor says to them in the way of further explanation. These people's first reactions develop more slowly over a later period of time.

Some patients try to erect a barrier against any intrusion of knowledge about the nature of the disease.

Mr. H.

Did not wish to be told anything else about tuberculosis, and what he should do about it. He thought people were better off not knowing.

Mr. 0.

Took two bottles of cod liver oil and felt so much better that he returned to his logging camp convinced that he had cured his tuberculosis.

Most patients expressed some feelings of inferiority, inadequacy, and

a real fear of rejection by those most important to them. Fear of loss of love, respect and status as a consequence of contagiousness was a strong component in the feelings of most patients. It was not confined to those patients with family attachments.

was a 40-year old single man. He told the public health nurse, when she discussed with him the matter of examination of contacts, that he would carry out the necessary precautions himself, but he did not want the family with whom he was living to know of his disease. He was afraid they would ask him to leave if they knew. He very much valued the congenial living he had enjoyed in their home for many years.

Even patients who show little apparent concern about their disease need to be helped, as this outward front is often a defence against underlying anxiety and decression.

Whatever a patient's initial feelings are regarding his illness, he needs the release of bringing them out into the open. Indeed this is an essential step in treatment, because until he can do so he is not ready to move on to proper orientation regarding the disease itself. It is here that the patient can benefit from casework help. This is one reason why all patients should be referred to the social worker as soon as possible after diagnosis. At this point, neither family nor friends can give the patient the release and support that a warm, accepting, professional relationship can.

Initial reactions to diagnosis are followed by the emergence of a patient's basic attitude towards his illness. This is, in the main, conditioned by his individual personality and life experience, and usually corresponds to his previous pattern of meeting life's difficult situations.

The medical social worker here makes an important contribution to the treatment plan. As soon as possible following diagnosis she poses and answers, as a result of her contact with the patient, the all-important questions:

What meaning does this illness have for this patient at this particular time?

Why did he become ill when he did? Why did he become ill in the manner he did?

What is the goal of his behaviour? What kind of person was he before he became ill? Does he view his illness as a punishment? Is he using his illness to punish somebody else? Does he view his illness as a welcome escape from responsibility, or an unbearable situation? Does his illness provide an acceptable and long-sought excuse to sink into dependency? Is he enjoying his illness because it makes him the centre of attention? Is he exploiting his illness to a neurotic pattern of living so that it becomes so much "stage property"?

Not until these questions have been satisfactorily answered can the treatment plan be geared to an individual patient's needs.

It is also important to know the facts about a patient's immediate social situation prior to diagnosis, as the two following cases illustrate:-

Mr. B.

Was a young man of 25. Following his admission to the sanatorium it was noted that he was extremely quiet and deliberately shut himself off from the other patients and the staff. The social worker learned that the patient and his fiancée had just set their wedding date when the patient received his diagnosis. He refused to see his fiancée again, without giving her any reason for so doing. Sherlearned of his hospitalization, phoned repeatedly, left messages, food and flowers. Yet it was a considerable time before the patient answered any of these overtures.

Miss Z.

Was a twenty year old single girl who was illegitimately pregnant when diagnosed for tuberculosis. She said later, "To be pregnant and to have tuberculosis too, was just beyond me". Consequently, patient made a very poor adjustment to sanatorium living. She told nobody, not even her doctor or her family, of her pregnancy until her condition was self-evident.

## Problems in Orientation

Orientation to tuberculosis is always a highly individual matter. It cannot be accomplished on a mass instruction basis. Even factual information regarding the disease is absorbed at different rates by different patients.

Their feelings about it are still more varied. It is a well-known fact that people tend to hear and interpret information selectively, according to the pattern of their psychological defense mechanisms. They unconsciously reject or misinterpret information which threatens or disturbs these patterns.

From the practical point of view, what a patient considers important about his illness is, in the long run, more vital than what the doctor knows to be important.

The two following cases illustrate this fact.

## Mr. Q.

Was a married man with children. He resisted all efforts to orientate him to his disease. He was surprisingly ignorant of the most elementary facts about tuberculosis, and maintained stubbornly that patients were better off "knowing nothing". One day in the sanatorium he picked up a book which he read out of sheer boredom. What he read left him so "scared and depressed" that he had to do more reading to find out if the prognosis was so serious in all cases. He began to read and absorb everything he could lay his hands on regarding tuberculosis, and to carry out medical recommendations he had previously ignored.

#### Mr. C.

Was a single man in his early forties, a known neurotic with hypochondriacal tendencies. He was forbidden to smoke because it caused him to cough excessively. He was resentful of the fact that other patients were allowed to smoke. He did not accept the doctor's explanation that if smoking resulted in coughing spells in them as it did with him, then the others would be forbidden to smoke also. Mr. C. continued to smoke, and told the doctor that he had read that smoking helps to cure tuberculosis, because "nicotine stops hemorrhaging", and "you should know that there is a comparatively low death rate among tuberculosis smokers compared to non-smokers". To the social worker the patient explained that he had to smoke, because "they" would not give him drugs.

Problems in an individual patient's orientation depend largely on his personality structure and the kind of emotional difficulty he experienced prior to diagnosis. The social worker plays an indispensable role in helping the patient work through any emotional patterns which are interfering with his acceptance of illness and treatment. She gives him an opportunity to think it through and talk

it out, thereby releasing his anxieties and misapprehensions.

One area in which the medical social worker is often called to give help is that of helping a patient deal with his fears. "Fear" it has been said, "can be a bigger black spot than the mark on the patient's lungs, and must be brought out into the open", if the patient is to respond successfully to treatment.

Fear of death is a very real one with many tuberculosis patients. Fear of suffocation is also common. Fear of confinement in an institution can prove an insuperable obstacle to treatment. Fear of the unknown, and fear of the future can negative medical efforts on the patient's behalf.

## Acceptance of Sanatorium Care

The acceptance of sanatorium care is an adjustment which most patients are called upon to make. Reactions to it vary widely. When a patient enters a sanatorium he in large measure gives up his right to self-determination. He no longer has the freedom of choice as to how he will live, what he will eat, where he will sleep, who will share his waking and sleeping hours, or what activities he will pursue. He gives up a great deal, and expects the gains to be correspondingly high. It is only the importance of his ultimate goal - recovery of health - which as a rule, makes him tolerate such an unnatural existence. For this reason, the modern sanatorium must offer to the patient more than mere custodial care during the period of his infectiousness to others.

The social worker's role in helping the patient accept sanatorium care is an important one. He needs individualized help in overcoming his reluctance or even strong resistance to sanatorium life. He needs preparing for the kind of life into which he is committing himself.

<sup>1.</sup> Dr. George Day, "Observations on the Psychology of the Tuberculous", The Lancet, Nov. 16th, 1946, p. 703.

The way that hospitalization is presented to him is important. If he can be helped to accept it positively as the best preparation for his life after recovery his adjustment to it will get off to a good start. It is most important that he should be convinced that the sanatorium has something to offer him as an individual patient. The patient and his family are primarily interested in what the sanatorium can do for him and are not usually receptive to interpretation of its necessity as a public health measure.

It has been said that.

"The greatest discovery anyone can make in a sanatorium is, that a substantial number of people conquer their disease and make that conquest permanent... This overcomes the fear, that despite all that can be done for him, his case will end fatally.. and that no man need remain forever slave to his previous habits and environment... that with patient and daily application, he can change his life and his mind."

The patient's motivation in accepting sanatorium care also needs to be examined, as it will often give the key to how the patient will use his period of sanatorium care.

- Mrs. K.

  Thought her family was trying to get rid of her.
- Mrs. I.

  Did not think she could get better in a sanatorium, but thought she owed it to her family to go there.
- Mr. U.

  Was foreign born, and for him a tuberculosis hospital had different cultural connotations. He needed to be helped to understand that the sanatorium is not a place where people are put away to die.

When a patient refuses to enter a sanatorium his motivation for so doing should be examined:-

<sup>1.</sup> Hudson, Holland and Fish, Marjorie. Occupational Therapy in the Treatment of the Tuberculous Patient, National Tuberculosis Association. The Livingstone Press, New York, 1944. p. 126.

#### Mrs. P.

A young married woman with far-advenced tuberculosis told the social worker that she could not enter the sanatorium because her husband did not wish her to. This proved to be correct, and concentrated efforts on the part of the doctor, public health nurse and social worker had to be exerted, before the patient's husband could be convinced of the value of sanatorium care for the patient.

#### Miss O.

A young single woman, said she could not go to a sanatorium, as she would die of loneliness. The social worker learned that the patient had been abandoned by her own family and had lived with a foster family to whom she was very much attached. She reacted with extreme anxiety to any attempts to separate her from them, even temporarily.

#### Miss L.

A twenty year old woman, refused a bed in the sanatorium because her father and sister had both died in the sanatorium, and to ask her to enter the same hospital was tantamount to asking her to sign her own death sentence.

## Orientation to Sanatorium Living

Having entered a sanatorium the patient needs help in utilizing its services constructively. The atmosphere can assist or hinder the patient's adjustment. Poor administration, niggardly budgeting, and indifferent staff members lead to low institutional morale, and intensify the inevitable periods of boredom, frustration, irritability and mild depression which all patients feel from time to time.

A patient entering hospital brings with him the omnibus of his life experience, to which he has reacted in his individualized way. He brings with him his feelings, motivations, prejudices, conflicts, defence mechanisms, preferred modes of satisfaction, and preferred modes of reaction to difficulties. All of which will manifest themselves in the communal atmosphere of sanatorium life. Even if an institution is ideally operated, most patients need considerable help in adjusting to this totally new way of life.

The medical social worker plays a vital role in assisting the patient in this area.

## Acceptance of Dependency

The hardest thing for a sanatorium patient to do is to rest. It is very difficult for any human being accustomed to the activity of daily living to lie quietly in bed twenty-four hours of the day, especially if he feels well, as many early tuberculosis patients do. No one on the sanatorium staff can make a patient rest. They can only make it easier for him to do so if he will.

In addition the bed patient must accept dependency on others, in meeting the personal needs which he has been accustomed to attending to himself. The difficulty of accepting the dependency role is often at the root of a patient's violation of rest orders, especially when rest means complete bed rest. Those patients who cannot be helped to accept dependency without undue guilt and anxiety never utilize their sanatorium treatment effectively, and sometimes the battle ends only with the death of the patient.

Jack S.

Was aged 21 when a diagnosis "moderately advanced active tuberculosis was made. He was the eldest son in a family of Yugo-Slav extraction. His father deserted, leaving his mother with four small children. Jack was always concerned about his mother and wondering how she was managing while he was in hospital ... He had the greatest difficulty in adjusting to sanatorium life. He discharged himself from the sanatorium on "personal business" grounds. About this time he married. Later he was given a prison sentence for retaining stolen goods. Because of his condition he was transferred to hospital from jail. In hospital he boasted he had played baseball every day while in jail for thirtyone months without any ill effects, that he was coughing less, and had maintained his weight. He again signed himself out when his wife deserted, leaving the younger of her two children on the doorstep of the Children's Aid Society. He then disappeared without trace, reappeared six months later, and went in the shipyards until a mobile X-ray survey showed he had active tuberculosis. He became very hostile to the tuberculosis control authorities, saying it was they who had caused him to lose his job by reporting his condition to his employers. Later he had to be re-admitted to hospital as an emergency. He was much more cooperative than formerly. When he learned that bed rost was the only thing, he requested to be sent to Tranquille so that he could rest without any distractions. By this time, however, little could be done to arrest the spread of the disease. Several months later he died.

He was 26 years old.

Sanatorium life inevitably reactivates a patient's conflicts regarding authority. Some patients difficulties in this area manifested themselves
in refusal to follow sanatorium rules. Such patients were in constant difficulty in their relationships with doctors, hospital personnel and other patients.

Mrs. F. was a case in point. She made herself very unpopular by her habit of swearing violently in the wards whether visitors were present or not, and by constantly making disparaging remarks about other patients. A considerable minority of patients in the group had similar difficulties, though not for the same reason.

There were those patients whose basic hostility manifested itself in poor precautionary technique, to the annoyance of both staff and patients.

Mr. T's attitude was typical. He said it was not altogether his fault that he got tuberculosis, so why should he be concerned about other people?

There were those patients whose hostility found more subtle and indirect outlets and were thereby a plague to the administrator and the staff, and a source of discord among other patients, in which they, the culprits, were never directly involved. Methods of non-cooperation in the sanatorium are multiple and devious, and the sample group contributed their quota.

Some patients made themselves very unpopular by being demanding of service. This is due, usually, to some underlying anxiety, as illustrated in the case of Mrs. R.

#### Mrs. R.

Became very hostile to sanatorium staff when her constant demands for service were not met. She accused them of neglecting her because she was not English. When the social worker talked with her, she learned that the patient's behaviour was related to the rejection she had experienced from her husband on account of her illness.

Some patients lack of cooperation was due to the fact that they had never really accepted the diagnosis. Mr. Y. was a case in point. He admitted

that following his first discharge from hospital, he lived a "fast" life because he did not believe he had tuberculosis. When he had to be readmitted, however, he reconsidered his opinion and was much more cooperative. Psychiatrically, this type of reaction is said to occur in rigid egocentric individuals accustomed privately to overvalue themselves and their opinions.

The social worker's help in uncovering the motivating anxieties which affect a patient's outward behaviour are a prerequisite to helping the patient to resolve them and improve his adjustment to sanatorium living.

There are some patients who settle down to sanatorium life exceedingly well, and offer no problems to staff or to other patients. The problems of these patients come at a later stage in illness. When rehabilitation begins, extraordinary difficulties are often encountered in getting them from the horizontal to the perpendicular.

# The Problem of Self-Discharge

There comes a time in most patients' lives when reaction to the length 2 of hospitalization reaches flood level and they consider self-discharge. The following are typical remarks.

- (1) I'm tired of all this sow business. I'm going to try a quick cure".
- (2) "I'm getting tired of being in hospital. I think I'll pick up better outside".
- (3) "They're not doing anything for me in this hospital, anyway".
- (4) "A tuberculous patient's life isn't worth a button, anyway.

  Why shouldn't I take a chance?"

l. Hartz, Jerome. "Human Relationships in Tuberculosis", Tuberculosis Control, Issue No. 56. Public Health Reports, U.S. Public Health Service, Vol. 65, October 6th, 1950. p. 1292 - 1305.

<sup>2.</sup> Wittkower, E. op. cit., p. 45, points out that in his survey, of a total of 785 patients, comparison of various sanatoria showed that premature self-discharges are related to sanatorium morale; the incidence rate of premature self-discharges goes up when the sanatorium morale goes down and vice versa.

Sometimes impatience with sanatorium living occurs because the patient feels so much better than he is prepared to take a chance as far as complete recovery is concerned. This reaction occurs most frequently following the abatement of acute symptoms, when the lesions are stationary, but certainly not well-healed. Yet the patient may experience a feeling of bodily well-being at this time which convinces him he is well on the road to recovery, and will be better off at home.

It is true that many patients control their disease at least temporarily without any form of treatment being administered. It is equally true that of all patients who are sputum positive at diagnosis, a great many are dead within ten to fifteen years regardless of the form of treatment administered.

Although there are no reliable records of the post-sanatorium histories of the self-discharged as opposed to the medically discharged, it is known that there is a marked correlation between length of treatment and survival 2 following treatment.

When the patient is going through this crisis, the services of the medical social worker are often a determining factor in helping the patient reach the point where he can decide to continue with sanatorium care. In many hospitals the medical social worker is routinely asked to interview all patients who are considering self discharge. This is not with the idea of talking them into staying, but because it is hoped thereby to give the patient an opportunity to discuss his reasons for so drastic a step, and perhaps, with the social worker's help, arriving at other ways of coping with his problems.

As Table 9 (page 69) shows, twenty-four per cent of cases in the sample group signed themselves out of hospital, though fourteen per cent later returned

<sup>1.</sup> Myers, op. cit. p. 395.

<sup>2.</sup> Hudson, Holland, op. cit. p. 97.

Table 9 Acceptance and Non-acceptance of Hospitalization by the Sample Group

Attitude to Hospitalization	People living in families	People living alone	No.	P.C.
Accepted when first recommended	33	14	47	55
Initially refused but later accepted	7	1	8	11 -
Discharged themselves but later returned	7	3	10	14
Discharged themselves and refused to return	7	0	7	10
Persistently refused hospitalization	3	2	5	. 7
Suitable for care at home	2	0	2	3
Total	59	20	79	100

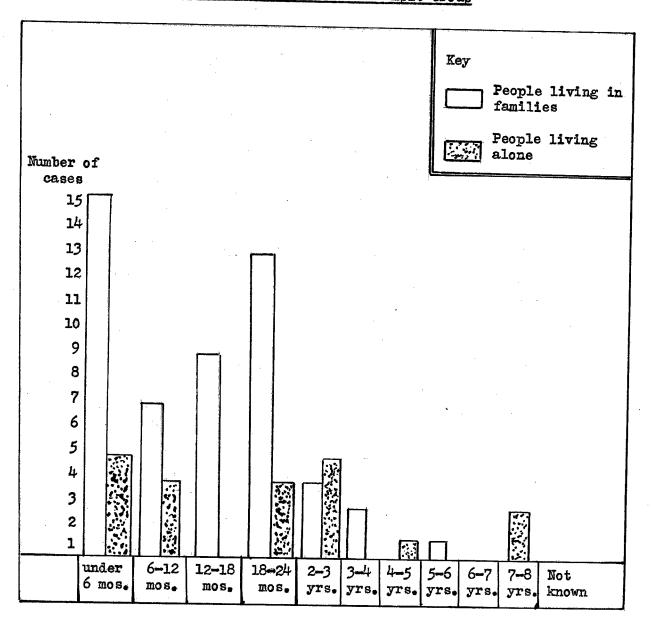
N.B. - Of those accepting hospitalization, 30% were readmitted once, 16% were readmitted twice, and 4% were readmitted three times.

to complete sanatorium treatment. This Table should be interpreted in connection with Figure 5, page 70, showing length of hospitalization in the sample group, which averaged eighteen - twenty-four months.

The reasons patients gave for self-discharge are illuminating:- Some of them seem trivial, but the medical social worker must remember that minor annoyances can be magnified into major ones in the artificial atmosphere of the sanatorium. These the patient could take in his stride if he were well. The reasons patients gave for self-discharge can be tabulated as follows:-

- l. Was going to die.
- 2. Couldn't rest in sanatorium.
- 3. To avoid surgery.
- 4. To settle marital affairs.
- Dislike of hospital life.
- 6. Was moved from a one bed to a ten bed ward.
- 7. Quarrel with room-mate.

Figure 5 Length of Hospitalization of the Sample Group



- 8. Afraid room-mates might find out she had venereal disease.
- 9. Personal business unstated.
- 10. Deaf mute patient, who was lonely.
- 11. Psychopathic personality.
- 12. To prevent stepson making a prior claim on dying husband's estate.
- 13. No reason given.
- 14. No reason given.

The reasons given by patients for self-discharge are not always the real ones, though some patients themselves are not always aware of this. Mr. L's case is one in point.

#### Mr. L.

Was a forty year old married man. He discharged himself when he discovered that his wife was living with another man. He divorced her and tried to get custody of their five-year old adopted son who had been placed in a foster home. The social worker noted that the strongest element in Mr. L's concern for the child seemed to be that he wanted to use the child as a weapon against his wife. Mr. L's real reason for self-discharge was thought to be his dislike of hospital life and fear of active treatment, because he refused to return to hospital after he had settled his personal affairs.

# Facing Surgery

Another major problem which the tuberculosis patient may have to face is the prospect of submitting to some form of surgical procedure, possibly even major surgery. Very few patients recover on bed rest alone, and if the various forms of pneumo thorax are considered as surgical procedures, it would be true to say that most patients have to face at least "the needle". Surgery is a crisis situation, yet the patient's usual method of meeting crises will not suffice here. In almost any other crisis there is something that a person can actively do. In surgery there must be a letting-go of the will; a complete surrender of one's life into the hands of another. This can activate subconscious fears of death, suffocation or mutilation, of which the patient may not be aware, or may be unable to face unaided.

The opinion of a psychiatric team is that:-

"To understand and help the patient master these fears often requires detailed understanding of the psycho-dynamics of personality. We have observed that recovery is facilitated when patients get psychological help in preparation for surgical treatment. The psychological trauma produced by recommendation for an operation produces tension states which are additional hazards to the surgical team. Adequate ventilation of the ideas and feelings associated with the tension will tend to reduce it, while neglect to do so often results in prolonged excessive pain and an extended period of invalidism\*.

Even pneumo-thorax can arouse great anxiety.

One woman patient in the group was "so scared and ill" following her initial pneumo-thorax that she refused to have refills. Needle phobia is by no means uncommon especially among women patients.

Sometimes refusal of surgery is based on misapprehension as well as fear, as the case of Mr. P. illustrates.

Mr. P.

Was thirty-nine years old, married, intelligent and an accomplished musician. He had far advanced tuberculosis at diagnosis and thoracoplasty was recommended. He could not face this and discharged himself from hospital. His condition retrogressed and he considered re-admission principally for the sake of his family. He discussed his apprehensions with the social worker, and it appeared that he was convinced that if he re-entered hospital he would "wake up one morning to find a hole in my side or a rib gone". Although the hospital authorities promised that no surgery would be performed without a patient's consent, Mr. P. did not consider that this was really hospital practice because "they compelled you to sign a statement on admission saying you would submit to anything they thought advisable. So you really have no choice about what is done to you". Mr. P. expressed a fear of being maimed for life or of dying while in hospital.

Whatever the reason for a patient's refusal of surgery, the medical social worker may be able to help him to "talk it through" and reach a point where from his own conviction, he can carry through the doctor's recommendation.

l. Coleman, Jules V., Hurst Allan, and Horbein, Ruth. "Psychiatric Contributions to the Care of Tuberculous Patients", <u>Journal of American Medical Association</u>. Vol. 135, No. 11, p. 699

Wittkower, in his survey of a total of 785 patients in many sanatoria, found that, while refusal of surgery may be due to many factors, it is most commonly, like premature self-discharge, related to low morale in the ward or sanatorium. The impression he obtained was that doctors often fail to give patients sufficient information regarding the nature and purpose of the operation, and to dispel their fears. Their own familiarity with the various surgical procedures lead them to presume that the patient knows more than he actually does. Hence the patient's main source of information is often other patients, who usually have a fund of knowledge, not all of which is correct, but which is imparted gratis to prospective candidates for surgery.

#### Economic Problems

An illness such as tuberculosis usually demands major adjustments in a family's economy. No matter how capably or willingly made, these entail eventually economic hardship and deprivation because of the chronicity of the disease. This can put an additional strain on family living to the point of break-up. It has been observed, even in families where there has been insufficient income over a long period, as well as difficulty in the management of it, that chronic illness places additional burdens on the family's adjustment. Increased economic hardship is often the factor which tilts the balance in an already precarious family equilibrium.

The patient's reaction to the loss of his own earning power is often a great problem in itself. Where the patient is the head of the family his loss of economic independence affects other lives as well as his own, and this is an additional source of worry and anxiety to him.

Many patients have real conflicts over the loss of their economic status, fearing it may lead to loss of all status within the family. The feel-

<sup>1.</sup> Wittkower, E., op. cit. p. 47.

ing of being a burden on one's family is a problem with which many patients wrestle long and hard before they come to peace within themselves. There were many examples in the group of patients resenting their wives going out to work to support the family and of patients reluctantly accepting partial or complete support from adolescent or married children.

Anxiety regarding economic affairs has a two-fold result in tuberculosis. First it prevents the patient from achieving the rest that is the corner
stone of the treatment. It is impossible for most patients not to worry about
how their families will manage when they are no longer able to provide for them.
If a patient feels that his family is suffering deprivation as a result of his
inability to provide for them during his illness, he in fact shares their deprivation, though he may outwardly be comfortably ensconsed in a well equipped
sanatorium, complete with all modern conveniences and three square meals a day.
If he feels that his family, in accepting social assistance is being reduced to
subsistence level, this in itself may be a continuous source of resentment and
inner conflict.

His anxieties may mount so high that he discharges himself from hospital or returns to employment before he is medically fit. There were several examples of the latter reaction among the males in the group.

The second effect of economic insecurity and deprivation in a family is that it intensifies any emotional problems which existed before onset of illness, or which have arisen because of it. Social and emotional needs are so inter-related that they are inextricably interwoven in daily living.

One of the greatest difficulties a patient may encounter during his illness is facing the necessity of having to accept social assistance for himself and family. It is an anomaly of our social system that we equate productivity with economic productivity, so that a person who becomes economically inadequate

loses not only his own self-sufficiency but also the respect of society, and often, along with it, his own self respect. While it is true that theoretically, illness is an acceptable form of dependency in our culture, the receipt of social assistance carries with it in practice a social stigma and a tacit implication that there is some inherent defect in a person who is unable to provide for himself and his family. This attitude can be a great blow to the patient and his family.

Of the sample group forty-five cases accepted social assistance, thirty at diagnosis and fifteen during convalescence. The accompanying table shows the economic status of those who did not accept social assistance. It is significant that about half of the non-acceptors were married women patients who were supported by their husbands. In almost all cases when the patients were breadwinners or single persons they had to accept social assistance.

Table 10. Economic Status of Patients who did not accept
Social Assistance

Married women supported by husbands	16
Single people who preferred to accept help from relatives	6
Refused social assistance, though eligible and no other visible means of support	2
Accepted diagnosis, but continued working	4
Refused to accept diagnosis and continued working	4
Newly diagnosed, living on savings	2
Total	34
	Single people who preferred to accept help from relatives

The mixed feelings of many patients are well illustrated by the case

Mr. D.

A single man, an orderly in a tuberculosis hospital, had just returned from a trip to his home country when he learned of his diagnosis. He told the social worker that his friends would take care of him until his admission to hospital and they did not wish him to apply for assistance.

A few weeks later, he applied for social assistance,

Complaints of the inadequacy of social assistance in terms of daily economic management were almost universal; in the group. Mr. E's case illustrates the general group feeling.

Mr. E.

Was very ill on admission and required thoracoplasty from which he made one of the quickest comebacks the medical staff had ever witnessed. He considered rehabilitation realistically. He did not think he would need social assistance except for a short while after he left hospital. He expressed real fear about his ability to live on social assistance. He said that patients were having breakdowns and requiring readmissions because they could not manage on social assistance. He wondered if the same thing would happen to him. He thought this was poor economy on the part of the Government. He resented having to report all his proceeds from his occupational therapy products. He thought this destroyed a man's initiative. In spite of these feelings he remained friendly to the social assistance worker and to the occupational therapist.

A small minority refused to accept social assistance though obviously in need. This refusal to "accept charity" was not confined to the older people. Some young people preferred to borrow from relatives or be supported by their families.

## Problem of Separation from Family, and Changed Family Relationships

Long separation from his family, both physical and psychical, is one of the hardest problems the patient has to face. His diagnosis brings this home to him forcibly when he is told that he must not kiss or caress his wife and children, and with this painful edict goes the lurking fear of the effect that long separation will have on his family relationships, especially marital and parent-child relationships.

The following cases show some aspects of the problem.

## Mrs. A.

Was a twenty-five year old married woman. She was concerned about her husband not writing regularly. She thought he was probably interested in other women. He had always been attracted to the opposite sex. But she wasn't going to worry like another patient who had died when her husband started divorce proceedings. Then relenting, she felt sorry for him, too because he would "go wild if he didn't have female company", and she had been in hospital for three years. But she intended to speak to him severely when he came at Christmas. Her underlying fear was that he might go home to Russia and leave her with the child. But the house was in her name, and was the only security she had.

## Mrs. Q.

Complained that her husband was very jealous. A male patient had lent her a radio and her husband accused her of infidelity because of this. She complained she gets little change apart from the radio, for when her husband visits her he just sits silent. When she tells him life is not very satisfactory to her, either, he laughs and says all she has to do is sign on the dotted line.

# Mrs. X.

Was twenty-six years old, married, with two children in a foster home. She felt she was neither needed nor missed at home. Her family ignored her, her husband comes once or twice a week, "depending on his mood". Her father didn't like hospitals and wouldn't visit. Brother just writes. She got no food or flowers like other patients did.

# Problem of Substitute Care for Children

This is usually a very acute problem where the mother is the patient and there is no suitable or available person to act as mother substitute. The income level of these families usually precluded ability to pay for full-time or even part-time housekeeper service. There is no community agency providing homemaker care on a free basis or on a sliding scale according to family income for indefinite periods. The Family Welfare Homemaker Service cannot undertake to provide the service indefinitely in cases of chronic illness.

l. Since the survey was made the Federal Government provided a fiscal grant in 1949 for a pilot project of this nature. The Metropolitan Health Committee administered the grant and the Family Welfare Bureau supervized the placement of twenty-five Homemakers in homes where the mother was a tuberculosis patient. This service was highly successful and much appreciated by the families concerned. However, it was discontinued in 1952 when the Federal grant ceased. The Provincial and local authorities, in spite of much campaigning by the Health and Welfare agencies, did not undertake financial responsibility for its continuance.

Consequently, placement of young children outside their families had to be considered by a number of families in the group. In ten cases children were cared for by relatives. Also a number of husbands were willing to undertake extra responsibility to enable school-age children to remain in the home when the mother was in hospital or convalescent. Three children were placed in the Preventorium. Fifteen others were placed in foster homes, either through Children's Aid Society or in private foster homes found by their relatives.

Some families refused to consider placements even when no other plan was feasible.

Placement planning for children always activates mixed feelings in the parents, as the two following cases show.

# Mrs. K.

Was a twenty-three year old married woman who had minimal active tuberculosis and was on bed rest at home. Placement of the child was not a new experience for her as she had once previously boarded him out so she could go out working. She consented to his placement in a foster home after she became ill. Becoming pregnant again, she expected the clinic doctors would recommend an abortion. When they did not, she said that if she was well enough to go through with a pregnancy she was well enough to look after her other child, whom she removed from the foster home. Then she looked after both children unaided except by her husband.

# Mr. N.

Was a twenty-three year old married man, very immature emotionally, and regarded his baby son as a rival for his wife's affections. When he learned his diagnosis they were living in one small room. As the patient was sputum positive it was recommended that he take a hotel room pending admission. He wanted his wife to place the child and come to Tranquille to be near him. He phoned his wife regularly from Tranquille until the doctor cut down the calls; so he sent wires. The wife, equally immature, was indecisive about continuing the marriage, as he had never supported her. Both seemed to look upon the boy as a burden. She asked Children's Aid Society to place the child while she sorted out her affairs.

#### Problems Created by lack of Family Cooperation

Lack of family cooperation can create manifold problems for the patient in the management of tuberculosis. Though an extreme case, Mrs. M's well illustrates this.

Mrs. M.

Was a twenty-three year old married woman who was readmitted following a breakdown attributed to excessive exercise and worry over marital affairs. Said she had to exceed her exercise because husband objected to her staying in bed and his having to look after her. He had also begun to drink and got in with a bad crowd. He made love to his girl friend in front of his wife, but "didn't know why, as he respected his wife". Doctor, public health nurse and social worker failed to help him understand tuberculosis, but the latter learned that his mother had been a chronic invalid. He resented having had to do many menial household tasks as a boy.

Following a reconciliation the husband's behaviour persisted, which greatly depressed patient. Her doctor stated that she needed "to want to get well". Her condition improved enough so that she could be discharged.

This time, however, she went to relatives.

# Problems in Preparing to Leave the Sanatorium Environment

It is a paradox that though most patients have great difficulty in adjusting to sanatorium life in the beginning, they almost all have some reluctance towards leaving. A patient being "built up for discharge" has mixed feelings. He is glad to be through the period of bed rest, but he has some qualms about his ability to resume his life outside the sanatorium. He wonders about the acceptance he will get from his family. He knows, too, that one purpose of the "building up" phase is to evaluate how well his lesions will stand up under increased activity, and he may therefore fear a reactivation of his disease.

To quote from the psychiatric team again:-

"Various suspicious and rebellious tendencies may appear at this time and patients may accuse the institution of rushing them in order to give their beds to incoming patients.... It is at this time that somatic complaints often assume a dramatic quality..... The somatic complaints should be treated as well as the underlying fears, and not coldly dismissed as psychological."

<sup>1.</sup> Coleman, Jules V., et al. op. cit. p. 699.

# Problems in the Rehabilitative Phase of the Illness

There must be a complete change in the patient's psychologic attitude if he is to adapt himself successfully to the next phase of illness — the rehabilitative phase. Until this time it has been demanded of him that he assume a role of complete dependency. Now it is demanded that he assume his independence again. Though he may ardently desire to do so, it is not without difficulty that he shakes off the comforting protection that sanatorium life offers him. One young girl, following discharge, said she would not mind breaking down again, as she missed all the girls so much.

It is not surprising, perhaps, that the most common difficulty in this period of illness is reluctance to take the recommended increase in activity. Persistent and unresolved difficulty in this area is often a sign of gross maladjustment in some area of the patient's life. The medical social worker can often be very helpful to the doctor in helping both him and the patient focus on what are the factors in a particular patient's personality which make the life of an invalid preferable to the satisfactions of normal living, or what it is in his life situation that he cannot face returning to.

Once this is discovered, the medical social worker can also help in evaluating the capacity of the patient to work through his difficulties, or the degree to which he can be helped to develop the capacity to cope successfully with such obstacles, whether in himself or in his environment. A small minority who from a medical point of view are extremely difficult to treat, are those patients for whom tuberculosis seems to serve the purpose of gradual suicide. Their wish to die is sometimes unconscious, sometimes consciously stated. Whatever is done from the treatment point of view, they get worse instead of better. As one doctor puts it, "A malign fate seems at work".

There are also those people who might be described as the "passive"

personality type; the ones who have given up trying in every area of life and sink back into an acceptance of chronic invalidism which defies all attempts to help them re-establish a more constructive pattern. There seems to be no point at which the doctor or social worker can get a foothold.

Some patients are aptly described as:

"increasingly disturbed patients who manage to achieve some precarious kind of equilibrium with severe pulmonary disease but remain chronically ill for years. They rarely become ambulatory, and if they do, are soon back in bed for years after an immediate and severe relapse. As personality types these patients tend to be introverted, withdrawn people who use their severe tuberculosis to guarantee care and affection for themselves. They seem to pay scant attention to their disease, yet manage to be the most discussed therapeutic problems in the sanatorium over long periods of time. They would probably be frank schizophrenics if their emotional needs were not somehow being precariously met by the care and sympathy they always manage to get for themselves in the sanatorium".

All these types of reaction were represented in the sample group.

Most patients, however, given adequate individualized help, can come through this phase and move on to the practical aspects of discharge planning. At this point the help of the medical social worker and the family case worker can be invaluable.

# Convalescence

Convalescence is considered the most important phase of tuberculosis, because during it the patient makes the transition to normal living. It is the phase during which most breakdowns occur, usually within six months of leaving the sanatorium. Physical aspects of living conditions are important and must not put undue strain on the patient.

l. Hartz, Jerome, "Human Relations in Tuberculosis", <u>Tuberculosis Control</u> Issue No. 56 of Public Health Reports, U.S.A. Federal Security Agency. Vol. 65, October 6th, 1950. p. 1303.

The emotional environment to which a patient returns is also important. The family need help in readjusting the living patterns they have developed in the patient's absence. They must also understand that he is not a completely well person.

The patient's feelings about returning home are usually mixed. He is on a rigid rest schedule which he must follow if he is to maintain the gains he has made in the sanatorium. It is very difficult for one person in a family to adhere to a schedule when nobody else in the house is bound by it, especially if there is no privacy. Many patients in the sample group did not have a room of their own where they could take their day-time rest. It should also be remembered that:-

"...while it is true that self-centered and introspective individuals are usually unduly concerned about their health, it is equally true that chronic sickness tends to make a person self-centred and introspective."

The two following cases indicate the problems which can occur following discharge.

#### Miss J.

Was a twenty year old single girl who returned to her family. Her mother, a confirmed neurotic, indulged Miss J. who exceeded her exercise, and compained that she could not rest in the small apartment which her mother, sister and brother shared. She and her mother were being supported by the brother, whom patient felt resented her presence and her illness.

#### Miss S.

Was a twenty-two year old single girl, one of a family of five children. The parents had separated many years before, and the patient was living with her mother and siblings who contributed to the family income. She had her own room, nicely decorated, with a new bed-room suite bought especially for her. She spent considerable time at leather work and knitting. She assured the public health nurse that she was carrying out clinic instructions faithfully. Her mother, however, said that the patient was hard to handle. She

<sup>1.</sup> Wittkower, op. cit. p. 22

swore at her mother and sometimes refused to speak for two or three days. She criticized her mother for keeping a male boarder whose payments helped the family income, but the mother did not like to ask him to leave because of patient's attitude. Mother suspected daughter of visiting her father down town, and patient was talking of going to live elsewhere. Mother thought she would be better boarding with girls her own age. Also said daughter was often out late. Patient had a boy friend and became engaged but her lesions broke down and she was readmitted to hospital.

A patient who is not well enough to manage on his own, and accepts city boarding home care also has problems in adjustment. During the past ten years at least five or six tuberculosis boarding homes have been opened and utilized by City Social Service Department for tuberculous convalescents. The operators of all except one requested to be relieved of their boarders within six months to two years. This was not primarily because of fear of infection but because of practical difficulties in daily management and discipline. The one boarding home which has been in existence fifteen years, owes its success largely to the personality of the landlady who has the knack of handling tuber-culous convalescents.

The patient who is discharged to a room of his own must be careful to strike the balance between too much and too little exercise. The problems of this group are discussed further in Chapter Five, as these patients are a special community problem.

Some of the patients in the group had "flareups" in their condition following discharge. For purposes of this study, "flareup" is defined as a reactivation of the disease in patients who had become well enough to leave hospital but had not yet been certified fit for full time light work. Flareups occurred in eighteen per cent of the total sample group, in the ratio of ten men to four women, most commonly within the first six months following discharge. Only two of the flareups followed self discharge from hospital, though their occurrence might have been anticipated in all but three of the fourteen cases,

because the patients were grossly exceeding their exercise orders.

It is interesting to note that while flareup was much more common in patients living in family settings, breakdown, that is recurrence of disease in those who had been certified well enough to undertake full time light work, was much more common in the group living alone. Flareup was often related to a too active social life on discharge, while breakdown was most commonly related to return to unsuitable employment.

## Rehabilitation

It is difficult to estimate the precise point at which the rehabilitation of a patient begins. In a sense, rehabilitation begins with diagnosis.

Actually, treatment and rehabilitation proceed together. In the restricted sense, rehabilitation begins when the patient has reached that point in his illness where he can begin to take an active part in the plan to restore him to community living as self-supporting as possible. The standard definition of rehabilitation is that drawn up at the National Conference on Rehabilitation at Washington, U. S. A. in 1942;

"Rehabilitation in tuberculosis is the restoration of tuberculous persons to the fullest physical, mental, social, vocational, and economic usefulness of which they are capable".

It is often possible to commence vocational re-training while the patient is in the sanatorium. As a preliminary or concurrent measure, some form of occupational therapy is usually recommended. Its function in a sanatorium is many-sided. It helps to maintain the morale of patients, it helps them to occupy time usefully, it may cultivate new interests which can later be turned into a part-time source of income, and it can help provide training for a more suitable type of work. Occupational therapy is, however, an adjunct to vocational training, not a substitute for it. A good deal of occupational therapy is craft therapy which does not appeal to those patients who may not have the interest or

skill to produce work of marketable standard.

Vocational re-training may involve academic educational courses, but should never be limited to these. It is often possible for a patient to complete the required high school grades while in hospital. Not till later can be undertake technical, industrial re-training.

In addition, the patient's work capacity needs to be evaluated medically and his work tolerance tested. He also needs the opportunity to develop confidence in himself and his capabilities. These conditions are usually found in sheltered workshops and in very light occupations.

A minority of patients in the sample group wished to return to their former jobs which were medically suitable. The majority, however, could be divided into two large groups; - first, those who because of their medical condition will never be more than partially self-supporting. This group requires specialized retraining, plus selective placement in sheltered workshops of some kind. The second group are those whose prognosis is good, and who can be completely self-supporting but who are unable to return to their former work because of its unsuitability.

Casework service to patients in the first group is directed towards helping them make a constructive adjustment to their disabilities. The second group often need help in accepting the change-over to sedentary employment. It is not to be presumed that most patients will welcome the idea of sedentary work merely because they realize it is in their best interests. Many patients who have lived a life of action and who suffer from what has been called "cultural poverty", have neither the capacity nor the inclination for sedentary work, as the following cases show.

Mr. A.

A young man in his early twenties, had been a logger before his illness. He returned the sheet the Rehabilitation

officer gave him completely blank. He said there was nothing in it for him. He was ruined anyway. He wasn't going to do anything for the rest of his life, he would rather have no job than a light job. It was no use planning for a future that for him wasn't there. It was a toss-up whether he would return to the woods and have a good time and then return to the hospital to die. The woods held more appeal than any light job, even though the light job helped him to live to be 100 years old.

Mrs. L.

Did not want any rehabilitation course. All her previous plans had had to be cancelled so it was better to live from day to day. She understood she should not return to her former employment, but she would wait and see - something would perhaps turn up.

The patient's emotional readiness to undertake any specific form of rehabilitation training is the requisite without which no plan can succeed.

The role of the medical social worker in evaluating the patient's weaknesses and strengths in terms of ability to use retraining facilities and helping him work through his feelings regarding the whole area of rehabilitation is a professional job demanding the highest in casework skills.

Rehabilitation is not completed till the patient is restored to the community again as fully self-supporting as possible. This implies the existence of a job-placement program. Because such facilities do not exist in sufficient measure in Vancouver, the tendency in the sample group was for patients to return to their former jobs. As these usually involved the things which are occupational hazards for the ex-tuberculous:— heavy manual labor, irregular hours, night work and exposure to extremes of temperature, it is not surprising that the percentage of breakdowns in the group was high, as Figure 6 (page 87) shows.

For purposes of this study, a "breakdown" is defined as a recurrence of active disease in those whose lesions had become sufficiently well healed previously, to allow them to undertake full time light work, on medical recommendation.

Breakdown occurred in eighteen per cent of the total sample. But if

the sample group of those living alone is considered separately forty-five per cent of the people living alone suffered a breakdown, as compared with a corresponding figure of ten per cent for those living in a family setting.

In five cases out of the total breakdown group, a breakdown was unexpected, as the patients! lesions were apparently well healed, and they were following a moderate regime. The remainder (over half of the group) were following a mode of life unsuitable to an ex-tuberculous patient, usually because of unsuitable employment.

Patients need to remember that having had the disease imposes some limitations on them which they must observe for the rest of their lives. Though a patient may recover his health, he still retains the bacillus within his tissues. No matter how well-healed lesions may appear to be this does not exclude the possibility that the bacilli he carries within him may be stirred into activity again by anything which lowers his powers of resistance. Therefore, for the rest of his life, he should observe moderation in living habits. If he does, the chances are that he will maintain his health and conserve the gains made at such a cost to himself, his family and the community.

KEY People living in a family People living alone Number of Men cases Women 3 Breakdown 1 -6-12 3-4 5 - 6 7 - 8 8 - 9 9 - 101 within following resumption mos. mos. yrs. yrs. yrs. yrs. yrs. yrs. of light work

FIGURE 6 Incidence of Breakdown in the Sample Group

#### CHAPTER 4.

## The Family and Tuberculosis

Tuberculosis is an illness whose impact affects a patient's entire family. Their understanding and cooperation are essential in the successful management of the disease. Like the patient, his family must be willing to accept major readjustments in living patterns as a result of the disease.

Changes in family roles are inevitable, whether the patient be the father, mother or single adult, musband or wife. The family must be prepared to accept constructively the consequences which the long absence and incapacitation of a family member entails. Some family members may have to assume the absent patient's role as parent or breadwinner. They must accept a reduction in living standards with the resulting readjustments. At the same time they must maintain high standards of nutrition, for their own and the patient's sake. They must be prepared to accept their part in the treatment plan and take responsibility for the daily management of the patient's illness while he is home. Family problems existing prior to the illness are usually intensified, while others may arise as a result of it. All these are important ingredients in the emotional atmosphere surrounding the patient, and their presence or lack may play a great part in determining the nature of the adjustment he makes to his illness, his eventual degree of recovery and the success of his rehabilitatory efforts. Without family support the patient finds fate's blow even harder to take.

The situation of the patient with no family presents, ipso facto, even greater difficulties.

Family attitudes varied as much as did those of the individual patients.

Mrs. V.

Received the public health nurse politely but resisted all suggestions that her son had tuberculosis.

Mrs. C.

Was cooperative regarding X-rays for herself and family, but did not want her roomers, who shared the household facilities, to know of her son's diagnosis.

Mr. M.

Mr. M. thought his daughter would die from the disease anyway and "would just as soon see her go now as live like an invalid for the rest of her life".

In some families there was a real fear of infection which fear the patient was made to feel. In others there was a fatalistic attitude; or complete unconcern. Sometimes a family refused X-ray checkup, or would ignore precautionary techniques. The following case illustrates this attitude.

Mr. P.

Was a married man with three children. He drove a city garbage truck. His wife who had severe tuberculosis, discharged herself from the sanatorium following the first stage of thoracoplasty and refused to return for the completion of the surgery. She was sputum positive, and told the public health nurse she did not practice precautionary measures as she thought it a lot of "tommy rot".

When the public health nurse discussed checkup examinations with Mr. P., he stated he was not worried about infection of the children or himself. "If you are going to get it, you can get it by walking down town" he said. "With all the precautions they took in hospitals a lot of nurses got it". There was as much tuberculosis walking round Vancouver as there was in his own home. Besides, "one that's got it is one that you don't need to be afraid of". He didn't believe in "taking dirty stuff from a cow and putting it into a child's body". He thinks his wife would be dead now if she had stayed in hospital, and after all, she doesn't need to worry about the housework.

Undoubtedly, Mr. P. took excellent care of the children. He prepared their school lunches and put them in the frigidaire for next day; was a good cook, handy with a needle, bought a washing machine and worked it, and tried to get a suitable woman to do the heavy work.

# Problems of Daily Management when a Patient is Home

All patients, whether they accept sanatorium care or not, are home for considerable periods of their illness, including the two most crucial ones from

the patient's standpoint — namely, when he is awaiting admission to the sanatorium and when he is convalescent. Family attitudes at these times are specially important.

The period when a patient is awaiting admission is an extremely difficult one for both him and his family. The recommendation "Admit" is interpreted to mean immediate bed rest. If the patient is sputum positive, the task of looking after him is doubly difficult. In order that the patient be given the required care, the home must be turned into a minature hospital. The British Columbia "Handbook on Tuberculosis" states that:-

- 1. Patient must have a room to himself if at all possible.
- 2. All excess and stuffed furniture to be removed.
- 3. Patient's linen and towels to be kept separate and disinfected with lysol solution or soaked in boiling soapy water before putting with family wash (ambulatory patients to use their own towels always).
- 4. Dishes and cutlery to be boiled if possible after each use or washed in boiling soapy water, and rinsed in clear hot water. If this is conscientiously carried out, there is no need to keep the dishes separate.
- 5. Blankets, comforters, pillows should be frequently hung in moving air, outside in the sun if possible.
- 6. Outer clothing, suits, dresses and topcoats are to be protected by careful conscientious use of the paper handkerchief. Any spotting which does occur is to be carefully cleansed with soap and water and the clothing hung in moving air. All outer clothing should be hung in the fresh air frequently. Pressing with steam whenever possible is also effective.
- 7. Damp dusting to be done daily.
- 8. Home to be thoroughly and frequently aired.
- 9. Asceptic techniques in the home should follow as closely as possible that followed in institutions.<sup>2</sup>

The difficulty of carrying out the necessary precautionary techniques is greatly intensified by the extremely unsatisfactory housing conditions in which many of the families in the group lived. Apart from those living alone in housekeeping or sleeping rooms, there were twenty eight patients living in houses,

<sup>1.</sup> Hatfield, op. cit. p. 89.

<sup>2.</sup> Hatfield, op. cit. p. 87.

and thirty one in suites. Those living in houses were better off as regards sanitary facilities, but at least half of the houses had defective heating equipment and food storage facilities. Very few of the suites were self contained. In most, bathroom and toilet facilities were shared, and in some, kitchen facilities were shared too. Quite apart from the fact that there was overcrowding according to the standard of "one person per room, excluding the kitchen and bathroom", it is significant that of all the fifty nine patients, in only eleven cases was it possible for the patient to have his own room.

# Overcrowding

Apart from the opportunities overcrowding offers for the spread of infection it can cause emotional conflicts of various kinds due to lack of privacy for any family member; it can make it impossible to show adequate respect for the rights of others; it engenders resentment when one is rights are interfered with; it fosters uncongeniality between family members; it helps to cut off young people from normal social relationships; it is the most potent single factor in the continuation of deleterious living habits; it prevents concessions which must be made to the patient because of his illness; it can impose a tremendous strain on both patient and family, from which there is no release when there is no privacy.

It is quite true that people react to unsatisfactory living conditions in a variety of ways, but most people in the sample group expressed some degree of frustration with their living accommodation.

## Children

It is dangerous to expose children to an open case of tuberculosis because it is impossible to control the amount of infection the child receives.

There is no way of foretelling a child's resistance level, and the chances of developing a progressive fatal infection are much greater among exposed children

than among non-exposed children.

For this reason tuberculosis patients are expected to separate themselves from their children at least during the period they are infectious. Difficult as this may be for the tuberculous parent and the remaining parent, it is most difficult for the child. An entire thesis could be devoted to the effects on parental tuberculosis on children. One brief glimpse of this can be illustrated by the case of Mrs. U.

#### Mrs. U.

Mrs. U's children were placed in a foster home when she went to hospital. She discharged herself while still sputum positive; directly against doctor's orders. She contacted one of the children in the foster home, and he visited her on the sly when he went to the public library. The ten year old boy admitted kissing his mother many times. The stepfather invited him to visit them oftener, but the boy knew he was doing wrong, though he did not like to disappoint them.

When the parents visited the boy at the foster home, the foster mother asked the mother not to come again, as she considered the mother a very sick woman.

# Effects of Tuberculosis on Family Relationships

Many families in the group successfully weathered the stress and strains on relationship caused by the patient's illness, but many others did not. No matter how great their concern for the patient a relative does not always have the ego strength to assume a new family role. Mrs. Z's case illustrates this.

#### Mrs. Z.

Learned that her husband had far-advanced tuberculosis when he was X-rayed for a logging injury. She gave him good care in the home, but nullified this by periodic drinking bouts, which later caused him to discharge himself from the hospital through worry over her after she came to visit him in an intoxicated condition. Later he refused an available bed because one day's notice did not give him time to make financial arrangements for her. Her dependency needs continued to be an undue strain on the patients.

Sometimes, though a wife may competently assume the breadwinner's role, there are underlying dissatisfactions which can have serious repercussions on

the marital relationships, as Mrs. B's case shows,

# Mrs. B.

Was a forty year old woman at the time of her husband's diagnosis. They had a five year old daughter. He was chronically ill for seven years but refused surgery, though his condition slowly retrogressed. She gave him excellent care and cooperated fully in the treatment plan. Finding Mother's Allowance not enough she went out to work. After seven years she asked for a divorce, saying she was having to neglect her child, in order to make a living. Also, she knew another man who wanted to marry her. Her husband, who had known him previously, said he approved of him and was glad that his daughter would have a good home, as there was not much chance of recovery for him. He admired his wife's frankness in the situation.

Later, he became well enough to be discharged and married a girl over twenty years younger than himself.

# Economic Problems Created or Intensified by the Illness

Economic hardship is another great difficulty which the family of the patient has to face. Almost all families in the group complained of the difficulties in this area. Without exception, those who accepted social assistance found it inadequate. Some of them borrowed from friends or relatives to supplement it. No matter how cooperative a family was or how great their strength, continued economic problems sapped them eventually.

This is well illustrated in the case of the P. family.

## Mr. P.

Was a thirty-nine year old married man with a four year old daughter when he was diagnosed minimal active tuberculosis. Though cooperative his condition did not improve. His wife, happy, intelligent and understanding, moved to a small farm holding in Kamloops to be near him. She took care of all heavy work and household duties while he made the furniture by hand. He wished to take vocational training for light work. Later he had to be re-admitted to Vancouver hospital for a reactivation of his lesions. Finally they bought a float house, the inside of which they fixed up splendidly. Mrs. P. made the rugs, curtains, chair-covers and kept everything always bright and clean. They had no taxes and well water cost them \$1.00 per month. Mrs. P. collected and sawed driftwood which kept the house always warm and dry. He spent much time fishing from the float. But after several years the P's, in spite of rigid budgeting and

making their own clothes and household furnishings, and collecting their fuel, could not live on Mother's Allowance, so Mrs. P. worked as a domestic, but only intermittently as they could get no reliable person to look after the small girl.

On his discharge Mr. P. took care of the child while Mrs. P. worked in a cannery. But the doctor ordered a cutting down of his household duties as being excessive. Consequently, Mrs. P. worked on the night shift, or from one to five p. m. only. Mr. P. spent one hour per day on a bookkeeping course, which they had to finance themselves because of her earnings. They continued to save a little each week, as they did not wish to be left homeless if industry took over their waterfront spot and made their property valueless. They also paid for music lessons for the child. Mrs. P. continued as cheerful as ever. But Mr. P. became depressed after eight years of illness, his lack of improvement and inability to take his share of domestic responsibility.

## Inadequacy of Social Assistance Set at Subsistence Levels

If we expect to obtain the patient's fullest cooperation in the treatment plan we owe it to him to take proper care of his family while he is incapacitated. It might be argued that the tuberculous group in British Columbia is in a privileged position as regards public welfare allowance. This is undoubtedly true but even with the extras they are allowed, it is still difficult for a patient and his family to manage adequately over the long period of the patient's illness. Basic social assistance rates make no allowances for the provision of such essentials as cleaning and toilet articles, clothing repairs, shoe repairs, household replacements such as brushes, pans, crockery, linen. It makes no allowance, whatever, for those "semi-luxuries" which have become almost necessities in modern living, and which do so much in preserving patients' sense of well-being — such things as newspapers, radio, tobacco, cosmetics, permanent waves, movies and the occasional ball game.

The heat and light allowance might be made to stretch if the family used one room only, eat only one hot meal a day, and went to bed early. If there is an infectious or sputum productive patient in the home it is practic-

ally impossible for a family or patient to have all the hot soapy water required to carry out the precautionary techniques regarding dishes, linen and clothes, and stay within the fuel allowance.

The British Columbia Social Assistance Act states that assistance should be given according to need, and according to the standards set. These standards, however, are set at subsistence levels. Our society is still influenced by the philosophy that social assistance levels must be placed as low as possible to act as a deterrent against people living on social assistance any longer than necessary. It is considered that assistance at higher than subsistence levels would undermine people's characters and make permanent paupers out of them. These views still persist regardless of our experience in depression years which provided irrefutable evidence that most people normally desire a fuller life than that provided by bare existence, and that most people want to work when the opportunity offers.

It is the frustration caused by enforced idleness which eventually makes some social assistance recipients unresponsive to normal satisfactions, thus resulting in what we have come to call "pauperization" of the individual.

Besides, as every social worker knows, the work-shy are not made worker conscious by deterrent social assistance rates. Their's is a social sickness which goes much deeper, and for which that kind of punitive "therapy" is entirely ineffectual.

Another argument unfailingly raised whenever social assistance levels are discussed is that the normal standard of living of such as those in the sample group barely reaches subsistence level, anyhow. Yet available evidence indicated that most people in the group were in the borderline income brackets and would not have fallen to subsistence levels had not illness pushed them over the edge. It is true that there was a small percentage of chronically destitute.

people in the group, but from the point of view of tuberculosis control it is our responsibility to raise such people to a better standard of living in the economic scale if only as a public health measure, quite apart from the broader question of their rights as human beings.

There are, as Dr. Wade Hampton Frost reminds us, two conditions favouring the spread of tuberculosis, intimate exposure and poverty.

# Family Attitude to Convalescence is Critical for Patient

All patients spend the greater part of their convalescence in the home. Family attitudes are especially important at this time. The patient needs to be handled understandingly but normally, and with due regard for his physical limiterations. The family, like the patient has to make major adjustments in this phase of the patient's illness. They have had to devise new patterns of family living during the absence of the patient. Now they must revise them and make a place for the returning patient. Casework help at this point is often a great facilitator of the readjustment process for both family and patient.

The onus for non-cooperation is not always on the family, for in some cases the returning patient refuses the family's proffered assistance. There were cases where the family offered the patient a home, yet saw their offer rejected in favor of a city boarding house. In some homes there was constant friction over the patient's refusal to follow rest and exercise orders. There was much evidence to justify the view that convalescence is the most trying time for the family as well as the patient.

# Problems of Families where more than one Member is Tuberculous

One tuberculous patient in a family creates a burden, but more than one patient in a family has a devastating effect on the whole family structure. The case of the A. family is presented as an illustration.

## The A. Family.

Consisted of parents and six children, the eldest of whom was sixteen. Mr. A. was diagnosed and accepted hospital-

ization. In the following year Mrs. A. contracted tuberculosis and was hospitalized. She worried about her children
in foster homes. In the opinion of the public health nurse,
the family was considered to be somewhat lax regarding precautionary techniques, and housekeeping standards were not
high. Nevertheless, family bonds were strong. There was
always a well-kept vegetable garden and chickens as additional
food supplies, and as time went on the family purchased
modern home appliances, as for example, a washing machine.

On discharge the father took unsuitable heavy work digging ditches which was all he could get. The eldest daughter contracted the disease, was hospitalized and made a good recovery, following which she took a stenographic course. The youngest daughter had a healed primary complex.

Because his work was too heavy the father reapplied for social assistance till he could get lighter work. This was refused because of the earnings of the two eldest sons, the younger of whom left home to go logging, where he got in with a "bad" crowd, started drinking and gambling. He was ashamed of the family history of tuberculosis, tried to conceal it and neglected to report for X-ray checkups though feeling ill. He contracted debts of over two hundred dollars which his sister repaid. The eldest son supported the family, though planning to be married himself. When reporting for his routine X-ray checkup, the eldest boy was diagnosed as moderately advanced active tuberculosis. The younger boy finally consented to X-ray and was found to have far advanced active tuberculosis. Both boys entered hospital. The younger boy died there.

Mrs. A. was distraught and refused to let the youngest son take a paper route for fear he would break down too. "I give them good meals, good clothes and a good home, yet one by one they get it".

While in Tranquille the eldest son learned that his father was working in a foundry because the family had been granted only reduced social assistance on the grounds that the daughter was earning. He became bitter, saying that he had been promised that his people would be looked after if he entered hospital. All he asked was that his father be helped to get lighter, more suitable work, so that social assistance would not be necessary for his family.

# Evaluation of factors determining successful management of the disease

There is no accepted index of success or failure in the management of illness. Yet examination of the case histories in the sample group shows that the degree of cooperation of the patient and his family are of paramount import-

ance, and might be said to be the greatest single factor influencing success or failure.

A patient's cooperation is affected by many things. The most important determinant is what is commonly called emotional maturity. This is a complex thing. It is most frequently found as the by-product of a happy life experience meeting all areas of need in the formative years. Its hallmarks are the problemsolving attitude towards life, freedom from undue mental conflict, the ability to be guided by reality principles and long term values, capacity to love someone other than one's self, good work adjustment, and all the other characteristics of the well-adjusted person.

In almost every case in the sample group where the patient was uncomperative, there was conspicuous absence of emotional maturity. Those patients who managed their tuberculosis successfully, usually showed evidence of maturity in other areas of living. The importance of this in relation to medical social work and to social services in general cannot be overemphasized.

#### CHAPTER 5.

In our modern world, community organization of welfare services is, or should be everybody's business. But in our complex, pressured way of life it is easier to leave it to the other fellow. Even with the cooperation of patient and family, the tuberculosis control program is ineffectual without the understanding and cooperation of the general public. "The battle against tuberculosis," as Osler once said, "is not a doctor's affair; it belongs to the entire public."

From the health and welfare view point, tuberculosis presents the most difficult administrative problems. Because of its communicability, it involves a multitude of social implications which no other disease presents to the same degree. Quarantine regulations cannot be established or enforced as in other communicable diseases, because it is impossible to estimate the time interlude between infection and the onset of the acute disease. Some patients, in spite of willing cooperation and long periods of sanatorium treatment, remain sputum positive all their lives, so that for them quarantine regulations are tantamount to life imprisonment.

"Anybody dealing with tuberculosis", says Rich, "is impressed by the great frequency with which it is impossible to trace the source of infection, and the number of people who have open lesions without knowing it."

Out of the sample group thirty-four per cent could name a known contact,

l. Rich, op. cit. p. 896. In his footnote (1019) Rich quotes one observer, Kalle, who could not find the source of infection in 71% of a group of adults, which Rich considers a reasonable average.

excluding the three cases where there were occupational exposures through work in tuberculosis hospitals. Doctors estimate that by the time a tuberculosis case has gone unrecognized until the far advanced stage, the person has infected at least five other people. On this basis the group would be responsible for the infection of about 150 people. Figure 7 illustrates the incidence of sputumpositive patients in the sample group. At least sixty-four per cent of the group had positive sputum at some time during their illness, twenty-five per cent of these were sputum-positive at diagnosis.

Therefore the community in its own interest and the patient's, should take responsibility for tuberculosis control services.

KEY Families with TOTAL children 64% 39%; Families 25% without children People living alone Scale - 1mm.-1 case Positive Sputum Positive Sputum at Diagnosis Later

Figure 7 Showing Incidence of Sputum Positive Cases in the Sample Group

N.B. - Positive sputum rate in people living in families - 66%

Positive sputum rate in people living alone - 64%

## Essentials of a Good Tuberculosis Control Program

The first problem which the disease presents to the community is responsibility for an adequate program of case-finding. This can only be done through the provision of a complete range of diagnostic services, free and avail-

able to all. The most important diagnostic tool is mass radiography of large numbers of apparently healthy people. This has the additional advantage that a high percentage of cases will be discovered in the early stages.

Presuming that there are enough beds, this should result in patients being admitted to sanatoria while the disease is still in the minimal stage.

The stage of the disease at which most patients are admitted to hospital is, say a some authorities. "the most important single factor in prognosis".

The next essential of an adequate tuberculosis control program is the development of adequate treatment facilities, both medical and social. These have already been outlined in an earlier chapter.

Tuberculosis control programs are judged by such standards as required ratio of beds to deaths, ratio of known cases and deaths, and the stage of disease at which most patients are admitted to and discharged from hospital.

According to these reliable guides the British Columbia Tuberculosis Control Program ranks high. But even if a community has the required ratio of beds to deaths this is not sufficient if there is still a waiting list for sanatorium beds. Some authorities believe there should be a bed for each case of tuberculosis regardless of the stage of the disease. Nor is it economical to cut down on the waiting list by discharging patients, whose disease is quiescent, sooner than would be medically advisable under more favorable conditions, to make way for those in the more acute stages of the disease.

The only real test of the adequacy of the community's tuberculosis services is that all the required services are readily available following diagnosis, or at the point in treatment that they are required.

<sup>1.</sup> Chadwick and Pope. op. cit. p. 73.

# A Tuberculosis Control Program Operated in a Social Milieu, Not a Social Vacuum

No tuberculosis control program, however complete its medical services, can be effective unless adequate ancilliary social services exist in the community. It is not generally realized that the patient's ability to benefit fully from medical care depends primarily on two things — first, his adjustment to his disease, and secondly, the fullest possible resolution of the social problems influencing his illness. Without social services the social aspects of tuberculosis cannot be treated. These are so important that tuberculosis has been called "a social disease with medical implications".

The costs of these services must be borne willingly by the community. It was estimated that in 1952 in British Columbia, the average cost of a tuber-culosis case was \$14,000, including money spent on the patient's family as well as on his medical care. Understandably, fiscal policies play an important part in tuberculosis control, but if they are allowed to determine the quality and quantity of tuberculosis control services then the whole community is the loser in the long run. Better services mean that more patients will get well in less time, and more will stay well.

#### Responsibility for Rehabilitation Services

Another problem for the community is the development of adequate rehabilitation services, the lack of which is a great weakness in the British Columbia tuberculosis control program. Having spent \$14,000 on one case, common sense dictates that all possible steps be taken to prevent spending another \$14,000 on the same person, which occurs unfortunately, through the lack of adequate rehabilitation services. Another aspect of this lack of service shows in the fact that eighty per cent of those released from sanatoria as cured die within ten years. Evidently, the bacillus is not solely to blame.

<sup>1.</sup> See address given by Dr. Myrom C. Weaver at the annual general meeting of the Vancouver Preventorium, 1952.

Adequate rehabilitation services include vocational retraining and job placement programs, and also sheltered workshops for those unable to compete in the general labor market. To be therapeutically sound the workshop program will always need some degree of subsidization. But the costs of maintaining patients in hospital and on social assistance after breakdown are higher than the costs of enabling patients to earn their living as far as they can. The psychological gain for patient and his family are incalculable.

### Responsibility for Preventive Measures

In practice, treatment and prevention cannot be divorced. Early isolation of infectious cases, and X-ray follow up of contacts, are as much preventive as therapeutic. A high level of public hygiene in general will assist the specific tuberculosis control measures.

For many years tuberculosis research workers have carried on extensive experiments to find a method of producing a significant degree of immunity without producing progressive disease. Innoculation with Bacillus Calmette-Guérin is the closest approximation to this yet discovered. Since its development in France in 1908 by Calmette and his associate Guérin it has been widely used in France and Germany for infants, and in Scandinavia for student nurses. Other countries were less receptive of it, though Britain, New Zealand, U.S.A. and Canada have all begun to use it recently.

Authorities differ regarding the merits of B.C.G., though its advocates claim that the vaccine produces artificially what the individual would have got by a small primary infection, thus protecting against a massive in-

l. Dr. C. J. Beckwith, President of the Canadian Tuberculosis Association said at the Annual Meeting of that society in 1952 that most disease could be eliminated if all were vaccinated, and that the negative reactor is four times more susceptible than the positive. Rich, op. cit. p. 810, is inclined to think it is advantageous in many cases, though bad for a minority — which would put it in the same category as small pox and diphtheria vaccinations and innoculations.

fection later on. Some authorities hold that the effect of our present tuberculosis control policies in deferring primary infections until adolescence and
early adulthood may be undermining the resistance of the race, and paving the
l
way for future increase in the severity of the disease.

# Problems of the Tuberculous Patient who Lives Alone

One quarter of the patients in the sample group were unattached men living alone. This group presents special problems to the community.

Many authorities believe that this group is the real crux of the spread of tuberculosis in a community. It was interesting to note that in the sample group fifty per cent of those living alone were in the far advanced stage of tuberculosis at diagnosis as compared with twelve per cent in the rest of the group. This might seem to confirm the view that this group consists mainly of the dregs of society - the vagrants, the alcoholics, the mental defectives, the drug addicts and others. It is true that there was a minority of such people among the group living alone. The majority, however, were men who had good work records in unskilled labouring jobs, and did not become public charges till they contracted tuberculosis. It was often just as difficult for these men to adjust to a reduced income at social assistance level as it was for patients who had families.

These patients are often judged to be among the least cooperative patients because their background and lack of family ties make it difficult to rehabilitate them. As regards the sample group, there was no evidence to support the theory that such people are in general less cooperative patients. If there is a higher incidence of breakdown in this group, it should be remembered

l. Rich, op. cit. p. 797, cites the opinion of Cobbett, an English observer who stated this in his book "The Cause of Tuberculosis", Cambridge University Press, London, 1917. p. 86

that this group encounters exceptional difficulties in convalescence and rehabilitation. While it is interesting to speculate on the emotional components of the illness in this usually close-mouthed, lone-wolf type of individual who for various reasons have severed their family ties, it does not necessarily follow that their psychological conflicts and personal problems are necessarily more severe than those of patients living in family settings.

The patient who returns to live in a room of his own is beset by difficulties unless he is lucky in his landlord or friends. Few in the group were
lucky in these respects and most of them found that the combination of unsuitable housing and looking after their physical needs meant overdoing their exercises.

There are not enough boarding homes to take care of all the patients, and the patient without housekeeping facilities, though he gains in rest, loses financially by eating all or most meals in restaurants; and the "tuberculosis extras" soon go the same way. Eating out can also interfere with exercise schedules especially if stair-climbing is involved. Mr. I's case was typical.

Mr. L.

Was a single man living in a hotel room. He complained that his allowance was not enough and he had to borrow small amounts from friends, but this he could do no longer. The City Social Service Department advised him to save by cooking his own meals. He said he had no cooking utensils but was told he should apply for them through the Red Cross Society.

This episode upset him and changed his previous friendly relationships with the Department.

It is to be noted that people living alone do not benefit from the social assistance concessions to tuberculous patients to the same extent as patients living in family settings. The maximum amount of social assistance for a patient living alone never exceeds the current city boarding home rate, which at present is \$55.00 a month.

Almost without exception this group had the choice of returning to unsuitable heavy jobs and thereby risking a breakdown, or remaining on social assistance, because of lack of vocational training and job placement facilities.

This group presents a special community problem, but not all the difficulties arise from within the group itself. Their degree of cooperation can not be fairly judged when there is no suitable rehabilitation program geared to their specific needs.

## The Uncooperative Patient - a Challenge to the Community

It may be thought that a community has fulfilled all its responsibilities in tuberculosis control when it has set up a program which finds, treats, and rehabilitates tuberculosis sufferers, and provides as many preventive measures as is humanly possible. But it is one thing to have a good program and another thing to get the people who need it to utilize the program constructively. No tuberculosis control program can be considered apart from the people for whom it is intended.

It is appropriate at this point to discuss the community aspects of the problem of "the uncooperative patient", that much-maligned misfit who would be better described as "misunderstood" or "mishandled". A considerable number of the group could be classified as uncooperative. The following cases are representative.

Was a cheerful little alcoholic who was always going to reform but never quite got round to it. Whenever he was in hospital his lesions healed well, but he never stayed long enough to complete his cure. He was sure to be found in one of three places — in hospital, in jail for shoplifting, or with a bootlegger family with whom he lived and fought with in the intervals when he was not in an institution.

Was a married logger who drank heavily. He had two children, and liked the ladies. After contracting tuberculosis he

terrified his wife by his complete lack of concern for his own and his family's protection. She contracted the disease and died, and relatives took the children, though Mr. H. retained legal guardianship.

He was discharged from hospital for repeated violation of sanatorium rules. He thought he was "putting one over" on the doctors because his X-ray showed improvement even while he wa drinking heavily. Though sputum positive he ate in restaurants, and when he got hopelessly in debt he decided to recenter hospital. He said he did not want to be cured. He was better off on social assistance.

Obviously, in both these cases the primary problem was not tuberculosis. This was also true in the case of Mr. V., whose lack of cooperation stemmed from mental disability or mental illness.

# Mr. V.

Was a forty year old single carpenter, who refused to believe he was ill. He told the social worker he had "passed" his X-ray and the doctor said he was cured. Actually his diagnosis was "moderately advanced tuberculosis".

He usually left his room early in the morning, wandered down town all day, often insufficiently clad, and returned to his housekeeping room late at night. He showed marked schizoid tendencies but refused psychiatric examination. As he was not committable there was nothing the doctor or social worker could do.

Intellectual ability does not necessarily mean patient cooperation, as the case of Mr. F. shows.

### Mr. F.

Was a University student, married, and was a contact of his brother who had signed himself out of hospital and taken his cure at home. Though a far advanced active case, Mr. F. refused hospitalization and told the public health murse he was under the care of a private physician, though it was known that he did not attend his doctor regularly. His D.V.A. grant was suspended for a time because he would not follow medical recommendations, but as his wife was working, they were able to get along financially. His condition improved enough to allow him, eventually, to attend University part time.

Nor is a person who is a community problem in one sense necessarily so in the management of their tuberculosis, as the case of Miss W. shows.

## Miss W.

Was an unmarried mother with four children, three of whom

were the product of her liaison with a married man. She had been in receipt of social assistance since the birth of her first child. She would not accept employment as she considered her place was at home with her children, to whom she gave excellent care. She was a cooperative patient and soon began to make a good recovery. When she was to be hospitalized a male friend, a cook on a transcontinental train who had wished for some time to marry her, came forward and offered to support the children and maintain a home for them in Vancouver, which he did.

The H. family were a community problem long before the onset of their tuberculosis. The combination of interior and exterior pressures in this family were so great, that to them, their tuberculosis was almost incidental. Certainly they all treated it as an "et cetera". From their viewpoint, the community was not interested in helping them until they became infectious to other people.

### H. family

Were Doukobors from the prairies, who had a hard time finding living accommodation during the war years. Mr. H. was jailed for drunken driving. Mrs. H. complained of intermittent non-support, and summonsed him for assault. Mr. H's mother lived with them, and apart from being the source of much family strife, was also believed to be the source of the family's tuberculous infection, but she always refused to be examined.

When given his diagnosis, Mr. H. refused hospitalization till he could find his family a home, then said they could not possibly exist on social assistance, so he would have to keep on working, which he did, until his death.

When Mrs. H. was diagnosed, she denied she had the disease, later also refused hospitalization, because she could not bear to be parted from her children, (with whom she was alternately over-strict and over-indulgent) and also because those who give in and go to bed die.

The eldest married daughter took her child from the preventorium, following her own return from hospital. The eldest son, a juvenile delinquent, was continually in and out of jail, and was also diagnosed. Another daughter, of borderline intelligence, was also delinquent. The youngest daughter had a primary infection.

The whole family of nine lived in two rooms in a converted store, the only accommodation they could find. Their attitude was that eighty per cent of the children in the neighbourhood had tuberculin positive skins, so why pick on them? Besides, Tuberculosis Control had known for a long time that their living quarters were unsatisfactory, but nobody had done anything about it. Perhaps the department would like to loan them the \$500 necessary to purchase the \$500 worth of furniture in the only other place they could find which would take children?

## Devising an Approach to the Uncooperative Patient

In every community today, there are adults who are not mature emotionally. As children, they did not, owing to stresses of various kinds within their families, receive the love, understanding and security so necessary to balanced emotional growth. Many among them belong to families who have become, in the accepted parlance, "pauperized".

Over the years, as their troubles mount, and their real needs go unmet, their attitudes crystalize into that anti-social behaviour not expected from adult human beings and which is unacceptable to their fellow men. While it is possible to isolate them for treatment of their tuberculosis, it is utterly impossible to isolate them for their anti-social behaviour. For good or evil, they are part of our social and economic body, and their social ill-health affects the whole social body. "For the good of the whole, as well as for that of the sick individual, we must provide remedial treatment for the sick part".

When such people are stricken with the bacillus in addition to all their other difficulties, most of them will be uncooperative patients. It could not be otherwise. From both the medical and the community point of view, they will remain uncooperative and thereby a potent source of the spread of infection, until our services are strong enough and ample enough to meet all their legitimate needs.

l. Govan, Elizabeth "Public Assistance in Modern Society", Canadian Welfare, Vol. xxviii No. 1. May 1952, p. 5

The attitude of the general public to these people is characterized by lack of understanding. It is sometimes difficult to remember, as Charlotte Towle reminds us that "Parents who fail have frequently been failed ... that we give as we are given to ... and that none of us can give from a vaccuum".

One of the problems facing the community is how to bring about a change of attitude towards these people. It will not become about by chance. Public education regarding community responsibility for such social ills is only part of the answer. It is fundamentally related to the much deeper question of how we can equip people for the complexities of living in modern democratic society. To answer that question is the great challenge to our civilization.

There is no short cut to making uncooperative people cooperative. The process is as slow as nature's healing of tubercular lesions, and almost as uncertain. We cannot make them cooperate in the treatment of their disease. We can only make them want to, through meeting their basic needs in other areas of living. If we wish them to accept their community responsibilities, we in the community must respect their fundamental rights as human beings.

The community must recognize the fact that some people have been so bruised by life that they cannot be reached. They might be said to be suffering from "inoperable social cancer". They are socially irreclaimable and we must accept responsibility for them as we do for the chronic tuberculosis patient who cannot overcome his disease.

But to those who can respond, and to those who come in the future, the community has a different responsibility. We must provide for them the requisite services to assist them to build up in their formative years those human relationships which are the root of their inner stability and security

<sup>1.</sup> Towle, Charlotte, "Common Human Needs", Public Assistance Report No. 8 U.S.A. Federal Security Agency, Social Security Board, Washington. 1945, p. 67

as individuals, and the foundation of socialized and considerate behaviour towards their fellows. We will thus create for the community citizen assets as against citizen liabilities.

## Chapter 6.

# Tuberculosis Control in the Future. Conclusions and Recommendations

In reviewing present success in our battle with the bacillus, we cannot escape the question:— "Are we doing all we can, within the present limits of our knowledge, to control and eventually eradicate tuberculosis?" Pasteur once said that it is within the power of man to cause all germ diseases to disappear from the earth. Some eminent medical authorities at the beginning of this century prophesied that by 1940 tuberculosis would be an almost extinct medical curiosity in western civilization. And indeed, in the opinion of two eminent present day authorities:—

"Sufficient knowledge is already available to make the eradication of tuberculosis a possibility within a few generations if the established techniques are effectively applied.... The heavy toll taken by tuberculosis economically and socially for centuries can be reduced to a minor public health problem in one generation, and eventually eliminated altogether by putting into practice the knowledge we have of its epidemiology and treatment".

It is evident that achievement of this goal in British Columbia would necessitate improvements in practically all aspects of the existing tuber-culosis control services.

# Recommendations regarding Medical Services

The standard of medical services in tuberculosis control in British Columbia is extremely high, yet existing deficiencies negate many of the positive features. One of the most important is the shortage of sanatorium

<sup>1.</sup> Chadwick and Pope, op. cit. p. vii and p. 100

beds. At the time this survey was made the new Pearson Memorial Hospital, opened in March, 1952, had not been built. Though it was hoped, and was actually stated in the press, that this unit of 264 beds would more than compensate for the shortage, this expectation has not been realized in practice. It has still not enabled tuberculosis control to meet the crucial practical test of immediate admission following diagnosis. Therefore, according to the best standards, there is still a bed shortage which should be remedied.

There is also a shortage of trained personnel, especially medical personnel in the tuberculosis field. This is partly due to lower salaries in Government medical appointments, as compared with the income which medical personnel can obtain in private practice. At present the appointment of Medical Director of Tuberculosis Control is not on a full-time basis, as it should be in a comprehensive program for tuberculosis control. Higher salaries are a necessity if tuberculosis control work is to attract top people in the medical profession.

#### Recommendations regarding Nursing Services

British Columbia is one of the few provinces to include a course in tuberculosis nursing in the curriculum in recognized Schools of Mursing. It might be expected that interest in the tuberculosis field would thus be aroused, but there is still a shortage of tuberculosis nurses. But there has always been, except in a few privileged spots in the world, a chronic shortage of nurses of all types in hospitals. Remedial measures to overcome this deficiency should be directed towards improving conditions in the nursing profession as a whole.

## Recommendations regarding legislation and hospitalization

Existing British Columbia legislation allows for compulsory removal

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of proven infectious cases of tuberculosis to hospital, but does not provide any authority for keeping them there. They are free to walk out the same day if they so wish. Also, as long as the bed shortage continues, it is somewhat ludicrous to insist on hospitalization of the uncooperative when there is a waiting list of patients.

Consideration should be given as to the possibility of amending present legislation to allow for the protection of the community from the proved non-cooperative sputum-positive patient while at the same time protecting the rights of the cooperative sputum-positive patient for whom compulsory hospitalization for the duration of his infectiousness to others would be tantamount to life imprisonment. All such legislation would have to be used extremely cautiously.

There would also have to be some decision as to the position of those patients who had not acquired British Columbia residence according to the "Residence and Responsibility Act", because after all, from the public health point of view, the non-resident is as infectious to the community as the resident.

Free hospitalization for tuberculous patients is recommended. At the present time, the Office of the Collector of Hospital Revenue decides whether a patient and his family shall pay hospital rates in full, in part, or be exempt. While it is quite true that many patients can pay a little, the chronicity of the illness is usually such a drain on the family resources that the advisability of depleting them further is to be questioned. Often by the time the patient reaches rehabilitation, there is little left to help re-establish the family according to its former standard of living. Observers in U.S.A. have noted how often even small payments which the family agrees willingly to

<sup>1.</sup> See "Regulations to the Control of Communicable Diseases Act", 1945, p.p. 15-16, King's Printer, Victoria, B. C. 1945.

pay in the beginning become an intolerable burden as the illness drags on.

Recommendations Regarding Building of Hospitals Near Urban Centres

It is recommended that future institutions for the treatment of tuberculosis should be built closer to the larger urban cetres. Since it is acknowledged that in the treatment of tuberculosis, no one climate is superior, there seems to be little justification for straining the fabrics of family living further, and intensifying the pain of separation for tuberculous patients and their families.

### Recommendation Regarding Mass Radiography

Inauguration of a public education program to encourage annual radio-graphy of all residents of the province is recommended as an implementation of the existing case-finding program. Compulsory X-ray's at six monthly intervals for all food handlers is recommended. This could be made a condition of employment as it is at present for hospital employees.

### Recommendation Regarding General Use of B.C.G.

At present, the use of B.C.G. innoculations in British Columbia is confined to certain specialized groups. A program of public education would assist public acceptance of it as a general preventive measure, which might be extended to other groups in the population, and might eventually become accepted on the same basis as innoculations against other infectious diseases.

#### Recommendations Regarding Medical Research

It has been previously stated that the control of tuberculosis is within our grasp if we apply the technical knowledge already available. It may therefore seem somewhat incongruous to place extension of medical research high on the list of priorities in tuberculosis control. Yet in the final analysis, we do not yet know what makes people get tuberculosis, nor how to cure them when they do. The most we can do, even with all our modern medical techniques,

is to assist by artificial means the body's natural defences to overcome the disease. There is as yet no specific cure for tuberculosis, no substitute method for nature's slow way of healing tubercular lesions. Until there is, we cannot expect to reduce the long protracted period of incapacitation which tuberculosis now causes.

## Recommendations Regarding Psychosomatic Orientation in Schools of Medicine

The adoption of the psychosomatic approach in Schools of Medicine is recommended so that medical students become oriented to this method of study and treatment of their patients by the time they become practitioners, and can thus more adequately fulfill their responsibility to treat "the whole man".

Some medical men today vizualize that in the medical practice of the future the general practitioner will come into his own again. He will however have undergone a metamorphosis, from which he will re-emerge with pivotal importance in the whole structure of medical services. He will be the practitioner trained in the basic speciality of "human biology" - that is, the study of the human personality and human relationships - and will call in as his technical assistants the various specialists who today outrank him.

## Recommendations Regarding Public Health Services

Public Health services in British Columbia are of a high standard, though naturally not so well developed in the rural areas as in urban centres. One would, however, like to see an enlargement of concepts in this area to include what has been called "social medicine", that is:-

"The idea of medicine applied to the service of man as socius, as fellow or comrade, with a view to a better understanding of and more durable assistance to all his main and contributory troubles which are inimicable to active health and not merely to removing or alleviating a present pathology. It embodies also the idea of medicine applied in the service of societas, or to the community of men, with a view to lowering the incidence of all preventable disease, and raising the general level of human fitness."

L. This is a quotation from an address given by Professor Ryle of Exford University on the social aspects of medicine, which the writer came across in a pamphlet, which has since been lost.

## Recommendations Regarding Medical Social Work

The role of the medical social worker in combating tuberculosis is a vital one. She is the medium through which the totality of services available to the patient are individualized to meet his particular needs. Through her associates in the public and private welfare agencies, the patient and his family are helped with other social difficulties.

It is recommended that all tuberculous patients be referred to the medical social worker as soon as possible after diagnosis. No matter how stable the individual, tuberculosis involves such major adjustments in living for the patient and his family, that there must be few indeed who would not benefit at least supportively from the services of the medical social worker. Though an individual patient or family may not be able to utilize a casework relationship constructively, the social history information which the medical social worker obtains during her contact with the patient and his family is of great diagnostic and therapeutic value. Indeed the findings of the "social laboratory" are just as important as the findings of the chemistry laboratory in the treatment of tuberculosis.

It is recommended that at least one member of the social service staff in tuberculosis hospitals be a qualified group worker, so that there can be experimentation in the value of group therapy for tuberculous patients. This has already proved successful in other chronic illnesses. One tool which has been particularly effective in rehabilitation work has been the use of psychodrama, in which patients enact dramatically, either impromptu or from prepared scripts, situations they are likely to encounter on leaving hospital, within their families, in seeking employment, and in social relations in general. Group discussion afterwards, guided by the worker, has been of proved therapeutic value to many patients in helping them to face the realities of such situations and their feelings about them.

It is also recommended that in order to enable the medical social worker to function fully in a medical setting, namely, to participate in the treatment process, and not merely to gather social history information and to help with environmental problems — there should be regular consultation with psychiatric staff regarding difficult cases. The medical social worker would then be able to help more effectively those seriously disturbed patients where her role in the treatment team though distinct from the psychiatrist's cannot be performed except in collaboration with him.

It is also recommended that experimentation be undertaken with programs for the extension of medical social services into the home. There has been some interesting pioneer work in this field in U.S.A., especially at 1. Montefiore Hospital in New York. There is great need for improvement in methods whereby medical care programs are adapted to the medical needs of people in our present-day society.

Provision for medical social work research is also recommended. The field of teleology has been very much neglected by medical social workers. They can make a significant contribution to medical care when they can answer more scientifically than at present, not only the question: "Why did this person become ill when he did?", but also the equally important questions: "Why did he get better when he did, and what were the mechanisms concerned in his recovery"?

It is fully realized that the implementation of these recommendations regarding medical social work will be costly. Individualization of services is always costly, but less costly than non-individualization.

<sup>1.</sup> See Field, Minna and Schless, Bessie, "Extension of Medical Social Service into the Home", in the <u>Journal of Social Case work</u> Vol. XXIX No. 3., March, 1948, p. 94

## Recommendations regarding Social Assistance Regulations

Success of tuberculosis control from the social point of view depends in large measure on adequate public welfare programs. Of prime importance is the social assistance program. What constitutes adequate assistance is difficult to define. Experience has shown that attempts to do so without regard to a family's existing standards of living are likely to be unsuccessful. It is important in dealing with the tuberculous group to help the family maintain some semblance of the standards to which they were accustomed before the disease struck. The special concessions allowed to tuberculous patients under the British Columbia Social Assistance Act represent an attempt to do this, but to judge from the experiences of the people in the sample group, they fall considerably short of their intended aim. They will continue to do so, in the opinion of the writer, until we broaden the concept of public assistance to include a sliding scale of additional financial and social privileges above bare subsistence level, which will be available for individuals and families according to their specific need.

It is also recommended that there be further extension of social assistance in the form of boarding homes for convalescent patients. Experience elsewhere has shown that the cottage type of unit, preferably managed by extuberculous patients, are the most successful.

A minor revision in social assistance regulations which is recommended is payment of travelling allowances for a patient's immediate relatives for purposes of visiting patients in tuberculosis institutions, at least twice a year.

It is the function of public welfare agencies to strengthen their clients.

"Valid public welfare services" it has been aptly said "can only be given in a society and in an administrative setting

which is receptive to social work aims, by workers who have the skills to provide the services that conserve the strengths and develop the capacities of the citizen group which the agency serves."

The implications for British Columbia are programs aimed at improving community understanding of social work, and the employment of more fully trained social workers in public welfare.

### Recommendations Regarding Rehabilitation Services

Inauguration of government sponsored rehabilitation programs for the tuberculous is recommended. The weakness of the present rehabilitation services in British Columbia seem to the writer to vitiate much of excellence of existing medical and social services in combating tuberculosis.

There is need for the development of adequate vocational retraining programs for discharged sanatorium patients: an educational program to soften up employer-employee resistance in the employment of handicapped people; practical help in developing work opportunities and locating suitable employment. The work of the Special Placements Branch of National Employment Services and the British Columbia Tuberculosis Society is excellent but extremely limited in relation to existing needs. The task is too great for voluntary agencies to meet the needs unaided.

One of the greatest obstacles to effective work in the rehabilitation field is the lack of a universally accepted definition of what constitutes light work. While both the patient and his doctor know very clearly what is involved in "full time light work", the same clarity does not exist on the labour market. Time and again, a patient has undertaken what is classified as light work on industrial files, but which proves in practice to be too arduous for an extuberculous patient.

l. Brown, Luna Bowdoin "Responsibility of the Public Agency for Strengthening Its Clients", Journal of Social Casework, Vol. XXIX No. 7, July, 1948, p.255

It is also recommended that the British system be adopted, whereby every employer of twenty or more persons is required to employ a quota of disabled persons, amounting to at least three per cent of his labour force. Also, under the British plan of "designated employment", future openings in certain occupations such as car park attendant and elevator operator, may be reserved for disabled people.

It is also recommended that an adequate sheltered workshop program be developed and subsidized from public funds. Such projects may range all the way from the work colony, where severe tuberculous chronics can live in village settlements with their families, as in Papworth village in England, to non-residential workshops where patients can work from one to six hours per day, depending on their capacity.

Dr. Myrom C. Weaver, Dean of the University of British Columbia School 2 of Medicine, recently suggested that ex-tuberculous patients form a self-help group similar to Alcoholics Anonymous, to help in their own rehabilitation. This is a recommendation well worth implementing. The arthritics of British Columbia have already formed their organization, and according to recent reports, are finding the project well worth while.

# Recommendations Regarding Subsidization of Work of Voluntary Agencies

Services of voluntary agencies are strained to capacity by the needs created by chronic illness. They cannot answer all requests for their services unless there is some public subsidization of those aspects of their work which, in our modern society, are primarily a community responsibility, rather than

<sup>1.</sup> If properly run, there is little danger of spread of infection in such projects. In Papworth, England, in thirty-two years, not one child born there to tuberculous patients has developed pulmonary tuberculosis.

<sup>2.</sup> In his address at the Annual General Meeting of the Preventorium Society, 1952.

that of a private agency.

It is recommended that the Family Welfare Bureau Homemaker Service be enlarged through public funds, to enable the agency to place and supervize homemakers in families where the mother is tuberculous, or suffering from any other chronic incapaciting illness.

Placement of a child outside his family because of chronic illness should be considered only as a last resort, and should not be dictated by financial considerations only. Implementation of the foster day care program is recommended to provide day care for the children of working fathers where the mother is incapacitated, so that full time placement of a child during the illness of his mother, is avoided except where absolutely necessary.

Private agency services to tuberculous people without family attachments should be strengthened. It is specifically recommended that a program similar to the British "Meals on Wheels" be adopted. At present there is no private agency which could undertake it without subsidization from public funds. If such a program were inaugurated, convalescent tuberculous people living alone would have a hot cooked meal brought daily to their homes by mobile canteens for which they would pay according to their means. This could be the greatest single measure in enabling this group to come through their convalescence successfully.

### Recommendations Regarding Primary Basic Public Welfare Measures

Because of the inter-relatedness of tuberculosis and major social problems, no program of tuberculosis control is complete without adequate provision in the national economy for those basic public welfare measures necessary to meet the primary needs of human beings in our society.

These include: - a comprehensive social insurance such as that outlined by Dr. L. C. Marsh in his report on Social Security for Canada; full employment policies; a health services scheme which will make medical care available to all according to need; government subsidization of low rental housing projects.

The provision of such a comprehensive health and welfare scheme is held back principally by two obstacles. The first is expense. The cost of such services may indeed appear prohibitive from the fiscal point of view. However, that depends on whether the long or short term view is taken. There can be no disputing the fact that it costs the community more, in the long run, to tolerate tuberculosis than to wipe it out. In terms of human unhappiness and incapacitation, it may well be that the present cost to the community in not providing these services is actually greater than the cost of providing them.

The second great stumbling block is current philosophy. It is still a commonly held view that the provision of adequate social security measures would result in the undermining of the moral fibre of a population. Social workers are often accused of favouring the removal of all difficulties from people's lives. But none of us can avoid conflict and pain. The tragedy is that those people who have had it meted out to them in overabundant measure often become unequal to the undertaking of mature responsibilities in the adult world. Freud once said that "it is the duty of medicine to make the patient strong enough to face the inevitable suffering of life". The same is true of social work and social security. If we are really concerned about people, we will provide the services to enable them to cope with the complexities of modern living, not as has been said, "as a sentimental move, but as a basic

<sup>1.</sup> See Report on Social Security for Canada, prepared by Dr. L. C. Marsh for the Advisory Committee on Reconstruction, Ottawa, King's Printer, 1943

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need for personal stability and social order".

According to the Human Rights Charter of the United Nations:

"Everyone has the right to a decent living; to work and advance his well-being; to health, education and social security...

There shall be equal opportunity for all to participate in the economic and cultural life of the community".

We have not yet implemented this in our culture. The life histories of the people described in this study are ample proof of this. Most of them ask nothing more than the very thing the charter describes.

It may be, as F. D. Roosevelt said, that the twentieth century will come to be dubbed historically as the "century of the common man", because of the improvement in his lot which it has witnessed. It is equally possible that posterity will judge our century by our tragic omissions in the field of human betterment in view of the extent of our scientific enlightenment and technical achievements. Such tremendous power will never be used to the advantage of mankind as fully as it might be until men understand themselves:-

"The critical, empirical attitude of the natural sciences must now be extended to the study of personality and to the social sciences in order to achieve the same mastery of individual and social behavior which we have acquired over the forces of inanimate nature".

It is the great challenge and the great privilege of the profession of social work to assist in this great undertaking.

Prevention and control of tuberculosis is inescapably linked with the raising of the general level of well being of all peoples, to which the profession of social work is dedicated. Human experience had already shown repeatedly that in dealing with tuberculosis, half way measures will not do.

l. See Hill, Reuben, "Are We Expecting Too Much of Families"? <u>Journal of Social Casework</u>, Vol. XXXII No. 4. April, 1951. p. 153

<sup>2.</sup> Alexander, Franz, "Our Age of Unreason, a Study of the Irrational Forces in Social Life., J. B. Lippincott Co. New York, 1942, p. 22

"In order to get at the roots of tuberculosis, it is necessary to understand where its springs arise. From some crater in the depths of society, among the most wretched poverty, misery, unemployment and inbecility, the fountain of tuberculosis infection is thrown up through the community, and seizes upon all who are susceptible. Until these social evils can be got under control, we shall never be quite free of tuberculosis. Until then, we shall not deserve to be. "

<sup>1.</sup> Olsen, H. C., The Fight against Tuberculosis in Bernholm, Acta Tuberculosis Scandinavia. Supp., 11, 1943

#### Appendix A

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